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Moving family interventions into the real world: What matters to oncology stakeholders?

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Abstract

Background: Family interventions targeting patients and/or informal caregivers are beneficial, but few are integrated in oncology clinical care. Understanding diverse stakeholder perspectives may inform implementation and dissemination efforts.

Methods: We are currently conducting a randomized controlled trial of CareSTEPS, a telephone-based intervention for caregivers of advanced lung cancer patients. CareSTEPS seeks to improve caregiver and patient self-care behaviors, quality of life, and satisfaction with care. With an eye toward integrating CareSTEPS into clinical care, semi-structured interviews were conducted with 7 experts in integrated care [practice thought leaders] and 26 individuals representing different oncology stakeholder groups (i.e., potential end users of CareSTEPS including counselors, social workers, nurse specialists, and psychologists) [N=13], decision-makers, including physicians and administrators [N=6], and key dissemination partners, including representatives from cancer and caregiving advocacy groups [N=7]). Questions focused on existing caregiver support services, barriers to integrating care for caregivers in routine patient care, and possible models for clinical uptake and dissemination. Interviews were transcribed and analyzed using directed content analysis.

Results: Stakeholders noted a mismatch between caregiver needs and services offered, and expressed interest in broader service offerings. Barriers for integrating caregiver support into clinical care included inadequate funding, lack of interdisciplinary training among providers, and concern that research-based interventions are often not flexible enough for roll out into clinical

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practice. To secure buy-in, stakeholders noted the importance of evaluating intervention cost, cost savings, and revenue generation. Possible avenues for dissemination, through bottom-up and top-down (e.g., policy change) approaches, were also discussed.

Conclusions: Findings highlight the importance of evaluating outcomes important to diverse oncology stakeholder groups to speed translation of research into practice. They also suggest that pragmatic trials are needed that allow for flexibility in the delivery of family interventions and that consider the resource limitations of clinical care.

Keywords

caregiving; psychosocial interventions; advanced lung cancer; implementation science; qualitative interviews

Introduction

Family-based interventions that target adult oncology patients and/or their informal caregivers (e.g., spouses/partners, close family members) have demonstrated efficacy in improving health and quality of life (QOL).^{1–3} However, few such interventions have moved beyond testing in randomized controlled trials (RCTs) to use in clinical settings. Applying implementation science to family-based interventions is a critical next step for advancing the science and improving the quality of care for cancer patients and their families.^{4–7}

Implementation science provides strategies to identify key stakeholders, barriers, and facilitators of intervention uptake in clinical care settings.^{8–13} Family researchers have traditionally focused on the needs of *beneficiaries* (i.e., patients and/or caregivers) when designing interventions^{14–18} without considering the needs and perspectives of key stakeholders in the healthcare system, including the *end users* who will deliver the interventions (i.e., oncology supportive care providers, including counselors, social workers, psychologists, and nurse specialists), *decision-makers* who decide whether to adopt interventions into clinical care (i.e., clinic directors and hospital administrators), and *key dissemination partners* who can assist with national roll out (i.e., nonprofit and advocacy groups focused on improving cancer and/or caregiver care).^{5, 6} Additionally, *practice thought leaders* in integrated care (i.e., national leaders integrated primary or cancer care, including guideline authors, implementation scientists, and policy makers) may provide insight valuable to developing translatable interventions. This study seeks to understand these often neglected stakeholders' values and perceived implementation barriers/facilitators of family-based interventions. Toward that end, we investigated the implementation and dissemination potential of CareSTEPS (NCT02414672),¹⁹ a 6-week family-based psychosocial intervention that targets the informal caregivers of patients with advanced lung cancer (LC).

CareSTEPS targets caregivers of patients with advanced LC due to the significant burden associated with this diagnosis for patients and their families. LC, the leading cause of cancer mortality in the US,²⁰ is often diagnosed at an advanced stage and patients have a median survival less than 13 months.²¹ Most patients with advanced LC undergo chemotherapy and/or radiation, and experience more uncontrolled symptoms than patients with other

cancers.^{22, 23} As the primary setting for care has shifted from hospital to home, families of LC patients have found themselves replacing skilled health care workers to deliver medical care (e.g., monitoring and managing symptoms), in addition to providing emotional support, assisting with treatment and end-of-life decisions, and coping with their own grief associated with their relative's impending death.²⁴ Informal caregivers often assume their role with little or no formal preparation, and lack adequate resources.²⁵ This is problematic because low caregiver self-efficacy is associated with emotional distress (i.e., depression and anxiety symptoms).^{26–28} Additionally, perceiving caregiving as burdensome is associated with a weakened immune system and increased risk of death.^{29–31} Caregiver mental and physical wellbeing also has serious implications for patient health.^{32–35} Thus, family-based interventions that focus on providing caregivers with the skills necessary to care for patients and themselves may have far reaching benefits.

