

Reducing informal caregiver burden in cancer: evidence-based programs in practice

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Abstract

Caring for people with cancer can be a burdensome and emotionally straining experience. Without adequate psychosocial support, distressed caregivers are at risk for psychiatric and medical morbidity, which can adversely affect patient outcomes. Although there is a tremendous need to provide effective and timely supportive care services for cancer caregivers, few community or clinically based services exist and the needs of these essential caregivers are profoundly underserved. This article describes three existing evidence-based programs and tools that address the needs of family caregivers of cancer patients: (a) the FOCUS Program, tested for efficacy in prior randomized clinical trials and implemented in community settings by agency staff; (b) the Program for the Study of Cancer Caregivers at Memorial Sloan Kettering Cancer Center (MSKCC), which addresses the needs of caregivers in a large health care system; and (c) CancerSupportSource[®]-Caregiver, an online platform for distress screening and referral developed by the Cancer Support Community to assess and address caregivers' needs. We also describe next steps related to broader dissemination for practitioners considering how best to support cancer caregivers now and in the future. Although each evidence-based program or tool represents a unique approach to supporting caregivers, together these approaches allow for a greater likelihood of meeting caregiver needs across a variety of contexts. Collaboration within and across organizations allowed for the development and effective implementation of each of the described initiatives.

Keywords

Cancer caregiving, Distress screening, Evidenced-based programing, Psychosocial interventions, Quality of life

INTRODUCTION

Cancer caregiving is pervasive and increasingly understood as an intensive, burdensome, and emotionally draining experience [1–4]. A growing proportion of Americans will serve as caregivers in coming decades due to an increasing prevalence of cancer (from population growth and longevity) [5]. Approximately 2.8 million or 7% of all informal caregivers in the USA provide care due to a primary diagnosis of cancer, and this is likely an underestimate as many provide cancer care secondary to another condition [3]. In addition, more than 1.6 million Americans are expected to receive a new cancer diagnosis in 2017 [6].

Implications

Practice: Describing evidence-based programs and tools for cancer caregivers will inform practitioners considering how best to support cancer caregivers now and in the future.

Policy: Cost-effective programs and tools that are accessible are needed to address the multiple concerns of a large number of caregivers.

Research: Research efforts going forward to address the supportive needs of cancer caregivers must be collaborative within and across organizations.

Cancer caregivers perform diverse roles and tasks. They are often part of a patient's health care team as they advocate, communicate, and contribute to decisions about treatment [1, 3], and perform many nursing-related tasks often with little preparation [3, 7, 8]. Caregivers frequently report high emotional stress and many experience poor mental health outcomes [2, 3, 9–11]. Poor emotional responses among caregivers create secondary effects on patient and caregiver outcomes, such as decreased caregiver health [2], depressed patient mood [12], and poorer informal care quality [13]. Having unmet needs is a strong predictor of poorer mental health among caregivers [14], while receipt of interventions that provide information and support have benefits for caregivers and care-recipients alike. Three meta-analyses [10, 15, 16] assessing psychoeducational interventions for caregivers alone or for patient-caregiver dyads (i.e., pairs) indicate a number of positive effects. Psychoeducational interventions can improve caregivers' physical [10] and mental well-being [10, 15, 16], reduce caregiver burden, and improve caregivers' coping skills, self-efficacy, and aspects of their quality of life [10]. In addition, interventions directed to caregivers and/or dyads can also improve patients' physical health outcomes [15, 16]. Yet, few existing interventions have been

implemented in practice settings [10], and clinicians and practitioners are often unaware that interventions are available.

The importance of developing and broadly implementing supportive programming for caregivers was highlighted on May 4 and 5, 2015 during a 2-day meeting on caregiving that was convened by the National Cancer Institute (NCI) and National Institute of Nursing Research (NINR). The meeting, entitled “Caring for Caregivers and Patients: Revisiting the Research and Clinical Priorities for Informal Cancer Caregiving,” summarized the state of the science in cancer caregiving. A paper summarizing this meeting reported key research and clinical priorities going forward to better support caregivers (and patients). These priority areas broadly pertain to (a) improving interventions (targeted at cancer patients, caregivers, and patient-caregiver dyads) by replicating them in multiple contexts; (b) facilitating the integration of caregivers into formal care settings; and (c) maximizing the impact of technology on informal cancer caregiving [7]. The report also emphasized the importance of outreach to promote broader dissemination of study results.

Guided by these priority areas and the goal of broader dissemination, the purpose of this article was to describe three existing evidence-based initiatives for cancer caregivers that are being implemented in practice settings. Each approach addresses at least one of the priority areas identified in the NCI/NINR report. We review each program with outcome data and offer next steps for ongoing sustainability and broader implementation. This latter information is vital for practitioners considering ways to better support caregivers of cancer patients now and in the future.

