

Supporting the Supporters: What Family Caregivers Need to Care for a Loved One With Cancer

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Abstract

Patients with cancer who live at home often require help with activities of daily living, basic medical care (eg, injections), social needs, and patient advocacy. Most of that support comes from intimate caregivers, typically members of the patient's family. These family caregivers themselves require support so that they can be effective and maintain their own well-being while caring for the patient with cancer. Research shows that support for caregivers contributes to achieving these goals. We propose a four-part framework for supporting family caregivers: (1) assess caregivers' needs using formal measures, just as the cancer patient's own needs are assessed, (2) educate caregivers for their caregiving roles, most notably, with training in the low-level medical support that cancer patients require at home, (3) empower caregivers to become full-fledged members of the patient's cancer team, all working toward common goals, and (4) assist caregivers proactively in their duties, so that they retain a sense of control and self-efficacy rather than having to react to imminent medical crises without sufficient resources at their disposal. Funding support for family caregivers requires refocusing on the overall well-being of the patient-caregiver dyad rather than just on the patient. It will necessitate a paradigm shift in reimbursement that recognizes the need for holistic cancer care.

[I]n the desperate race for cancer cures, I also hope that doctors, politicians, and scientists will remember to look to the dark side of that moon—where the caregivers live—and find a way to ease their journey.¹

An estimated 4.6 million people in the United States care for someone with cancer at home.² Too often, these caregivers—spouses, other family members, or friends—are poorly prepared for this vital but demanding role that takes a toll on them and, by extension, the patient.^{3,4} Only one third of all caregivers report being asked by a health care provider what they need to care for the patient; even fewer are asked what they need to

care for themselves.² That lack of preparation can worsen the anxiety that caregivers already feel about a loved one's health.⁵⁻¹⁰

An at-home caregiver, whom we simply call the family caregiver, typically provides the patient with cancer with at least four types of assistance: (1) daily living activities (eg, transportation, meals); (2) medical care (eg, wound care, medication management, injections); (3) social support (eg, companionship, encouragement, communication with friends and family); and (4) advocacy (eg, with providers and insurers).¹¹ If the patient's illness progresses, a caregiver's responsibilities often consume even more time, energy, and emotional resources. The patient may need help with



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walking, bathing, toileting, and self-feeding, just as hope for disease remission is fading.¹⁰

A family caregiver's work can be a full-time occupation—an average estimate of 8.3 hours per day for 13.7 months, according to one U.S. study,¹² and of 66 hours per week during the patient's last year of life, as documented in another study.¹³ Caregiving also is a high-risk occupation¹⁴ whose effects on the caregiver have been linked empirically to diminished quality of life, depression, impaired immunity, heart disease, and early death.^{10,15-21} Many family caregivers also have to quit a paying job or take extended leave, which worsens the financial impact of a cancer diagnosis.^{2,22} Lifestyle disruption and social isolation are common, as one family caregiver's comment illustrates¹:

Jonathan now has a quality of life that can only be described as poor. And so, truthfully, is mine. The fact that he is incapable of leaving the house and enjoying a movie or a walk in the park means that I no longer can do these things, either. Like other well-spouse caretakers, I am a victim, too, of his illness.

The psychological burden may be even greater for family caregivers than for the patient, especially as the disease advances,¹⁰ and greater for female than for male caregivers.⁷ Stress is particularly heavy if caregivers feel ill prepared: a sense of low self-efficacy heightens the perceived burden, so it is important to develop self-confidence for the caregiving role.¹⁶

As patients with cancer benefit from advances in therapy and extended survival, treatment is shifting from inpatient to outpatient settings, and more daily caregiving now occurs in the home. In-home support may have bidirectional health effects: the patient's health affects the family caregiver's health and vice versa.²³ Nevertheless, family caregivers are often not seen as valuable human resources who themselves require support to give support.^{8,11,23} With cancer and other serious diseases, support services must extend beyond the patient to his or her primary source of home assistance, if any. A 2016 report calls for a national strategy on family caregiving that advances the goal of achieving family-centered care.²⁴

EVIDENCE ON SUPPORTING CANCER CAREGIVERS

Meta-analyses of caregiver interventions reveal positive outcomes for family caregivers and patients alike. As Northouse et al^{16(p1229)} wrote, “[W]hen the patient-caregiver dyad is treated as the unit of care, important synergies are achieved that contribute to the well-being of both patients and caregivers.”

