

Caring for Caregivers and Patients: Research and Clinical Priorities for Informal Cancer Caregiving

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Informal/family caregivers are a fundamental source of care for cancer patients in the United States, yet the population of caregivers and their tasks, psychosocial needs, and health outcomes are not well understood. Changes in the nature of cancer care and its delivery, along with the growing population of survivors and their caregivers, warrant increased attention to the roles and demands of caregiving. This article reviews current evidence presented at a 2-day meeting examining the state of the science of informal cancer caregiving that was convened by the National Cancer Institute and the National Institute of Nursing Research. The meeting sought to define who is an informal cancer caregiver, summarize the state of the science in informal cancer caregiving, and describe both the kinds of interventions developed to address caregiving challenges and the various outcomes used to evaluate their impact. This article offers recommendations for moving science forward in 4 areas: 1) improving the estimation of the prevalence and burden of informal cancer caregiving; 2) advancing the development of interventions designed to improve outcomes for cancer patients, caregivers, and patient-caregiver dyads; 3) generating and testing strategies for integrating caregivers into formal health care settings; and 4) promoting the use of technology to support informal cancer caregivers. *Cancer* 2016;122:1987-95. © 2016 American Cancer Society.

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INTRODUCTION

The growing population of cancer patients and survivors, now numbering more than 14.5 million in the United States,¹ has taught us many lessons. Key among these is that cancer is a family affair in which many family members and friends serve as informal cancer caregivers.² Caregivers are defined as individuals (eg, adult children, spouses, parents, friends, and neighbors) who provide care that is typically uncompensated and usually at home, involves significant amounts of time and energy for months or years, and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding.³ Although not all cancer patients are in need of caregivers, cancer can have major effects on caregivers as well as patients. Yet too often both the role and needs of caregivers are overlooked by health care systems. The physical and mental health outcomes of patients and their caregivers are often related; if patients are faring poorly, often caregivers are as well.⁴ Similarly, caregivers' distress can be distressing for patients⁵ and can have lasting and long-term health effects on both patients and caregivers.⁶ Although many individuals report positive experiences as caregivers, large numbers also report simultaneous unmet needs and substantial burdens.⁷ Caregivers are often underprepared to perform the many tasks needed to care for their loved ones,⁸ and they often struggle quietly.⁹

Distinguishing Features of Informal Caregiving in the Cancer Context

Several unique features distinguish the cancer caregiving experience from caregiving for other chronic health conditions.¹⁰ The nature of cancer, in contrast to other chronic illnesses such as dementia, can lead to rapid health deterioration over a

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short period of time and cause heightened distress in family caregivers.¹¹ Cancer caregivers typically spend more hours per day providing care, provide more intense care over a shorter period of time, and are often more likely to incur out-of-pocket expenses than caregivers of individuals with other chronic illnesses.^{10,12} Cancer patients experience more variability in symptoms and toxicities from different multimodal therapies than do individuals with other chronic illnesses. This necessitates that the caregivers monitor the patients' health status frequently and use a variety of technical and psychosocial skills to promote the patients' health.^{13,14} The growing number of adults living for a long time after a cancer diagnosis, with or without evidence of disease, is expanding both the length and burden of care for families. Few other diseases have a clinical course in which an individual may have no evidence of disease, only to be diagnosed again years later with recurrence or a new cancer. The virtually universal concerns about disease recurrence and the pattern of progression are also unique hallmarks of cancer and are stressful for the individual and his or her family alike.¹⁵ Not surprisingly, many cancer caregivers report cancer-specific stress that can have a measurable impact on physical health and immune functioning.¹⁶ The unique inflection points specific to the cancer care continuum (ie, diagnosis, treatment, transition off treatment, survivorship, recurrence/secondary cancer, progression, and end of life) also lead to variability in the level of the care burden and ongoing adjustments unique to cancer.¹⁷ Final distinguishing features are that the health care system is providing more complex treatment regimens, necessitating the use of new targeted therapies and more intensive decision making, and that the system is moving toward more care provided at outpatient and community-based centers or at home rather than tertiary or inpatient centers. All of these features are increasing the day-to-day demands on informal caregivers.¹⁸

In recognition of the unique role that informal cancer caregivers play, the advocacy community led by the National Coalition for Cancer Survivorship revised the term *cancer survivor* in 1986 to include caregivers: "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition."¹⁹ Although there are shared attributes of caregiving across diverse chronic disease trajectories, to date, there is limited research on the many unique aspects of informal cancer caregiving.