PROGRAMS AND TOOLS DESIGNED TO SUPPORT CAREGIVERS OF CANCER PATIENTS

The FOCUS Program

Relevance to NCI/NINR priority: improving interventions (targeted at cancer patients, caregivers, and patient-caregiver dyads) by replicating interventions in multiple contexts

Overview of program

The FOCUS Program is a psychoeducational program developed 15 years ago in the academic setting to improve outcomes for cancer patients and their caregivers [17]. A primary premise of the program was that patients and caregivers influence each other's response to illness, and hence, programs need to address both patient and caregiver needs [18].

Program content and delivery

Based on the available literature, the FOCUS Program incorporates five content areas, including family involvement (i.e., promoting open dyadic communication and support); optimistic outlook

(i.e., maintaining hope, living in the present); coping effectiveness (using active vs. avoidant coping and healthy lifestyle behaviors); uncertainty reduction (obtaining information, managing uncertainty); and symptom management (addressing patient and caregiver physical and/or emotional symptom distress; i.e., F-O-C-U-S). The original program, delivered by masters-prepared nurses to the patient and his or her primary caregiver, consisted of three face-to-face home visits and two telephone calls. More recently, a brief version of FOCUS (two home visits, one telephone call) and extensive version (four home visits, two telephone calls) have been delivered [19].

The efficacy of the FOCUS Program was tested in a series of three randomized clinical trials (RCTs). Patient-caregiver dyads were randomly assigned to usual clinic care plus the FOCUS Program or to usual clinic care only (control). The program was initially tested among breast cancer (recurrent) patient-caregiver dyads ($N = 134$ dyads) [20], followed by prostate cancer patient-caregiver dyads ($N = 263$ dyads) [21] and then advanced cancer patient-caregiver dyads (lung, colorectal, breast, and prostate; $N = 484$ dyads) [19]. Statistically significant positive outcomes were found for FOCUS Program participants versus controls in these RCTs, including less negative appraisal of the illness [20, 21], uncertainty [21] and hopelessness [20, 21], and symptoms [21], as well as greater self-efficacy [19, 21], dyadic communication [19], enhanced coping [19, 21], and mental and/or physical quality of life (QOL) [19, 21]. Although not all outcomes were assessed nor found to be statistically significant in each study, the findings from the RCTs provide support for the efficacy of the program when delivered to patients with various types and stages of cancer and their caregivers and when delivered in various intervention doses. The effect sizes for the FOCUS Program ranged from 0.22 to 0.40, similar to effect sizes reported in prior meta-analyses of interventions for cancer patients and their caregivers [10, 15, 16].

Program implementation and testing

Initial implementation study

A next step after determining program efficacy was examining effectiveness when implemented by agency clinicians in a community setting. The Cancer Support Community (CSC) affiliate in Ann Arbor Michigan was ideal because (a) it is part of a large, well-recognized network of affiliates internationally providing free support and education to patients and caregivers; (b) programs are led by masters-prepared oncology social workers; and (c) the agency had funding to potentially sustain the program.

Prior to implementation, the Program Director (PD) of CSC and the FOCUS Program developers/researchers considered modifications for delivery in

the community agency context. As such, FOCUS was adapted to a small group format, consistent with the agency's program implementation model in which small groups are used to reach more people at a lower cost and to enhance universality among CSC members. The original FOCUS protocol manual and intervention checklist were modified to a small group format that extended over six weekly 2-hr sessions, consistent with the length of other CSC programs. Two affiliate facilitators received training on how to implement the FOCUS Program with intervention fidelity and met regularly with researchers to address any questions that arose during program implementation. The modified FOCUS-CSC Program was offered to small groups of three to four patient-caregiver dyads. During the implementation process, the facilitators consulted regularly with the program developers to address any concerns.

The effect of the FOCUS-CSC Program was examined in a small pre- and post-intervention pilot effectiveness study (no control) with 34 patient-caregiver dyads who were predominately White patients (89.2%) and caregivers (86.5%; see Dockham et al. [22] for specific details). Recruitment to the small groups was the main challenge (enrollment rate 60%) because of the difficulty of finding a common time for patients and caregivers to participate in six weekly group sessions. In addition, to achieve an adequate sample size for the study, in light of an inconsistent stream of eligible dyads, the program needed to be delivered continuously for 2 years. In contrast, other CSC programs are typically offered annually or quarterly, which requires fewer participants and allows for greater sustainability of services. Although recruitment was a challenge, once dyads enrolled, retention in the program was high (92%); loss of participants was due primarily to deterioration in the patient's health. In addition, the agency social workers were able to maintain high intervention fidelity (94%) when implementing the program. Dyadic analyses indicated that patients and

caregivers (as pairs) reported statistically significant improvement in overall QOL, physical, functional, and emotional QOL, self-efficacy, and perceived benefits of the illness (i.e., the illness brought couples closer together; see Table 1). Participants also reported high satisfaction with the program (mean of 4.3 out of a 5-point scale) [22]. Intervention effect sizes and program satisfaction ratings were similar to findings when the FOCUS Program was delivered in prior RCTs to individual dyads at home.