Family-based Interventions in Advanced Cancer

In recognition of the critical role that informal caregivers play in patient care, palliative care conceptualizes the family as the unit of care.³⁶ Nevertheless, real-world support for caregivers is less than ideal.³⁷ Caregivers receive little to no training,³⁸ and inadequate psychosocial care.³⁹ Furthermore, most educational materials in the palliative setting are geared toward patients, even though caregivers prefer their own educational materials on providing care and maintaining their own health.⁴⁰ Thus, informal caregivers have multiple unmet needs that span across several domains (i.e., information, skills training, social support), indicating room for improvement in delivering quality care to family caregivers – a critical component of the family unit. Evidence-based interventions directed toward caregivers may fill those gaps.

Meta-analyses of psychosocial interventions targeting caregivers have found small-to-medium effect sizes (i.e., Hedges' $g = .15-.47$) on patient and caregiver QOL, patient physical health, and relational outcomes.^{1–3, 41} In light of this, national organizations have called for integration of evidence-based practices supporting informal caregivers into routine clinical care.⁷

The CareSTEPS Intervention

CareSTEPS was designed to complement existing palliative care services, and fill an important practice gap by providing education, skills training, and support to caregivers of advanced LC patients. CareSTEPS is an acronym for six domains that are central to the caregiving role: self-*Care*, *S*tress management, symp*T*om management, *E*ffective communication, *P*roblem-solving, and *S*ocial support. Caregivers randomized to the intervention receive a manual providing education and skill-building activities in each of these domains and 6 weekly telephone calls with a Masters-level trained interventionist (e.g., social worker or counselor) to tailor the materials to the caregiver's needs, reinforce skills, and provide feedback. The goal is to empower caregivers and improve patient and caregiver QOL and satisfaction with healthcare.

In order to understand the potential for clinical uptake of CareSTEPS, the principal investigator applied to participate in the NIH/NCI-sponsored workshop *S*peeding Research-

tested INTerventions (SPRINT).⁴² The SPRINT program, adapted from the National Science Foundation's Innovation-Corps,⁴³ is an 8-week course for behavioral interventions taught by entrepreneurs experienced in launching successful startup companies. Program activities involved 1) identifying and conducting semi-structured interviews with key intervention stakeholders to understand their broad values and priorities (rather than gathering feedback on a specific product or intervention), and, 2) using that information to determine the components of program participants' specific products or interventions that would either add value or need to change in order to maximize integration potential.^{44–46} Below, we present findings from these interviews, and suggest ways to bridge the gap between family-based intervention research and clinical practice within the oncology palliative care setting.

Methods

Recruitment

All interviews conducted as a part of the SPRINT program were determined to be exempt from institutional review board (IRB) oversight by an independent IRB (Chesapeake IRB, Columbia, MD).

Given our extensive previous work identifying the needs and values of the beneficiaries of CareSTEPS (i.e., patients and caregivers) as part of the intervention development process,^{14–18} we focused our efforts in the SPRINT program on four key stakeholder groups: 1) the *end users* who would potentially deliver the intervention; 2) the *decision makers* whose buy-in would be required in order for CareSTEPS to be adopted; 3) potential *key dissemination partners* who could help us roll out the intervention; and 4) *practice thought leaders* in integrated behavioral health who could provide perspective on barriers and facilitators to integrating CareSTEPS into the health care system.^{44, 45} We identified local (i.e., within our institution) and national (i.e., contacts from professional organizations) representatives of each stakeholder group. Additional interview candidates, previously unknown to the authors, were identified using institutional websites and interviewee referrals (i.e., snowball sampling). All interview requests were sent via email.

Procedures

Participants completed 30–45 minute semi-structured interviews conducted by the first and senior author (CR and HB). The interview guide was informed by the SPRINT curriculum,^{44–46} and focused on the following domains: 1) perception of informal family caregiver needs; 2) existing resources for caregivers; 3) perceived challenges of integrating caregiving interventions in cancer supportive care; 4) possible models for integration; 5) key metrics to guide planning, evaluation, and sustainability efforts; and, 6) potential avenues for dissemination. Due to their varied expertise, interviewees did not comment on every domain.