Meeting Description and Objectives

On May 4 to 5, 2015, the National Cancer Institute and the National Institute of Nursing Research cosponsored a 2-day meeting entitled "Caring for Caregivers and Patients: Revisiting the Research and Clinical Priorities for Informal Cancer Caregiving" (<http://cancercontrol.cancer.gov/ocs/resources/icc-meeting.html>). The purpose of this meeting was to convene stakeholders to share their expertise about the state of the science of informal cancer caregiving for adult cancer patients and to identify gaps in the science from the perspectives of patients, caregivers, health care providers, and researchers. The meeting focused on the cancer caregiver burden and the reciprocal relation that exists between patients' and caregivers' physical and emotional responses to illness. More than 75 invited experts attended, including researchers, clinicians, advocates, and representatives from national funding agencies. Participants were challenged to consider the state of the current science of informal cancer caregiving across the care continuum, identify knowledge gaps, and propose short- and long-term recommendations to fill identified gaps. The meeting comprised 4 sessions with the following scientific objectives: 1) appraising the prevalence and burden of informal cancer caregiving; 2) reviewing intervention outcomes for cancer patients, family caregivers, and patient-caregiver dyads (ie, pairs); 3) examining potential models of integrating informal caregivers into cancer care; and 4) discussing the promises and pitfalls of using online and digital technologies to advance cancer caregiving research and practice. In this article, we review the findings from the meeting and give recommendations for the further development of informal cancer caregiving science (Boxes 1–4) with the intention of building on and complementing other efforts to build research in informal cancer caregiving.

SESSION 1: PREVALENCE AND BURDEN OF INFORMAL CANCER CAREGIVING

In this session, what is known about the prevalence of, characteristics of, and tasks performed by informal cancer caregivers in the United States was reviewed. There are vast differences in the estimated numbers of family caregivers nationally, which depend on the type of survey method used.²⁰ Care recipient–based surveys, which are based on data obtained from the person with the illness or disability (eg, the National Long Term Care Survey²¹), offer lower estimates of caregiver prevalence rates than caregiver-based surveys, which are based on data from people who self-identify as caregivers on representative national surveys (eg, caregiving in the United States²²).

Meeting participants discussed additional drivers of the discrepancies in estimates, including periods of disability, sampling from primary or secondary caregivers, and the intent of the research to drive either advocacy (calling attention to the problem) or health system needs (risk stratification).

Because of these discrepancies, however, accurately estimating the number of current informal caregivers is a critical first step to understanding the myriad challenges they encounter. The most recent estimates of caregiving for a patient with a serious/chronic care condition are reported by the National Alliance of Caregiving. According to its 2015 report, approximately 43.5 million adults in the United States provided care to an adult or child (for any serious/chronic health condition) in the preceding 12 months.²² The majority of caregivers are female (60%) and have provided care for a relative (85%). Cancer was identified as the fourth main reason for which people needed a family caregiver, and 7% of the caregivers interviewed ($n = 1248$) indicated that the main problem/illness for which the care recipient needed care was cancer.²² Because of the increasing commonality of individuals living with multiple chronic conditions, including cancer, this percentage may be an underestimate. Regardless of the figure cited, the number of cancer caregivers that currently exist is in proportion to the number of individuals with cancer and thus can be expected to grow.²³ This anticipated growth will be accompanied by simultaneous increases in the demands placed on caregivers as cancer care continues to move further into the outpatient and home setting.²⁴

