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Commentary

Fit for Duty: Lessons Learned from Outpatient and Homebound Hematopoietic Cell Transplantation to Prepare Family Caregivers for Home-Based Care



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Article history:

Received 30 September 2022

Accepted 16 December 2022

A B S T R A C T

In the past decade, the demand for home-based care has been amplified by the Coronavirus disease 2019 pandemic. Home-based care has significant benefits for patients, their families, and healthcare systems, but it relies on the often-invisible workforce of family and friend caregivers who shoulder essential health care responsibilities, frequently with inadequate training and support. Hematopoietic cell transplantation (HCT), a potentially curative but intensive treatment for many patients with blood disorders, is being increasingly offered in home-based care settings and necessitates the involvement of family caregivers for significant patient care responsibilities. However, guidelines for supporting and preparing HCT caregivers to effectively care for their loved ones at home have not yet been established. Here, informed by the literature and our collective experience as clinicians and researchers who care for diverse patients with hematologic malignancies undergoing HCT, we provide considerations and recommendations to better support and prepare family caregivers in home-based HCT and, by extension, family caregivers supporting patients with other serious illnesses at home. We suggest tangible ways to screen family caregivers for distress and care delivery challenges, educate and train them to prepare for their caregiving role, and create an infrastructure of support for family caregivers within this emerging care delivery model.

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At least 53 million people in the United States serve as family caregivers, defined as family members and friends who provide

unpaid care to patients with life-threatening, incurable illnesses [1]. The number of family caregivers in the US has grown by >20% since 2015 [2]. This dramatic increase reflects in part the enormous impact of the Coronavirus disease 2019 (COVID-19) pandemic, which has overwhelmed hospital capacity and resulted in expansion of ambulatory and telehealth services that rely heavily on family caregiver support [3]. Beyond the recent impact of the pandemic, growth in outpatient treatment and home-based care was already occurring in preceding years [4] due to rising healthcare costs, shorter hospital stays, and patient preference for these treatment settings [5].

Financial disclosure: See Acknowledgments on page 148.

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<https://doi.org/10.1016/j.jtct.2022.12.014>

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Outpatient and home-based care delivery models have benefited both patients and providers [6,7], and the COVID-19 pandemic encouraged examination of new models of home-based care [8] and payment structures to support such programs [8,9]. Oncology has led this shift in care, as the pandemic prompted global changes in cancer care delivery, with efforts made to minimize unnecessary COVID-19 exposure, particularly for vulnerable patients [9,10]. The Penn Cancer Care at Home (CC@H) program [11] is one successful example of this movement. There is growing evidence that home chemotherapy infusion results in comparable care and improved patient and family caregiver experience at lower costs than inpatient or outpatient infusion [12–16]. Indeed, the home may become the new cancer center [8].

While home-based care programs are emerging, gaps in reimbursement and the absence of standards for equity, quality, and safety have prevented broader adoption [17]. An additional—and addressable—barrier is the often-unrecognized but critical role played by family caregivers in the setting of home care and the need for training and support to assist them with their increased responsibilities [18]. Family caregivers are expected to navigate the intricacies of our healthcare system as they provide care coordination [9] and assistance and manage complex medical needs at home. Family caregivers shoulder these responsibilities with inconsistent preparation and suffer negative physical and mental health consequences as a result [19–21]. This is a hidden cost to home-based treatment, as outcomes are often measured by patient satisfaction, disease outcomes, or financial savings [22]. Moreover, little is known about what constitutes a caregiver who is “fit for duty” to support patients receiving homebound care.

Hematopoietic cell transplantation (HCT) is one particular treatment modality increasingly offered in the home-based care setting that depends heavily on family caregivers to take on significant responsibilities in patient care [23]. Given the proliferation of outpatient and home-based care programs, there is an urgent need to establish standards and guidelines to train and support family caregivers of patients receiving care in these settings. Herein we offer recommendations to better support family caregivers of HCT patients receiving home-based care in an effort to further define how caregivers may be “fit for duty” and better supported throughout HCT treatment. These recommendations include tangible ways to (1) screen family caregivers for distress and care delivery challenges, (2) educate and train family caregivers to prepare them for their caregiving role, and (3) create an infrastructure of support for family caregivers within this care delivery model. Our collective experiences inform these recommendations as clinicians and researchers caring for patients with hematologic malignancies undergoing HCT.