Data Analysis

Interviews were digitally recorded, transcribed, and validated by the interviewer to ensure accuracy. The six above-mentioned domains served as our *a priori* codebook, permitting us to identify data from each interview relevant to these domains. Each interview was

deductively coded using directed content analysis by two of the authors (CR or HB) and two research assistants.⁴⁷ One author and one research assistant coded half of the interviews, and the other author and research assistant coded the other half. Codes were compared and discrepancies between coders were resolved through mutual discussion. A subset of interviews were also coded by all four coders to ensure consistency and discrepancies were similarly resolved through mutual discussion. Research assistants aggregated data for each of the six domains in separate documents for further in-depth analysis (i.e., a separate document was created for each domain, for example, perceived caregiver needs, existing caregiver resources, etc.). The first author (CR) read these six documents, and used inductive coding to identify *a posteriori* themes within each domain. The senior author (HB) then reviewed these themes and provided further refinement. Findings and exemplar quotes are presented below.

Results

Sample Demographics

Thirty-three individuals were interviewed. The 13 *end users* were currently providing supportive care to oncology patients and, to varying extents, informal family caregivers, and included 4 oncology social workers, 4 nurses, 3 clinical psychologists, and 2 licensed professional counselors. The 6 *decision makers* included 4 physicians (2 directors of palliative care clinics, 2 directors of oncology multidisciplinary clinics) and 2 hospital administrators with business backgrounds. The 7 *key dissemination partners* included 5 leaders of national cancer patient advocacy groups and 2 leaders of national caregiver advocacy groups. These interviewees had backgrounds psychology, biology, social work, public health administration, and law. The 7 *practice thought leaders* included 5 clinical psychologists, 1 physician, and 1 social worker who were all leaders in the field of integrated primary or cancer care (e.g., guideline authors, policy makers).

Perception of Caregiver Need.

Nineteen interviewees shared their perception of caregiver needs (Table 1). They noted that caregivers need 1) emotional support (i.e., validation/normalizing), particularly around relational strain associated with caregiving (65%), 2) practical support, such as help with transportation, finances, and respite care (59%), 3) support around treatment decision making and end-of-life care, including training in communicating effectively with the patient's healthcare team (53%), and 4) practical training in symptom management (47%).

Existing Caregiver Resources.

Table 1 provides a side-by-side comparison of interviewees' perceptions of caregiver needs and resources currently available to support caregivers in their respective institutions. In response to caregivers' need for emotional support, most interviewees (59%) noted that they referred caregivers to community-based support groups for emotional support (e.g., Gilda's Club, local groups at community centers, churches or other hospitals), but acknowledged that caregivers often have a difficult time attending due to time constraints and competing responsibilities. Many (47%) noted that supportive care typically focuses on patients, not caregivers. Importantly, several interviewees (24%) noted the dearth of supportive care

services for patients, let alone caregivers. “Everyone is trying to cover what should be handled by someone trained in [supportive care],” said one. Another quipped, “We’ve just been handling or mishandling those issues by ourselves.” Regarding caregivers’ need for practical resources (e.g., transportation, finances, respite care), interviewees mostly referred caregivers to the community, again noting that resources were often insufficient. Regarding caregivers’ need for assistance in treatment decisions, including end-of-life care, most (53%) indicated that their setting provides caregivers with educational materials and/or interdisciplinary family meetings. However, some lamented the reliance of healthcare on educational materials to support caregivers during the end-of life stage, noting the value of face-to-face contact.

Challenges to Integrating Care for Caregivers.