Burden of Informal Cancer Caregiving

The adverse impact of cancer on the health and functioning of individuals and their caregivers was highlighted as a significant area of research need at the meeting. Caregivers of cancer patients often provide complex care in the home (eg, symptom management and treatment monitoring¹⁴) but often lack the information, support, and self-confidence necessary to perform these tasks.⁸ Longitudinal studies indicate that caregivers have many unmet needs across the care continuum.¹² In addition, because many caregivers of cancer patients experience moderate to high levels of stress and multiple demands on their time,¹⁴ their own physical and mental health may be negatively affected,⁴ and this can negatively affect the patient's health outcomes.⁵ Studies aimed at identifying high-risk subgroups indicate that caregivers who are younger, are female, or are caring for someone with advanced-stage disease often report higher levels of emotional distress.^{9,25}

Challenges in Assessing the Prevalence and Burden of Informal Cancer Caregiving

Several issues continue to hinder our understanding of the prevalence of cancer caregivers and the extent of the burden that they experience. Challenges include the divergence in estimates of caregivers across studies, the lack of consensus in defining the population of interest, and the difficulty in using consistent methods to identify caregivers on national surveys. There is also a wide variety of measures that have been used to assess caregiving tasks, burdens, and health outcomes, and this makes it difficult to generalize findings across studies, although the Family Caregiver Alliance has compiled a selected repository of measures to assess the caregiving burden.²⁶ Generalizing findings beyond many studies can also be challenging because most have been conducted at major cancer centers among well-educated, non-Hispanic white populations,²⁷ with a few important exceptions of studies among minority caregiver populations.²⁸⁻³⁰ Although there is scant research on caregiving in low-socioeconomic status/limited-health literacy populations, one study in Denmark suggested that lower education levels and low income were predictive of caregiver nonparticipation, whereas cancer characteristics had little effect.³¹ There is a continued need to develop risk stratification methods for identifying caregivers in addition to patients at highest risk for poor physical and mental health outcomes. Meeting presenters and participants also indicated that it is particularly difficult to recruit patient-caregiver dyads (pairs) for research studies and to retain them because 2 people rather than 1 need to agree to participate in the study. In addition, not all cancer patients have caregivers or a caregiver willing and able to participate in research. Finally, participants indicated that there are limited data examining the long-term health effects and positive benefits of cancer caregiving, although some studies do report enhanced intimacy and personal growth among caregivers.³²

BOX 1. Research Recommendations for Improving the Assessment of the Prevalence and Burden of Informal Cancer Caregiving

1. Create infrastructure for more comprehensive caregiver surveillance at national and/or state levels.
2. Increase research on the most vulnerable caregiving populations (eg, socially isolated caregivers, rural residents, elders, those with a low socioeconomic status, racial/ethnic minorities, and those with care recipients with complicated care regimens).
3. Incorporate risk stratification to target highly stressed patients and caregivers and determine the impact on patient outcomes.
4. Refine models of caregiving burden with careful attention to constructs and measures and build on existing repositories of caregiving measures.

SESSION 2: OVERVIEW OF INTERVENTIONS TO TARGET CANCER PATIENTS, CAREGIVERS, AND DYADS

Interventions aimed at improving informal cancer caregiving generally focus on 1 of 3 sets of outcomes: patient outcomes, caregiver outcomes, or combined patient-caregiver (dyad) outcomes. Findings from a few recent meta-analyses examining the effects of psychosocial interventions on caregiver and patient-caregiver outcomes in cancer^{27,33} and other chronic illnesses³⁴ indicate that interventions can significantly improve patients' and caregivers' physical and mental health and dyadic communication and also improve caregivers' knowledge, burden, self-efficacy, and coping. However, results have yielded small to medium effect sizes (ie, 0.10-0.47),^{27,33-38} and several limitations, including a lack of rigor, small sample sizes, and short-term assessments, have been identified. Because interventions delivered to caregivers alone or to patient-caregiver dyads often have different aims and study designs, this session focused on findings pertaining to patient, caregiver, and caregiver-patient dyadic outcomes resulting from these studies.

Patient Outcomes

In studies in which patient outcomes are the focus, the populations include primarily breast and prostate cancer patients,²⁷ and the outcome measures vary widely; they include patient physical and mental health and functioning, depression, anxiety, symptom control and management, and health care utilization.³⁹ Few intervention studies have examined outcomes pertaining to patient safety, patient functional recovery, health care utilization, or cost of care. Little is known about the optimal intervention dose that is needed to affect patient outcomes, the mechanisms through which caregiver interventions improve patient outcomes, and how risk assessments can be used to determine which patients could benefit from more active caregiver involvement.