Although HCT exemplifies the shifting treatment landscape toward home-based care significantly relying on family caregivers, the recommendations offered herein also apply to caregivers supporting patients with other types of serious illnesses at home.

OUTPATIENT AND HOMEBOUND HCT AND THE ROLE OF FAMILY CAREGIVERS

Although HCT traditionally is conducted in the inpatient setting, the conditioning regimen, transplantation, and subsequent care are being increasingly offered in outpatient settings (ie, outpatient HCT) as an acceptable alternative to inpatient HCT. Additionally, a small number of programs have piloted completely homebound HCTs, where patients receive their transplant and then return home (or to a homelike setting)

immediately, with the remainder of care delivered in the home [22]. However, both outpatient and homebound HCT protocols depend on the availability and willingness of caregivers to provide demanding, complex, and unpaid care for 24 hours per day, 7 days per week, for up to 100 days post-transplantation [5,24,25]. Indeed, HCT teams conducting homebound protocols require the formal documented consent of one family caregiver who agrees to fulfill such responsibilities for patient care [26,27]. As such, outpatient and homebound HCT places a significant burden on family caregivers, and there is often inadequate preparation for those entering into this role. In the outpatient and homebound HCT setting, family caregivers must manage their loved one's direct care, bridge communication between the patient and clinicians, and manage general life and economic demands, including other caregiving and childcare responsibilities. Strikingly, despite these significant responsibilities, to our knowledge, there is no routine screening of family caregivers' readiness to serve in this role, and no existing guidelines to direct such screening and subsequent provision of support.

In one of the few studies explicitly examining the experiences of caregivers providing care to patients receiving homebound HCT, Jenkelowitz et al. [27] highlighted this model's potential strengths (eg, a sense of normalcy for patients and caregivers in the home environment) and challenges (eg, caregivers feeling unprepared for nursing responsibilities, managing adverse medical events, and supporting the emotional well-being of patients). These findings parallel challenges reported by caregivers of inpatient HCT recipients, including physical concerns (eg, fatigue, cognitive dysfunction, sexual issues, sleep disturbance), psychological and spiritual distress, social isolation, financial concerns, and strained family relationships [28]. Lack of caregivers' preparedness for this role likely mediates observed challenges, such as strained patient/caregiver relationships and caregivers' diminished internal (eg, sense of control) and external (eg, financial stability, ability to care for oneself) resources [28]. Because family caregivers are essential to the recovery and clinical outcomes of HCT recipients [29], especially in the outpatient and homebound settings, supportive interventions are critically needed to address caregiver distress, facilitate coping, and provide training to increase caregivers' confidence in their ability to manage patient care responsibilities.

SUPPORTING FAMILY CAREGIVERS OF PATIENTS UNDERGOING HCT: LESSONS LEARNED

Several psychosocial interventions have been developed to support family caregivers of inpatient HCT recipients [30–33]. Those demonstrating the greatest promise in improving caregivers' quality of life incorporate cognitive behavioral therapy (CBT) skills, relaxation training, coping strategies, and communication skills training. For example, BMT-CARE [30] is a family caregiver intervention involving 6 sessions starting before HCT and continuing up to 60-days post-HCT. BMT-CARE includes skills pertaining to preparing for transplant and symptom and medication management, managing expectations, mobilizing social support, and assessment of postdischarge needs during the HCT course. BMT-CARE also teaches family caregivers CBT skills-based strategies, including cognitive reframing, mindfulness, communication, and acceptance while living with uncertainty, as well as behavioral self-care to facilitate effective coping and promote caregiver physical and mental well-being. Secondary analyses of BMT-CARE underscore the central role of coping skills and self-efficacy in facilitating improvements in caregiver mood and quality of life [34].

Another promising CBT-based stress management intervention is PsychoEducation, Paced Respiration, and Relaxation (PEPRR) [31], which is delivered over 8 sessions and has been shown to positively impact perceived stress, depression, and anxiety in caregivers of inpatient HCT recipients. PEPRR includes an overview of key domains: stress management; impact of stress on physical and emotional health; training in coping skills; addressing lack of control, uncertainty, and fear; improving communication strategies; adapting to changing role(s); using effective social support; using biofeedback; and managing health-related behaviors [35]. To date, however, the effects of supportive interventions such as these have not been evaluated among family caregivers of homebound HCT recipients [36].