Twenty-five interviewees discussed challenges to integrating services for caregivers in routine cancer care. Table 2 provides illustrative quotes for the most common challenges. Some applied to the provision of supportive cancer care generally (i.e., to patients or families). For example, most interviewees (52%) identified inadequate interdisciplinary team-based care, due to insufficient training or lack of provider buy-in, as a major challenge. Furthermore, 35% expressed concern that interventions targeting patients or caregivers, developed in the context of a RCT, may not be flexible enough in terms of duration and required content to translate into clinical settings. Specifically, five interviewees expressed concern about delivering standardized content, noting that “real world” interventions must be tailored to individuals’ specific needs. Nine were hesitant about delivering six weekly sessions to each caregiver. “A set number of sessions is not realistic for this population,” said one end user, “some [caregivers] are going to need support over a much longer period, some may only need to talk once.” Interviewees also highlighted challenges unique to providing supportive care to caregivers, many of which stem from the fact that, as one key dissemination partner said, “the US healthcare system has not formally defined its relationship with the family.” For example, 29% of interviewees noted the lack of routine screening of caregiver needs, due to insufficient funding or infrastructure (e.g., where to document screening results, how to triage to appropriate care), as a barrier to providing services for caregivers. Furthermore, 16 of the 25 (65%) interviewees who spoke about challenges identified lack of reimbursement and, relatedly, lack of time as major barriers to clinical integration. Specifically, they noted that reimbursement is very low for supportive care delivered to patients and essentially non-existent for caregivers, as caregivers are (typically) not considered patients by the healthcare system.

Possible Models.

Twenty-three interviewees posited models for integrating care, drawing from the successful integration of supportive care for patients in palliative care and primary care settings. Table 2 provides a side-by-side comparison of challenges and solutions discussed. Interviewees noted that successful provision of interdisciplinary, team-based care requires supportive care providers to be co-located in the same physical space as the medical providers, and available for immediate or same-day consultations. They also suggested that attempts to integrate family-based care should be accompanied by top-down support, in the form of physician champions (i.e., physician leaders promoting care integration). Several pointed to research

indicating that co-location, same-day consultation, and physician-champion support increase use of supportive care services (at least by patients) in primary care settings.^{48, 49, 51} Additionally, some interviewees felt that to be maximally effective and conserve resources, routine screening for supportive care needs should be followed by stepped care, such that caregivers with low supportive care needs receive no or low intensity intervention (e.g., psychoeducation or support group referrals), and those with high intensity supportive care needs receive more intensive interventions (e.g., individual counseling).⁵⁰ Potential financial models to pay for integrated family-based supportive care were also discussed, including fee-for-service, using diverted clinical (medical) revenue, philanthropy, or grant funding. Most interviewees (8 of 11) who spoke about funding models unequivocally discouraged using the fee-for-service model, which requires supportive care providers use behavioral and mental health codes to bill for their services to support their salary. Instead, they suggested sustainable supportive care for families be funded by medical oncology (e.g., diverted clinical revenue, much like nurse or support staff funding). “Supportive care cannot be its own line item!” stated one end user emphatically. Some interviewees noted that newer models of reimbursement, based on gain-sharing or on increasing physician productivity, may hold promise.^{52–55}

Essential Outcome Metrics.

Seventeen interviewees identified specific metrics essential for making the case for integrating caregiving interventions into palliative or oncology care to clinic directors and hospital administrators. The majority (76%) indicated the importance of demonstrating the intervention’s potential cost savings or revenue generation. One decision maker said, “a patient who’s had an excellent experience...they’re gonna be your best advocates, and that theoretically leads to more patients choosing you in a competitive healthcare environment.” Satisfied patients may not only lead to increased patient volume, but also “maybe an interest in participating philanthropically in your organization,” added another. Interviewees also pointed out that payers and accreditation agencies also consider patient satisfaction, readmissions, and inpatient stays. Thus, changes to these metrics also could result in increased hospital revenue. As one decision maker said, “[A caregiver intervention] will bring money, because if your [Press Ganey¹] patient satisfaction numbers are in the tank, your reimbursement levels will be cut by insurers.”

Even if family-based supportive care interventions do not directly increase hospital revenue, interviewees posited that they could result in cost savings, by decreasing unnecessary healthcare utilization, length of hospital stay, and readmissions. For example, a key dissemination partner noted, “[With] appropriate caregiver training, medical tasks, like getting pain under control, can happen without a hospitalization.” Interviewees also noted that targeting the highest risk (and highest cost) patients and caregivers may facilitate demonstration of impact. “You’re going to have a lot of difficulty saving money if you don’t focus on the most expensive, complicated patients or the most distressed, miserable caregivers,” said one practice thought leader in integrated care. Another recommended a cost

¹Press Ganey is a national provider of patient satisfaction surveys. Scores on these surveys can impact hospitals’ Medicare reimbursement rates.

analysis (i.e., comparing 12-month healthcare costs of patients before and after intervention implementation), adding “if you don’t do it prospectively, it is very easy for CFO’s [Chief Executive Officers] to not believe you.” Finally, when making the pitch to healthcare administrators regarding the adoption of family-based interventions, some interviewees (24%) suggested presenting decision makers with personalized stories in addition to quantitative data. A key dissemination partner stated, “If you can pair data that shows that you get better clinical outcomes with stories from your patients and clinicians... people are gonna pay for that.”