Caregiver Outcomes

When caregivers are primarily the focus, quality of life, mastery, burden, preparedness, self-efficacy, loss and grief, hope, depression, anxiety, bonding, coping, distress, and strain are the primary outcomes.^{40,41} Meeting participants discussed factors that affect caregiver outcomes, which include the delivery method, the dose of the intervention (number of contacts and length of time of contacts), and the delivery target (caregiver vs dyad). Intervention effect sizes for caregiver outcomes are generally stronger for benefit finding, knowledge, and

coping, with moderate effects evident for physical well-being, self-efficacy, and relationships with care recipients. Samples tend to be primarily female and non-Hispanic white and from mostly middle-aged groups (age, 41-69 years).³³ Major gaps include 1) scarce information about the needs of caregivers who are adult children, 2) little information on the experiences of male caregivers and particularly the effects of caregiving on male caregivers' psychological outcomes, and 3) little information on the impact of interventions on caregiver health behaviors and chronic health conditions.

Patient-Caregiver Dyadic Outcomes

In contrast to studies that focus on the patient or caregiver as a separate individual, some interventions involve the caregiver-patient dyad and dyadic outcomes. These dyadic interventions and outcomes are based on the perspective that patients and caregivers cocreate an interpersonal environment that affects the well-being of both individuals.⁴² Dyadic outcomes include measures of relationship quality, dyadic adjustment, and interpersonal support. Limitations to existing dyadic research described by meeting participants include a failure to explicitly describe the application of a theoretical framework in given studies, a lack of common dyadic measures used across studies, and an overreliance on self-reported measures.

Challenges in Conducting Intervention Studies With Caregivers and Patient-Caregiver Dyads

One challenge for intervention research is the difficulty in enrolling patient-caregiver dyads. Enrollment rates are generally between 53% and 58%,^{27,33,43} and this can result in slow accrual and small numbers of caregivers from racial/ethnic minority and underserved groups. Identified research gaps also include a lack of information on the impact of caregiver/dyadic interventions on family-provider communication and goals of care, the cost-effectiveness of caregiver/dyadic interventions, the effect of interventions on patient health care utilization (eg, emergency department use or hospitalization), and effective methods for incorporating tailored, Web-based technology into the delivery of caregiver/dyadic interventions. Participants also noted that although some efficacious caregiver and dyadic interventions exist and there are some exemplars that have been successfully implemented in practice,⁴⁴⁻⁴⁶ far more need replication, further development and testing, and broader implementation.

BOX 2. Research Recommendations for Improving Interventions Targeted at Cancer Patients, Caregivers, and Patient-Caregiver Dyads

1. Prioritize health outcomes of interest, define constructs, and harmonize measures where possible to advance caregiving intervention research.
 2. Conduct research that examines the effects of interventions on patient and caregiver outcomes, health care utilization, and cost-effectiveness.
 3. Test the effects of tailored, interactive caregiver or dyadic interventions on patient, caregiver, and dyadic outcomes.
 4. Identify strategies for increasing the diversity of caregivers and dyads who participate in research studies (eg, minorities, lower socioeconomic status, sexual orientation, and high risk for poorer outcomes).
 5. Replicate interventions that show some benefit and attend more closely to intervention fidelity and dose in those studies.
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SESSION 3: INTEGRATING INFORMAL CAREGIVERS INTO FORMAL HEALTHCARE SYSTEMS IN CANCER CARE

Although the importance of informal caregivers has been well acknowledged, most health care systems do not have a formal, standardized mechanism for integrating caregiver physical and mental health outcomes and support into the plan of care and assessments of quality of care. This session focused on different models of care for targeting informal cancer caregivers directly.