The benefits conferred by current CBT-based interventions for family caregivers of HCT recipients help family caregivers serve as an extension (ie, the eyes and ears) of the healthcare team. Diverse skills and approaches—in addition to those conferred by these psychotherapeutic packages—are crucial to ensuring that family caregivers can adequately monitor changes in patient symptoms (eg, development of infection) and protect against poor medical outcomes. Lessons from other cancer and chronic illness populations provide insight regarding opportunities to bolster family caregiver support for homebound HCT recipients and potentially other vulnerable oncology caregiver populations. For example, in an integrated dyadic psychosocial intervention delivered to patients with incurable cancers receiving home-based palliative care and their family caregivers [37], the benefits of psychosocial support for patients and families plus homecare conferences with the palliative care team contributed to significant improvements in family caregiver anxiety and depression. Moreover, one-on-one training with a palliative care nurse increased family caregivers' knowledge about cancer pain, helped them manage pain effectively, and enhanced their self-efficacy to perform various nursing tasks independently [38]. Finally, a home-based self-management intervention for patients with heart failure and their family caregivers that included education for caregivers about heart failure management, supportive resources about caregiving, and a needs assessment for intervention tailoring was found to improve caregivers' confidence in self-management and, subsequently, their well-being [39]. These findings underscore the potential of targeted interventions to effectively increase caregiver preparedness for their patient care responsibilities at home.

Protocols for existing outpatient and homebound HCT programs, such as those at Memorial Sloan Kettering Cancer Center [24], Duke Cancer Institute [25,40], and Froedtert & the Medical College of Wisconsin Cancer Center [41,42], highlight the importance of additional evaluations and training for family caregivers beyond psychosocial skills enhancement. These approaches include (1) an assessment of cleanliness and suitability of the home and community environment for HCT recovery; (2) safety evaluations of the home and the patient/family caregiver relationship (eg, history of domestic violence, illicit drug or alcohol use, history of mental illness in the household, presence of firearms in the household); (3) determination of family caregivers' comfort in using technology for telemedicine and communication with the healthcare team; and (4) distance and accessibility to the nearest cancer center. Together, these exemplar programs and studies in other serious illness populations suggest the need for and benefits of in-depth screening and multicomponent supportive interventions for family caregivers of patients receiving home-based HCT care that entail education about medical issues and

physical symptom management, caregiving skills training, psychological interventions, and self-care strategies to prepare family caregivers for their upcoming responsibilities. Indeed, a standardized screening and support program for family caregivers integrated into HCT protocols has the potential to improve family caregivers' capacity to be “fit for duty.” Family caregivers who are fit for duty have the ability to navigate resources and services to manage patients' complex and diverse needs. Furthermore, fit for duty family caregivers have the training to manage their own emotional and physical well-being and to adequately address challenges that may accompany their caregiving role.

RECOMMENDATIONS

Informed by the existing literature and our collective experiences as a multidisciplinary group of clinicians and researchers who care for vulnerable oncologic populations, including patients undergoing outpatient and homebound HCT, we provide the following recommendations for services to promote the quality of life and well-being of caregivers providing care for homebound HCT recipients and, by extension, caregivers of patients receiving other complex medical care in the home setting. In Table 1, we explore the potential challenges and barriers to implementing these recommendations and suggest potential solutions.

1. Development of an infrastructure to support the documentation and storing of family caregiver data. Creating separate official medical records for caregivers will facilitate the ethical storing of caregiver-specific data, including documentation of screening data and psychosocial interventions delivered [43]. Such an infrastructure must be established to successfully implement the following recommendations.
2. Delivery of comprehensive family caregiver screening pre-HCT. Screening for a family caregiver's ability to effectively take on the role of caring for a loved one recovering from HCT should include an assessment of (a) the family caregiver's past caregiving experiences and comfort with the caregiving role; (b) the family caregiver's physical health and capacity to carry out physical tasks of caregiving; (c) the family caregiver's mental health, including psychiatric history potentially exacerbated with increased stress at home due to recovery needs following HCT, current mental health concerns, and engagement in or desire for mental health care services; (d) the family caregiver's cognitive capacity and ability to take on caregiving responsibilities; (e) existing resources and social determinants of health to identify ways in which transplantation teams can further support families receiving outpatient and homebound care (eg, financial and food stability, transportation needs, availability of secondary support persons, ability to manage other responsibilities in the home, such as childcare); f) cultural factors/context that may impact the experience of home-based care (eg, language barriers and health literacy); and (g) factors related to the patient-caregiver relationship (eg, psychological interdependence of the patient-family caregiver dyad). These assessments, conducted by social work team members, can guide family caregiver education, support, and training to ensure that supportive resources match individual needs, particularly for those new to the family caregiving role.
3. Identification of a “family caregiver champion” on the HCT team who will serve as the point person for