Dissemination Avenues.

Twenty-one interviewees discussed avenues for dissemination through bottom-up (e.g., via advocacy groups, professional organizations, or direct to provider) and top-down (e.g., national policy) approaches. For example, national advocacy groups could potentially directly refer caregivers to a specific intervention, or supportive care providers to a specific intervention training program. However, interviews revealed that advocacy groups often prefer to be involved at an early stage in the development of interventions that they disseminate. One potential key dissemination partner shared, “We say no [to disseminating research] unless we can be part of it, edit, provide feedback, be part of the data collection, help talk through the issues we think are important.” Professional organizations may offer another avenue for national dissemination to supportive care providers. Sixty-nine percent of end-users (9 out of 13) reported learning about new psychosocial treatments through professional organizations and conferences, and recommended “rolling out” caregiving interventions in this manner –by providing online or in-person workshops to organization members. Many interviewees (43%) discussed avenues for national, top-down dissemination via the creation of clinical guidelines, but were also careful to note that guideline creation alone does not always directly translate into clinical practice changes. A key dissemination partner shared, “I believe strongly in carrots and sticks...for over 30 years, [inclusion of families in healthcare] has always been done just because it the right thing to do, and now I’m thinking, no, it needs a stick, and the stick can be soft, like requiring two or three CEUs on working with families in the healthcare setting, because I’m not sure that everyone is really prepared to work with families.” Another said, “Once you mandate something, America has to figure out how to provide it...I think that’s gonna be the case in caregiving.”

Discussion

This paper presents the voices of key healthcare stakeholders whose perspectives have not been traditionally represented in the literature on family-based interventions in cancer. Within the context of the NIH/NCI’s SPRINT program, the authors used these findings to determine several possible next steps to enhance the implementation potential for the CareSTEPS intervention. These interviews may also provide valuable insights for couple and family researchers seeking to move their interventions into routine cancer care. Overall, though there are many challenges to implementation, stakeholders see caregiver-focused interventions as valuable and suggested possible avenues for implementation and dissemination.

Across stakeholder groups, interviewees noted a mismatch between the perceived needs of informal family caregivers, and the existing supportive care available to them. For example, though most interviewees recognized emotional support as a major caregiver unmet need, they indicated that the current healthcare system focuses on the needs of the patient, often referring caregivers to external support groups that they are unable to attend. Additionally, none of the interviewees described training caregivers in the provision of complex medical tasks, though many noted this as need. These findings suggest that integrating a caregiver intervention like CareSTEPS, which combines emotional support with education, into a palliative or oncology setting would not be duplicating services, and that it may be well received by stakeholders, particularly end users (e.g., supportive care providers), as filling a noticeable gap in care.

Results also highlight a variety of challenges to implementing caregiver interventions as a part of clinical care. For example, end users expressed concern that RCT-tested psychosocial interventions may not translate to their particular clinical setting. Specifically, they valued short (i.e., less than six sessions), modifiable (e.g., flexible length and content) interventions that could be tailored to caregiver need. This may mean that in order to translate to real-world settings, family-based interventions, including CareSTEPS, may need to use adaptive designs, changing in intensity, duration, and focus based on what is best for the recipient at a given time.⁵⁶ Interestingly, all interviewees were asked their opinion about the delivery format of CareSTEPS (i.e., telephone-based) and whether it might hinder or facilitate roll out efforts. While some end users indicated they had not previously provided supportive care over the telephone, none voiced opposition to the format. In fact, several noted that telephone or online modalities could potentially provide the flexibility and convenience required to meet the needs of already overburdened caregivers and utilize fewer healthcare resources (e.g., provider time, clinic space) than in-person delivery.