Education, skills training, and therapeutic counseling for caregivers favorably affect how they perceive their burden, quality of life, coping skills, and knowledge while lowering their levels of depression and distress.^{7,16,25-29} By the same token, patients who are effectively supported by a caregiver are less symptomatic and experience better physical and mental health than are controls.^{16,25,27-29}

Most cancer centers and clinics do not offer comprehensive caregiver support programs, despite clear evidence of benefit.¹⁶ One barrier is the lack of a cohesive framework that outlines which types of services to offer—and how to pay for and measure the effects of those investments. We propose such a framework, so that cancer organizations can discuss its merits and adopt the components best suited to their institutions.

A FRAMEWORK FOR SUPPORTING CANCER CAREGIVERS

Family caregivers fall into two broad categories. One group cares for patients with an advanced metastatic cancer that is unlikely to be cured but requires chronic management for months to years. Not unlike patients with advanced heart failure or lung disease, many cancer patients experience periods of stability interspersed with high-stress, high-need spikes, ultimately culminating in irreversible decline. A second group cares for patients who undergo curative-intent therapy that is often highly intensive. The physical and emotional toll may be overwhelming for families of patients who receive induction therapy for acute leukemia, allogeneic and autologous stem-cell transplantation, or complex multimodality care (eg, for osteosarcoma). We have identified four categories of interventions to support both types of family caregivers and, by extension, the patient and clinical-care team.

Assess

The clinical team for the patient with cancer must first identify who (if anyone) will assume primary home-caregiving duties and which other people constitute the wider caregiving circle (because they can periodically assist the patient, the primary family caregiver, and the clinical team). Visually rendering the entire structure of clinical and family caregivers is a practical way to link everyone in the caregiving network so that they can communicate easily (Fig 1).

Just as a comprehensive assessment of the patient is used to formulate a treatment plan, so should the family caregiver be assessed to formulate a caregiver support plan. Ideally, an assigned nurse or social worker navigator would conduct the