- communication with family caregivers. This person likely will be a nurse or social worker and also may be responsible for initial family caregiver consent, distress screening, and follow-up screening throughout the HCT process and recovery.
4. Repeated screening for family caregivers' unmet needs at critical points along the HCT trajectory. Although caregivers' physical and mental health history does not require rescreening, we recommend screening caregivers' current mental health, unmet support, and informational needs weekly for the first 2 weeks, every other week until the 100-day mark, and then monthly through 6 months [44,45].
 5. Education delivered to family caregivers pretransplantation. Priority areas include (a) discussing indicators of potential complications, such as signs of infection and graft-versus-host disease, as well as common burdensome symptoms (eg, pain and fatigue); (b) reviewing the importance of the patient's medication adherence, an overview of common medication side effects post-HCT, and training on the organization and administration of medications (including potential aids in this area, such as strategies to organize pillboxes); and (c) training in nutritional and metabolic support [46]. Increasing family caregivers' knowledge and literacy on the intricacies of expected recovery trajectories following HCT will facilitate timely clinician communication for symptom management that warrants clinical attention.
 6. One-on-one family caregiver training in medical/nursing tasks pre-HCT. Family caregiver education and training to perform basic medical and nursing tasks to ensure safe and effective patient support in the home. Such training should include evidence-based methods such as simulations, teach-backs [47], and opportunities for family caregivers to receive direct supervision from an HCT nurse to practice basic nursing skills (eg, wound care in patients with skin graft-versus-host disease) safely before performing them independently with patients at home.
 7. Ongoing, open communication between family caregivers and the HCT treatment teams. Regular family meetings with the clinical team should be held pretransplantation and post-transplantation. The family caregiver champion should be in attendance, along with possibly other representatives from the multidisciplinary treatment team, including nursing, psychology/social work, and dietitians. We recommend these meetings weekly for the first 2 weeks, then every other week until the 100-day mark, and then monthly through 6 months. These meetings should include a discussion of the family caregiver's questions about their various responsibilities and nursing educational needs, as these may change with the patient's illness trajectory. The repeated screening procedures recommended above should be conducted in advance of these meetings so that results can be discussed with the medical team.
 8. Delivery of targeted psychosocial interventions for family caregivers. All family caregivers should be offered psychosocial support during the first 100 days post-transplantation. Interventions should incorporate psychoeducation and distress management skills from diverse psychotherapeutic modalities including CBT, dialectical behavioral therapy, mindfulness-based relaxation techniques, and acceptance and commitment therapy. Results from routine family caregiver screening can be used to facilitate triage and appropriate psychosocial care that best addresses family caregivers' needs. Interventions should incorporate a focus on self-care and wellness (eg, physical activity, sleep hygiene), social support (eg, who is the existing network and how needs can be met), and effective communication skills for use both with the patient for whom they provide care and the medical team. Family caregivers of patients who suffer medical challenges post-HCT and for whom transplantation is not successful will benefit from interventions that address existential distress and anticipatory grief [41]. Virtual technologies and telemedicine should be used to provide psychosocial support to family caregivers when and where they need it, to mitigate additional burden on family caregivers and HCT teams [48].
 9. Adoption of innovative models for family caregiver supportive service delivery. HCT teams should consider the delivery of supportive interventions by a variety of health-care providers, including psychiatrists, psychologists, social workers, nurses, advance practice providers, and chaplains. Given the shortage of specialty-trained psychosocial oncology clinicians, exploring established innovative models of care for family caregiver support that have been applied effectively with patients (eg, SMART trials [49,50], peer-to-peer support [51], trained volunteers, and community health workers [52]) is imperative. As outpatient/homebound HCT programs expand, developing new strategies to enhance and extend interprofessional team-based support of family caregivers will be necessary.
 10. Identification of critical family caregiver-focused research priorities. Research is needed to adequately define what it means to be a family caregiver who is "fit for duty." There also is a need for randomized controlled trials of family caregiver supportive interventions delivered to caregivers providing care in the homebound setting to establish the efficacy of intervention content, optimal delivery methods, duration, and frequency. Implementation science should translate effective interventions into routine clinical practice [53–55]. Additional priority areas to be addressed include (a) investigation of the roles of cultural factors (eg, acculturation, length of stay in the US, English and health literacy) on the experience of, or definition of, family caregivers of foreign-born patients; (b) determination of when and how the patient-family caregiver relationship should be evaluated and identification of dyadic factors shaping the experience of homebound HCT; (c) exploration of family dynamics and how a particular family caregiver is chosen to consent to the HCT when multiple family caregivers are available; and (d) evaluation of various mobile applications and telehealth care options to reduce cost and enhance scalability and accessibility to diverse caregivers, especially those who live a longer distance from their cancer centers. Notably, efforts are also needed to ensure that screening tools and educational materials are culturally sensitive, translated or easily adapted to different languages, and written at a 5th or 6th grade level.