Of note, interviewees cited inadequate team-based care as a major barrier for integrating care for caregivers in routine cancer care. Two reasons for inadequate team-based care noted by the end users we interviewed were a dearth of interdisciplinary training and a perceived lack of physician buy-in regarding the need provide dedicated caregiver support services. However, research suggests that providers' perceived duplication of services could be an additional factor.⁵⁷ For example, if medical providers feel that patients and caregivers psychosocial needs are already being adequately addressed by existing resources (e.g., clinic brochures and handouts, national hotlines and community resources that patients/caregivers can seek out on their own, and palliative care meetings with families to discuss goals of care, etc.), they may be less amenable to devoting additional time and precious clinic resources to providing specialized supportive care programs for caregivers. Since supportive care providers may be less likely to perceive such service duplication given their role on multidisciplinary supportive care teams, more research is needed to further understand the perspectives of physicians and health care providers regarding this issue.

Interviewees also acknowledged that most healthcare systems do not currently have the infrastructure in place to routinely screen caregivers for distress and other unmet needs. One potential solution may be to provide caregivers with their own medical record, but this will not solve the problem of payment for these services. This relates to the final challenge noted

– inadequate funding for supportive cancer care. Though fee-for-service payment models reimburse for services related to psychological disorders and, to a lesser extent, behavioral health needs, there is no reimbursement for caregiver education or training in symptom management. In light of this, practice thought leaders indicated that funding from medical oncology or palliative care clinics (though diverted clinical revenue) or through progressive reimbursement models might be a more successful approach to providing an intervention like CareSTEPS as a part of routine care.^{52–55}

Because sustainable, family-based supportive care largely depends on clinic leadership deciding to invest in these services, it is imperative that researchers include metrics that can communicate the value of family-based interventions to these decision makers. Specifically, results suggest that researchers must determine the cost, cost savings, and revenue generating potential of any intervention in order to make a business case to clinic directors and hospital administrators. This means that interventions targeting caregivers must demonstrate the intervention's impact on patient outcomes that affect the hospitals' bottom line, including health service utilization (i.e., hospitalizations, length of stay, readmission rates) and patient-reported outcomes valued by payers, including satisfaction with their healthcare experience. To our knowledge, no such studies have been published, but these outcomes are being examined in the ongoing CareSTEPS trial. Additionally, researchers should consider conducting cost effectiveness analyses, to quantify the interventions' cost relative to its effect on patients and caregiver QOL. Though several studies have demonstrated cost effectiveness of interventions for caregivers of patients with dementia,⁵⁸ we are unaware of any that have been conducted on caregivers of patients with cancer, suggesting that is an important area for future research.

Interviewees discussed several avenues for potential dissemination. National advocacy groups hold the potential for far-reaching, “bottom-up” or grassroots dissemination, but are typically deeply involved in the development and testing of disseminated material. Professional organizations may be an optimal avenue for taking a bottom-up approach to disseminating training on the provision of evidence-based interventions to end-users (e.g., supportive care providers embedded in palliative or oncology settings). Notably, dissemination efforts may require researchers to adopt a “train-the-trainer” position, assessing implementation-related outcomes (e.g., adoption, fidelity, maintenance) as opposed to solely evaluating caregiver and/or patient outcomes. Researchers may wish to simultaneously evaluate implementation and caregiver/patient outcomes by using pragmatic⁵⁹ or effectiveness-implementation hybrid designs,⁶⁰ which emphasize external validity. Pending demonstration of efficacy, next steps for the CareSTEPS intervention may thus include partnering with national professional organizations to facilitate dissemination, applying for funding to support train-the-trainer dissemination efforts, and/or designing a study assessing both effectiveness and implementation-related outcomes.

Finally, interviewees discussed “top-down” or policy-related avenues for dissemination. Several noted that national clinical guidelines may be necessary for widespread implementation of caregiver interventions, particularly in light of tight budgets and overburdened providers in healthcare settings. Many noted that clinical guidelines are borne from extensive evidence of the need for and effectiveness of a particular clinical practice

(e.g., early referral to palliative care, routine distress screening in oncology settings, survivorship care planning). Current evidence on the efficacy of caregiver interventions^{1–3} may warrant steps to address caregiver needs at the state and national levels.⁶ The American Association of Retired Persons' (AARP) Caregiver, Advise, Record, and Enable (CARE) Act is a step in this direction. The CARE Act requires hospitals to record the name of a family caregiver on patients' medical records, notify family caregiver when the patient is to be discharged, and give the family caregiver instructions on medical tasks to perform at home. Thirty-eight states have passed the CARE Act, formally incorporating caregivers into the healthcare system. To make the Care Act a reality, more research is needed regarding the processes by which healthcare systems support family caregivers. This finding again suggests that CareSTEPS must be evaluated from an implementation standpoint, perhaps using a pragmatic⁵⁹ or hybrid⁶⁰ design.