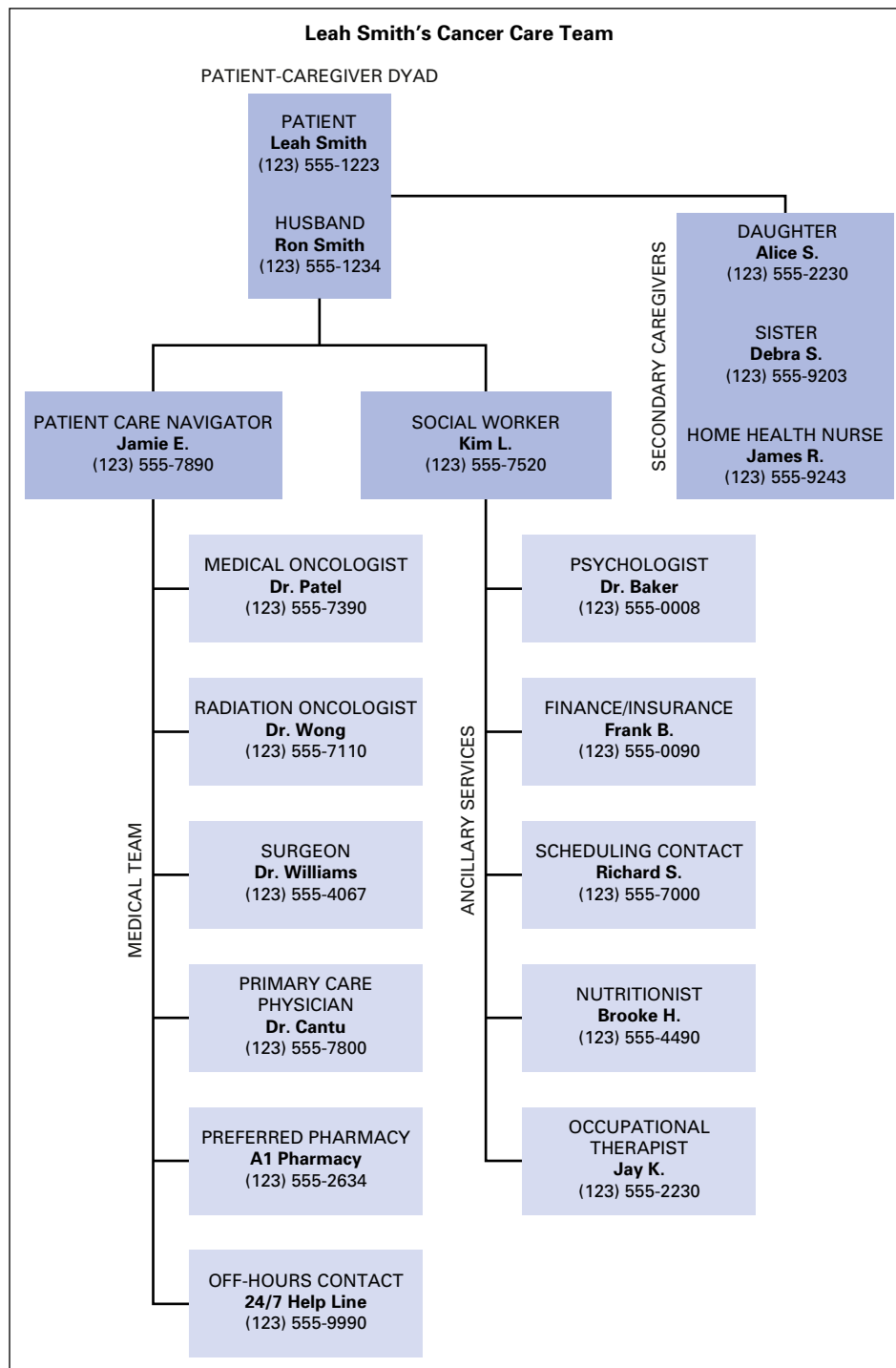


FIG 1. Visual rendering of a patient's support network, with contact information, captured in the electronic health record and available to all stakeholders involved in the patient's well-being.

initial caregiver assessment in person. This early face-to-face contact can help to establish trust between the patient's home-based and outside support networks and reveal what

the family caregiver needs to fulfill this role. The caregiver assessment should include the caregiver's availability (employment status, family responsibilities, community

activities); competency (formal education, caregiving experience, medical skills, mental stability); family dynamics (strength of relationship with the patient, family, and friends); financial situation (insurance status, income, savings, transportation); and willingness to give care.¹⁶ Salient information from the interview can be entered in the patient's electronic health record (EHR).

Validated scales exist for measuring a family caregiver's needs and evolving burden (eg, quality of life, social isolation, family impact, financial stress, physical and mental health). These scales include the Caregiver Reaction Assessment³⁰ and the Cancer Caregiving Tasks, Consequences, and Needs questionnaire.³¹ The selected scale, administered to the caregiver soon after the patient's cancer diagnosis, would provide baseline data. It can then be administered every 3 to 6 months (more often, if indicated), with data recorded in the EHR so that the clinical team can track the caregiver's changing needs. Administering the scale electronically is feasible if the caregiver can access a computer, tablet, or smartphone—and if the EHR can capture the data. All of these steps may seem cumbersome, but in the long run, they offer the potential to improve clinical outcomes; lessen the patient's, caregiver's, and clinical team's burdens; and save money.

Educate

Preparing family caregivers for their role must involve explicit education, including skills training.^{16,32-36} Larger cancer centers should consider developing a caregiver curriculum with standard general offerings (eg, medication management, treatment adverse effects, symptom management, nutrition, stress management) and specialized offerings tailored to individual caregivers' needs (eg, family communication, financial/insurance guidance, community resources, behavioral counseling). An interdisciplinary faculty could include community volunteers, such as clergy, clinical psychologists, and nutritionists (if not already on staff). A combination of in-person and remote (telephone, online, videoconferencing) approaches can be used with both the patient-caregiver dyad and the caregiver separately.