CHALLENGES

While there is critical need to develop guidelines that support family caregivers of homebound HCT recipients and their often-unmet needs, several challenges remain. For instance, by the nature of their role, family caregivers are not considered patients by the healthcare system, which creates a barrier to accessing many of the supportive services highlighted above. Furthermore, although supporting family caregivers is critical to HCT and successful patient outcomes [56], billing insurance for these services can be challenging, especially in the absence of family caregivers' own medical records [43]. Moreover, the

perceived stigma associated with prioritizing their own needs and receiving support also may be an internal barrier for many family caregivers to obtaining the necessary support [57]. Several policy initiatives may have momentum in acknowledging the burden placed on family caregivers [58,59] such as the Caregiver Advise, Record, Enable (CARE) Act [60],

but more work must be done. Indeed, addressing barriers to reimbursement, limitations of current paid family leave policies, and other public policies is needed to comprehensively implement our recommendations. These and other challenges to implementing the proposed recommendations are outlined in Table 1.

Table 1
Potential Challenges, Solutions, and Exemplars of Proposed Recommendations

Recommendation	Potential Challenges and Barriers	Possible Solutions and Exemplars
Development of an infrastructure to support the documentation and storing of family caregiver data	Limited buy-in from institutional leadership Concerns about HIPAA violations	Maintaining separate medical records for caregivers addresses concerns about privacy and confidentiality of caregiver data. Memorial Sloan Kettering Cancer Center has implemented medical records for caregivers since 2011 for caregivers receiving care in the Caregivers Clinic [61].
Delivery of comprehensive family caregiver screening pre-HCT	Increased burden of work for psychosocial oncology clinicians	Assessment tools, such as the CancerSupportSource-Caregiver [62], can quickly identify areas of distress and unmet needs to facilitate triage to appropriate levels of care to maximize use of available services.
Identification of a “family caregiver champion” on the HCT team who will serve as the point person for communication with family caregivers	Increased burden of work for clinical teams if no established mechanisms to communicate and liaise with family caregivers exists No clear guidelines for which clinical team member would be the best champion to fulfill this role effectively	In many cancer centers, there is one social worker whose work focuses primarily on supporting family caregivers. However, other team members, including nurses or physician assistants who actively care for patients, could also serve in these family caregiver champion roles.
Repeated screening for family caregivers’ unmet needs at critical points along the HCT trajectory	Lack of clarity on who conducts screenings and where information should be housed, especially if/when family caregivers do not have medical records Lack of trained mental health professionals to respond to needs/crises identified by screenings	Family caregiver screening can be built into patient protocols (roadmaps) to trigger screening procedures when patients reach particular treatment and care milestones. Without mental health professionals to support distressed family caregivers, the HCT team should establish a community referral network offering support for caregivers.
Education delivered to family caregivers pretransplantation	Lack of easily accessible evidence-based materials and resources Limited resources for training delivery for individuals who live far from the transplant center Information overload for caregivers (typically focused on patient well-being) during an already stressful period pretransplantation	Beneficial virtual psychoeducation to caregivers of patients with dementia [63] also may benefit HCT caregivers. Consultation with education experts (eg, nurse educators) and in-house simulation teams to explore effective methods for in-person versus virtual training could be helpful. Work with transplantation coordinators and HCT teams to determine a schedule of check-ins to provide caregivers the opportunity to ask questions and inquire about resources they may need across the transplantation trajectory. Leverage multidisciplinary teams to create caregiver-focused support resources. At the Froedtert & the Medical College of Wisconsin, HCT caregivers receive a folder with resources to support their role in the medical care of the patient, as well as resources to address their health and well-being as a caregiver [41].
One-on-one family caregiver training in medical/nursing tasks pre-HCT	Lack of funding to support one-on-one family caregiver training for medical/nursing tasks pre-HCT, given that it is not yet a standard of care (eg, a clinical team member needs to be identified to do this) Lack of training tailored to diverse caregivers based on their backgrounds and ability to engage in medical/nursing tasks	Leverage interprofessional teams to create a list of potential medical/nursing tasks required and apply established learning models to create tailored educational programs for HCT caregivers; caregivers who may already have experience are able to start with more advanced skills. This responsibility can be built into the role of the caregiver champion, if feasible, or shared with other team members.
Ongoing, open communication between family caregivers and the HCT treatment teams	Need to determine optimal site-specific ways to facilitate this line of communication without increasing burden on clinicians and without HIPAA violations	When available, caregiver portals can help streamline communication between family caregivers and HCT treatment teams. Develop a family engagement interprofessional workgroup to determine opportunities in day-to-day clinical practice (eg, during rounds, handoffs) in which structured time for family caregivers is provided by the healthcare team.