Although we did not interview patients and caregivers in this particular study, patients and caregivers were interviewed as part of the development of CareSTEPS¹⁴ and numerous studies in the oncology literature document patients' and caregivers' unmet supportive care needs.^{14–18} Thus, a strength of this study is the focus on perspectives of previously underrepresented oncology stakeholder groups. Another strength is the explicit inquiry into metrics needed to make a business case for integration of family-based interventions, as this information may inform future endeavors. There are some limitations to note. First, though overall sample size of the present study is comparable to similar qualitative studies, the size of some stakeholder subgroups was small -- particularly for decision makers (i.e., physicians and healthcare administrators). A more robust examination of this stakeholder group's perspective is needed. Second, the study does not include perspectives from payers (e.g., insurance companies), which will be important to evaluate in future research. Third, this study only included one type of key partner (e.g., advocacy organizations). Other key partners may lie outside the bounds of traditional healthcare. For example, corporate human resources or wellness departments, charged with increasing wellness and productivity for employees, may have a stake in reducing toll of caregiving for their employees, and may be considered as potential partners in dissemination of caregiver interventions in the future.

Taken together, our findings suggest that psychosocial interventions for informal caregivers of patients with cancer are needed and wanted by key healthcare stakeholder groups. Though many obstacles to implementation were identified, stakeholders offered several potential solutions, including developing brief, flexible interventions and presenting patient- and cost-related outcomes deemed important to hospital administrators and decision-makers. Dissemination of training on evidence-based interventions may ideally take place through national professional organizations, but may also require the creation of national guidelines and accompanying implementation recommendations for the delivery of supportive care to caregivers. These findings will guide next steps for the CareSTEPS intervention, and may help effective family-based interventions advance from tightly controlled clinical trials to sustained use in clinical settings.

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Implications for Psychosocial Oncology:

- Researchers of family-based interventions must evaluate outcomes important to oncology stakeholders, including interventions' cost, cost savings, and revenue generation potential in order to translate effective interventions from research to practice.
- Pragmatic trials that allow for flexibility in the delivery of family-based interventions are needed.
- Dissemination of training on effective family-based interventions may take place through national professional organizations, and success of dissemination efforts may depend on the creation of national guidelines for the delivery of supportive care to caregivers.

Table 1.

Perceived Caregiver Needs and Existing Resources

Perceived Need (n = 19)	Quote	Existing Resource (n = 19)	Quote
Need Emotional Support (i.e., validation around stress and relational strain)	<i>The stress of cancer is obviously so great and it can put a strain on relationships and I think caregivers also need help understanding that. I think they need help and support trying not to necessarily take things personally... caregivers do need a place, they need to be able to say, "I just, I hate him. You know I hate him" and have and no judgment - Advocate I think caregivers... [need] emotional support or a better understanding of what this experience is going to be like and kind of just normalizing the experience for them... it's huge just to know that what they're feeling, this is what other caregivers feel, because thankfully most people haven't done this before. ... People have no clue what the dying process is like. - Supportive Care Provider</i>	Refer to Community-Based Support Groups Provide family-based care	<i>There are some caregiver support groups at [our hospital] and the community, but most of the time, when they are caregivers, they can't really attend them because it takes away time from the patient. - Decision Maker</i> <i>Caregivers are kind of the forgotten members of the health care team. ... I always tried to see caregivers at least once, but the focus was definitely on the patient. ... I didn't work directly with caregivers on their own needs. - Supportive Care Provider</i> <i>[Our appointments are] so patient-focused that the caregiver does kind of sometimes take a backseat. You know if they do have questions or needs, sometimes they might be a little bit overshadowed by the patient and their needs. - Supportive Care Provider</i>
Need Practical Support (i.e., respite care)	<i>Becoming too much of a caregiver creates a fundamental change in the relationship to the patient that is not helpful - they become more of a nurse than a daughter or wife, for example.... In practical terms, this often means connecting caregivers to respite resources.... to preserve their relationship with the patient - Supportive Care Provider</i>	Home care Refer to Community Resources	<i>I mean most caregivers that do hospice care at home or do palliative care at home; they still don't have anybody to sit with the patient when they work. - Decision Maker</i> <i>Honestly, financial [need] is kind of across the board ... I can point towards resources or give some limited supportive care for the caregiver but I don't have anything specific you know built up for them. - Supportive Care Provider</i>
Need support around treatment decisions, including end of life care	<i>[CGs often have] questions about treatment options and what do I do next and how is this working for me and how do I manage these side effects. - Supportive Care Provider</i> <i>[CGs would benefit from] training that enabled them to access information or communicate with healthcare providers more effectively to be able to advocate as effectively as possible, and be skilled at seeking out information about treatment options. - Supportive Care Provider</i>	Provide Educational Materials & Family Meetings	<i>[Transition to end-of-life care] is this enormous emotional distressed situation for the family that we don't have, I don't have a good answer for them - Supportive Care Provider</i> <i>I think we've all gotten so good at giving people educational materials, but we don't do the one-on-one time, which is what makes the difference for people. What they tell me over and over again is what the difference that it made is when somebody was there, putting the time in, the eye-to-eye contact. - Supportive Care Provider</i>
Need training in symptom Management	<i>[CG need help with] things like 'I don't know how to change a bed with the patient in it' ... or 'I don't know what to do about my patient not eating' - Advocate</i>	No specific training in symptom management indicated	None noted.