One example, a pilot project at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center, trains family caregivers of children with cancer to safely manage central venous catheters at home. The project includes structured education and teach-back, simulation using a mannequin, and longitudinal knowledge and skills assessment. Another approach is to integrate prerecorded educational material into

the care process. For example, MD Anderson offers patients and caregivers educational videos during the unavoidable wait time between rooming by the nurse and the physician encounter. Financial concerns also burden many cancer families.^{22,37-39} Lacks Cancer Centers offer financial navigation services, tailored to a family's circumstances, that save the family money and reduce Lacks' use of charity care and its burden of bad debt.^{11,40}

Although some educational offerings must be delivered one-on-one to ensure privacy, others work in group settings. The group appointment model, commonly used to educate patients who share a newly diagnosed chronic disease, can be used with cancer caregivers.^{11,25}

Preparing caregivers should be an ongoing process so that benefits are sustained and educational services evolve as needed.^{19,32} Investment in a caregiver curriculum can be a shared responsibility among cancer practices, professional cancer and caregiver organizations, and community organizations, particularly in communities lacking a large health system. In addition, just as many cancer centers match newly diagnosed patients with volunteer mentors (eg, post-treatment patients who have the same type of cancer), they could match new cancer caregivers with experienced ones. Research shows that when patients with advanced cancer receive early (rather than delayed) palliative care that involves the family, caregivers experience significantly less depression and stress.²⁶

Empower

The concept of empowerment is typically used in employment contexts,^{41,42} but it is relevant to any ongoing role in which someone needs to feel confident; in control of his or her tasks; responsible for performing well; included, respected, and listened to by a larger group; and appreciated for contributing to the mission at hand. Feeling empowered also requires being well informed about what is occurring and what lies ahead.

Family caregivers are more likely to be effective and less likely to feel overwhelmed if both they and their ill loved ones are empowered as full-fledged members of a care team working toward a common goal. Cancer, more than most other illnesses, demands ongoing formal care in medical facilities and informal care where the patient lives. The formal and informal providers, as well as the patient, must coordinate with one another and pool resources to reach the best possible outcome, just as a team does. Each team member's expertise is integral to achieving the goal. Consider these examples:

- A nurse, who was the primary caregiver for her father and husband, made this statement at a 2015 Institute for Healthcare Improvement forum: “Caregivers have so much to tell. The clinicians need to hear from them.” She identified her most important caregiving roles as protecting, advocating for, and ensuring respectful, dignified treatment of her family members.
- A woman whose husband had bladder cancer said in a personal interview, “I would say to the nurses, ‘Give him saline with that.’ They would say, ‘It is not needed,’ and I would reply, ‘It makes him feel better.’”

Because many caregivers are not as proactive as these family members, an explicit invitation to join forces with the formal care team—and processes that facilitate involvement—are essential. Investing in teamwork empowers caregivers by fostering transparency, responsiveness to team members’ needs, open discussion and problem solving, mutual learning and appreciation, and, of course, trust.^{42,43}

Assist

Any caregiver-support program must strengthen caregivers’ sense of control over their lives and provide greater peace of mind. That happens when family caregivers know that they can receive assistance when they need it, ranging from getting a medication question answered to dealing with an emergency.

Current practices are mostly reactive (ie, the caregiver initiates contact and the provider organization responds). To offer proactive assistance, a provider must anticipate issues, monitor patients, and intervene early. At Michigan’s Henry Ford Health System Cancer Center, for example, pharmacists use a standard checklist to proactively phone the households of all of the center’s patients who are receiving oral chemotherapy so that they can intervene when needed.

Cancer centers could also consider using low-cost, high-speed technology proactively. In a 2015 national study, 71% of caregivers reported being interested in using technology to support them in their caregiving roles.⁴⁴ Imagine a family caregiver consulting videos on an organizational YouTube channel,⁴⁵ lessons on an eLearning website, or interactive media via a take-home CD⁴⁶ when facing a challenge, or using the EHR patient portal to regularly report the patient’s symptoms and access contact information for support personnel.⁴⁷ Caregivers also could benefit from enhanced real-time assistance from national organizations (eg, American Cancer Society, National Cancer Institute, National Alliance for Caregiving, and Family Caregiver Alliance) through mobile applications with credible

references and educational media (akin to the physician resource UpToDate), thereby replacing cold searches online.⁴⁸

Reactive assistance is also needed, of course, but it often comes with delays, such as when an anxious caregiver calls the physician’s office only to land on the busy staff’s long list of return calls. During off hours, delays are even worse. Patient navigation services (now a cancer-center accreditation standard of the American College of Surgeons) can offer timely, reliable assistance to family caregivers and patients. An effective navigator (usually a nurse or social worker) or navigation team (nurse plus social worker) can be a go-to resource for patient and caregiver needs, such as clarifying a doctor’s instructions, scheduling appointments, resolving transportation difficulties, and managing medications.^{49,50} These triage services could even be offered as an online chat feature on the EHR patient portal, which could help staff assist multiple individuals more quickly.