(continued)

Delivery of targeted psychosocial interventions for family caregivers	Limited evidenced-based psychosocial interventions tailored to the needs of this specific HCT caregiver population Logistical questions regarding best delivery methods and frequency of interventions Caregiver-specific barriers to engagement in psychosocial care, including availability and interest	A large body of data from other caregiving groups underscores the benefits of support delivered over telemedicine platforms. Significant evidence supports the use of CBT techniques to assist caregivers to cope with shifting demands across the caregiving trajectory [64]. Create an HCT caregiver advisory committee to partner with research teams and clinicians to share perspectives about the feasibility and acceptability of existing interventions to collaboratively develop, test, and translate interventions into HCT standard of care.
Adoption of innovative models for family caregiver supportive service delivery	Cost of developing and maintaining support services	With medical records for caregivers, hospitals can bill for supportive services delivered to caregivers to generate revenue. Expand existing services to include caregivers as the recipient of care (eg, registering as a “patient”). Memorial Sloan Kettering Cancer Center has a Caregivers Clinic housed in the Counseling Center, and at the Froedtert & the Medical College of Wisconsin Cancer Center, caregivers are seen in the Psycho-Oncology Clinic (patients and caregivers seen separately).
Identification of critical family caregiver-focused research priorities	Limited caregiver-centric and family-focused funding opportunity announcements	New funding opportunities through the National Institutes of Health that allow for the development and evaluation of supportive programs for caregivers are needed.

CONCLUSIONS

The availability and health of family caregivers are critical to ensuring optimal outcomes in patients with cancer and other serious illnesses. Through a focus on HCT, a particularly complex treatment that is being increasingly offered in a homebound setting, we suggest guidelines for the screening, training, and support of family caregivers to promote their well-being as care continues to shift to the home. Although cost savings and patient preference are compelling reasons for homebound care and home-based programs such as outpatient HCT, to date no formalized, comprehensive, and evidence-based training programs have been established to prepare and support family caregivers throughout the transplantation journey. As family caregiver burden continues to rise in the context of the ongoing COVID-19 pandemic and the delivery of oncologic and general medical care shifts, more attention is needed on promoting family caregivers' capacity to be “fit for duty” so that they can effectively care for patients at home without compromising their own health.

Although many of the recommendations proposed herein are aspirational, and significant challenges to implementation exist, we must nevertheless work together to support family caregivers, who—like all of the authors—are vital members of the healthcare team.

Conflict of interest statement: There are no conflicts of interest to report.

Financial disclosure: Time for preparation of this manuscript was supported by the National Cancer Institute (Grants K08CA251654 to H.A. and P30 CA08748) and the Cambia Health Foundation Sojourns Scholar Leadership Program (N. M.). A.A. receives funding from Blue Note Therapeutics.

ACKNOWLEDGMENTS

The authors are grateful to Rebecca Gebert, BA, for her support in developing this manuscript.

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