Table 2.
Challenges and Potential Models to Integrate Supportive Care for Caregivers into Healthcare

Challenges (N = 25)	Quotes	Models (N = 23)	Quotes
Inadequate interdisciplinary care	One [challenge] is, of course, workforce development... Everyone's training separately and then ...they get thrown together in a clinic, but everyone's still working independently because they've never been taught how to work collaboratively. – Supportive Care Provider One of the things we struggle with is really varied levels of buy-in by healthcare provider partners. You know we've got some that are really on board, and others that see us as more of a burden. – Supportive Care Provider	Interdisciplinary Care Facilitated by Co-Location Physician champions	Giving [medical professionals] immediate access [to behavioral health providers] I think is really helpful. I mean most medical professionals think of mental health as being this black hole, that folks get sent there and they never hear anything from them ever again...so nobody wants to use them because you know they, they don't perceive it as being useful. – Integrated Care Expert [Our clinic] had top-down support where they had somebody who was identified in the senior leadership who that was their job to help facilitate the integration of behavioral health providers within [our] primary care setting. – Integrated Care Expert
Research-based interventions may not translate to real-world care	I think in the broad sense that yeah, something like that I think definitely could be helpful for caregivers. I just don't know, given the logistics of like our specific clinic, how that might work. – Supportive Care Provider	Internal, local stakeholders take ownership of intervention and implementation plan	I think you're going to get a lot more response from [decision makers] if the push [for your program] is coming from the system's internal customers... from patients, providers, hospital policy makers, finance people, people on the board, people that are part of the electronic health record working together to come up with a plan that they think is important, then they have ownership of that. – Integrated Care Expert
Lack of routine screening of CG needs	We do not have, at this point, regular tools for caregiver evaluation... Is the caregiver and the family part of the unit of care? 100%, but you know regrettably, they do not have a clinical record number and there is no payment for that... They're out of the healthcare system really right now and that's one of the tragedies. – Decision Maker	Screening for supportive care needs followed by stepped care	[Routine screening and stepped care prevents supportive care providers from] spending tremendous amounts of time with every single person because there are not enough... behavioral health professionals to be able to sustain that. – Integrated Care Expert
Lack of funding and time	I think the elephant in the room is who's gonna pay for it. I've found time and time again that you can have good science, you can have patients that want it, providers that want it, it makes good sense, and if nobody pays for it, it's not gonna happen. – Integrated Care Expert We are so short staffed on our team ... it's impossible to slice out other things for us to do... You can't put [anything] on top of what the palliative care team already does without having an extra person. – Decision Maker	Financial models Fee-for-Service Grants or Philanthropy Diverted Revenue	I worked on an integrated oncology team, but we were a team in name only and ultimately had to discontinue the program. We [supportive care providers] did not generate as much reimbursement revenue as our colleagues in traditional behavioral health setting, because it is difficult to bill for the kinds of things we do in oncology settings. – Supportive Care Provider Our funding stream is essentially about 75 to 80% developmental activities, either individual donations or, or gala or other kinds of fundraising events, then [our hospital] underwrites the remainder. – Supportive Care Provider [At comprehensive cancer centers, supportive care is] considered part of the cost of doing good cancer care. They're part of the cost structure. They're just part of what you need in place in order to run a credible cancer clinic. – Integrated Care Expert