Providing off-hours care at a cancer urgent-care clinic, where staff access a symptomatic patient’s EHR to assist the patient and the worried caregiver, is one option for high-volume practices. Arizona-based Hospice of the Valley offers another choice: an off-hours call center staffed by nurses who have EHR access. If indicated, a nurse is sent to the patient’s home within 2 hours. Almost all of the incoming calls on a Saturday when one of us (L.L.B.) was listening were from spouse caregivers. Consider the potential benefits for patients, families, providers, and payers if an experienced call-center nurse were available to all cancer families, not just patients receiving hospice care.¹¹ Many emergency room visits and subsequent hospitalizations could be avoided.⁵¹⁻⁵³

Veterans Affairs centers are exemplary in providing caregiver education and assistance. In 2016, 23,000 caregivers used Veterans Affairs services developed specifically for them, including support phone lines, support coordinators, peer-support mentoring programs, online training, in-home skilled nursing care, and up to 30 days per year of respite care.⁵⁴

HOW TO FUND THE SUPPORT

Now for the elephant in the room: money. Health systems and cancer centers make money treating people who are sick. Fee-for-service reimbursement effectively blocks robust investment in caregiver services. If a patient with cancer uses more health care because informal, in-home care is lacking, more fee income is generated. This unintended but serious consequence of an outdated reimbursement system ignores the real value that family caregivers of seriously ill patients provide.

A common mistake of corporations is to be blind to invisible, long-term costs while pursuing clearer short-term gains. A cancer practice that ignores the hidden value of caregiver services reduces its short-term costs while raising the risk that the patient will need more-formal, higher-cost services down the road. In short, the practice is not fully leveraging the resources that could be provided by unpaid caregivers if they are well prepared for the caregiving role. All stakeholders, including the payer, should have an interest in changing that reality.

The Center for Medicare & Medicaid Innovation's Oncology Care Model, which bundles payments for all provided services, includes a shared-savings component,⁵⁵ thereby making long-term costs more visible to the provider organization and shifting risk from the payer to the provider.⁵⁶ Risk transfer can work, however, only if the provider can control (or at least influence) the assumed risks.⁵⁶ If a health system is going to accept risk, it must keep its patients as healthy as possible, and family caregivers help to achieve that goal.^{16,25}

Because caregivers are more vulnerable to becoming sick (or sicker) themselves, well-designed value-based payment systems that encourage investment in caregiver services strengthen the business case for such programs. One model worth testing by the Centers for Medicare & Medicaid Services and commercial payers is a value-based system that incorporates two care-management fees for cancer practices. One fee would fund patient services, such as patient navigators, who are not typically reimbursed because they are not coded treatments; the other would fund caregiver support services. Both fees could be paid several times a year on a sliding scale, according to prespecified benchmarks of performance using documented metrics.

Bigger, forward-thinking employers are potential allies in funding family caregiver programs if they work directly with cancer centers that treat employees or family members or if they partner with an insurer. After all, employers suffer losses when employees who have a seriously ill family member miss work.^{57,58} For many companies, presenteeism (when workers are less productive because they or someone in their family is ill) represents a much larger (although less visible) cost than that of health insurance benefits.^{59,60}

SERVING THE PATIENT-CAREGIVER DYAD

Research consistently shows the benefits of well-planned services that support family caregivers in a role for which they often are ill prepared cognitively and emotionally.^{16,25} A cohesive program of caregiver support can mitigate that

burden, yet a considerable gap remains between what is known to benefit cancer caregivers and what actually gets implemented.^{16,24} Prioritizing the acute medical needs of a patient with cancer makes sense, but evidence reveals the upside for the patient if the focus of care expands to the patient-caregiver dyad.²³ Making the family caregiver an afterthought or a peripheral concern is a missed opportunity in cancer care. It is time to move beyond the concept of merely patient-centered care and place both the patient and the family caregiver at the center of care that benefits all stakeholders in the complex task of serving patients with cancer. **JOP**

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