A new model for integrating caregivers that has been successful is the use of multidisciplinary, hospital-based clinics to provide individual and group therapy, education, and limited clinical care to informal cancer caregivers.⁴⁷ This structure allows caregiver research and outreach as well as multidisciplinary team training to recognize caregiver distress. Providing caregiver interventions in the hospice and palliative care setting has also been successful in one research network.^{48,49} This network has supported video-based problem-solving therapy and the integration of family members into pain management meetings with the hospice team. A third program that formally recognizes caregivers more broadly than the cancer care delivery context is the Department of Veterans Affairs Family Caregiver Program, which includes several services for caregivers, including the placement of a caregiver support coordinator at each Veterans Affairs center, adult day health care centers, a peer support program for caregivers, and expanded services for caregivers of post-9/11 veterans, including monthly stipends.⁵⁰ A key element in the success of these programs has been the incorporation of caregivers in the development of training materials and partnerships with local home care and hospice agencies.

Finally, the American Association of Retired Persons has sponsored legislation called the Caregiver, Advise, Record, and Enable Act, which requires hospitals to record the name of a family caregiver when a patient is admitted to the hospital, notify that person when the patient is to be discharged, and give instructions of medical tasks for transitioning the patient home. At the time of this writing, 18 states and Puerto Rico have already passed this legislation, and this further warrants the development of an evidence base for how to best prepare caregivers for the roles that they may be expected to play.

Challenges in Incorporating Informal Caregivers Into Health Care Systems

Specific recommendations for the inclusion of family caregivers in cancer care are lacking; thus, interventions aimed at helping caregivers are generally unsupported within health care systems. In addition, a lack of financial incentives (eg, insurance, billing, and other funding), licensure constraints, organizational constraints, and staff turnover are key challenges to implementing into practice evidence-based interventions that recognize and integrate caregivers in health care settings. A better understanding and translation of models of care in which caregivers are successfully integrated into practice (eg, the Veterans Affairs program⁵⁰) are needed. Integration will require assessments of caregivers' capacity or readiness to be able to perform necessary tasks for individual patients.⁵¹ There was strong recognition among meeting participants that to assist health care systems in focusing on helping caregivers and patient-caregiver dyads, stakeholders must work collaboratively to incorporate informal cancer caregiving into the health care delivery process.

BOX 3. Research Recommendations for Facilitating Further Integration of Caregivers Into Formal Health Care Settings

1. Develop standardized formal recommendations for integrating informal caregivers in diverse clinical settings.
 2. Translate models of caregiver integration (eg, care coordination, caregiver or family navigation, and handoff communication between caregivers and clinicians) that have been successful in other disease or clinical settings or, when necessary, develop and test novel models for caregiver integration.
 3. Evaluate caregiver capacity and establish reasonable levels of expectations of responsibility and accountability for informal caregivers.
 4. Disseminate and implement successful interventions and models on multiple levels (hospital, clinician, and caregiver or dyad level) with existing and newly developed platforms and resources.
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SESSION 4: THE ROLE OF TECHNOLOGY IN SUPPORTING CANCER CAREGIVING

The rapid evolution of technology and media continues to provide new opportunities and challenges for informal cancer caregiving. Today, more than 84% of American adults report using the Internet,⁵² and an estimated 64% own a smart phone.⁵³ The continued implementation of electronic health record systems and the expanded use of hand-held technology, along with the rapid growth in the number of cancer survivors, point to an urgent need to systematically evaluate the role of technology in supporting cancer caregiving. This session highlighted exemplary projects that leverage technology to support caregivers and overcome geospatial and access limitations.

Automated Cancer Symptom Reporting Systems

Originally designed as an adverse event reporting system to help identify and rapidly address treatment-associated symptoms and disease self-management (as originally introduced in the Chronic Care Model⁵⁴), technology-facilitated automated systems (eg, interactive voice recognition systems) have been used to deliver support to cancer patients and caregivers.^{55,56} Over the last decade, such systems have been implemented in a variety of cancer care settings and have demonstrated benefits in symptom management, outpatient self-management, and improved patient psychological well-being.^{57,58} Although commercially available interactive applications to aid caregivers in task management (eg, appointment scheduling) have a longer history, the use of interactive platforms to address the needs of both patients and caregivers is relatively new and is just being tested.⁵⁹ One major observation, based on an ongoing study of a cancer caregiving support system, is the importance of connecting such systems seamlessly into the existing clinical workflow. Although more tests are needed to ascertain the efficacy and effectiveness of these technology-mediated caregiving support interventions, these systems have the potential to be highly scalable and can be easily disseminated in cancer care settings.

Online Peer-To-Peer Support Networks

A set of separate and in many ways complementary technology-based interventions aimed at reaching caregivers to provide informational and emotional support include online networks and social media platforms (eg, the Association of Cancer Online Resources⁶⁰). To better leverage such online platforms for caregiver support,

researchers are beginning to study the structure, use, and functional dynamics of online communities. Specifically, they are seeking to identify potential active ingredients needed to ensure a given online community's vibrancy and sustainability, such as content contributions of individual members, community members' mutual validation, the amount of activity needed for benefit, and the optimal group size and network structure.⁶¹ It is hoped that this expanded information can inform the development of future social media approaches to better support cancer caregivers and improve psychosocial outcomes.

Challenges to Developing and Implementing Technological Interventions for Caregivers

Two major challenges to implementing evidence-based technological interventions identified by meeting participants are 1) the common development of new interactive health communication technologies without empirical testing or attention to scientific evidence and 2) the lack of social media integration despite overwhelming support and need.⁶² In addition, beyond the challenges already facing the development of technologies to support patients, caregivers have unique and often unmet needs for informational, emotional, and logistical support that require attention when technology-mediated interventions are being developed. Some of these needs could be met by the facilitation of caregivers' access to electronic health record data (eg, via online patient portals) so that they can be informed and active participants in decision making and care. However, further study is warranted to understand how caregivers and patients differ with respect to the use of technology-enabled tools and information and to develop and test tools that best support caregivers.

BOX 4. Research Recommendations for Maximizing the Positive Impact of Technology on Informal Cancer Caregiving

1. Connect stakeholders, including developers, researchers, and patient/caregiver advocates, to develop and test evidence-based, patient- and family-centered technologies.
2. Monitor potential problems with increased peer-to-peer connectivity, including the spread of misinformation, distress, and mistrust of health care providers and health care systems, especially for those with limited health literacy.
3. Consider the conditions under which online peer-to-peer support is most effective (eg, for geographically isolated caregivers).
4. Develop evidence-based technologies to support caregiving, including enhanced communication, virtual support, smart monitoring, adaptive coaching/prompting systems, and wearable technologies.

CONCLUSIONS AND FUTURE DIRECTIONS

There is a growing appreciation of not only the critical role that informal cancer caregivers play in the health of those for whom they care but also the toll that this care may take on their own health and functioning. Despite many commonalities of the caregiving role, a number of the challenges that these individuals face are unique to the cancer context. The large attendance of members from the research community in this informal cancer caregiving meeting gives further credence to the need for pushing the science in this topic area.

Throughout the meeting, caregiver attendees spoke about their own personal journeys with cancer caregiving. One indicated that being a cancer caregiver is not just about providing care; caregivers are also needed to provide support and hope. Another described her husband's cancer diagnosis and emphasized that they experienced the cancer journey together as partners. Their remarks are a reminder of how personal these issues and experiences are for families and that the impact of cancer on caregivers can be substantial.

The 2-day meeting highlighted several challenges and directions that need to be addressed in future research with cancer caregivers and with patient-caregiver dyads. In addition to the recommendations presented thus far, additional resources could have a significant impact on the goal of advancing informal cancer caregiving research. Examples include the following:

1. A network of scientists and clinicians to share best practices to advance informal cancer caregiving research.
2. A toolbox of measures to capture the caregiving experience along with potential outcomes of interest that could be targets for intervention studies.
3. National tracking of the number of cancer caregivers and the level of burden that they experience.
4. Outreach to promote broader dissemination of study results.
5. Collaborations between federal and nonfederal agencies to generate research in informal cancer caregiving.
6. Periodic state-of-the-science conferences and panels at national conferences to track progress toward achieving the meeting objectives and identify new directions for future research.
7. An expansion from the current health care focus of being patient-centered to being family-oriented.

All of the these recommendations will require a fundamental recognition of the importance of informal cancer caregivers and collaboration among cancer patients,

caregivers, health care providers, researchers, clinicians, federal and nonfederal funding agencies, and advocacy groups to move research forward and ultimately respond to the needs of cancer patients and their families.

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