Second implementation study

A second implementation study was completed recently at two CSC sites outside of Michigan (i.e., California and Ohio). The program length was decreased from six to five sessions to facilitate recruitment and reduce delivery cost. Forty dyads enrolled (71.4%) and 36 dyads completed (90%) the implementation study, which included predominately White patients (88.9%) and caregivers (77.8%). Better enrollment might be due to the shorter program and the CSC sites having a larger member base from which to draw. The second implementation study findings were similar to the first implementation study (see Table 1); patient-caregiver dyads reported significant improvement in overall QOL, emotional and functional well-being, benefits of illness, and less emotional distress. Both statistically significant and clinically significant [23] improvement was found for dyads' self-efficacy. The cost of delivering the five-session FOCUS-CSC Program was also assessed by examining preparation and wrap-up time, session delivery time and program oversight (i.e., marketing, screening, assembling materials). The total cost of delivering a five-session FOCUS Program to three to four dyads per group was \$669.45 or \$168.00 per dyad (see Titler et al. [24], for additional details). Findings from the pilot study indicated the evidence-based FOCUS Program could be implemented successfully by

Table 1 | Outcomes from implementation of FOCUS in two implementation studies

Outcomes	Initial implementation (<i>N</i> = 34 dyads)	Second implementation (<i>N</i> = 36 dyads)
	Main effect of time <i>p</i> value	Main effect of time <i>p</i> value
Quality of life		
Total score	.002	.014
Physical	.019	.986
Social	.455	.061
Emotional	.004	.012
Functional	.003	.049
Benefits of illness	.032	.013
Communication	.297	.075
Self-efficacy	.002	.001
Emotional distress		.002

Emotional distress was assessed as outcome in the second implementation study only.

agency social workers in local CSC affiliates even though program modifications were necessary.

Challenges and future directions

The process of implementing the evidence-based program in CSC sites took time and required collaboration between community and academic partners. Challenges included scheduling collaborative meetings, problem-solving recruitment, and obtaining a diverse sample. Next steps include more in-depth cost-effectiveness analyses and assessment of indirect costs such as participant out-of-pocket costs to attend a program. These types of costs need to be examined in conjunction with intervention effectiveness (effect sizes) obtained on primary outcomes (e.g., quality of life). Analyses will also include whether the cost per outcome is equitable to other similar programs.

To sustain the program, it is necessary to identify resources within agency budgets to support ongoing delivery. CSC Ann Arbor offers the program twice a year via a new line-item in their operating budget. However, to serve a greater number of caregivers via more offerings, additional budgetary resources and sites will be necessary. Future goals include examining the feasibility of online small group programming or use of video conferencing particularly to serve those from rural or underserved areas.

PROGRAM FOR THE STUDY OF CANCER CAREGIVERS AT MEMORIAL SLOAN KETTERING CANCER CENTER

Relevance to NCI/NINR priority: facilitating integration of caregivers into formal care settings

Overview of program

Identifying and assisting distressed caregivers at patient point of care is an important, but rarely available, extension of patient care. The Program for the Study of Cancer Caregivers at Memorial Sloan Kettering Cancer Center (MSKCC) was established in 2011 to identify caregivers experiencing significant burden and provide them with effective psychosocial services. To attend to the needs of caregivers across the care trajectory, the Program involves four components: (a) clinical care, (b) research, (c) professional teaching, and (d) outreach.

Program content and implementation

Clinical care

The Caregivers Clinic provides psychosocial support to family members and friends of patients at MSKCC with all sites and stages of cancer. Particular groups of caregivers with unique needs have also been identified and are the focus of targeted services, including caregivers of patients who suffer from neurological complications of cancer and/or its treatment, caregivers of pediatric cancer patients, caregivers of patients undergoing

hematopoietic stem cell transplantation, and young adult caregivers. The Clinic is staffed by two clinical psychologists and two psychiatrists who work in the clinic part-time with caregivers using a variety of approaches, including cognitive behavioral, existential, supportive, and bereavement interventions. Care is delivered primarily individually and in groups, although couples and family sessions are offered on an as-needed basis. Referrals are provided via various channels, both across the institution and via self-referral. The Clinic also works closely with the Department of Social Work, which offers virtual groups for current caregivers and in-person groups for bereaved caregivers.

As of February, 2016, the Caregivers Clinic received 148 referrals within the Department of Psychiatry and Behavioral Sciences and 71 referrals from outside MSKCC departments, including Social Work, Neurology, Bone Marrow Transplant and Medicine. These referrals translated into 114 psychodiagnostic visits, 462 follow-up visits, 3 time-limited groups, 21 couples or family therapy sessions, and 103 patients requesting or requiring medication management and referral to a staff psychiatrist. Caregivers seen in the clinic since 2011 were, on average, 55 years old and primarily female (67.2%) and White (84%). The majority (74%) were in spousal/partnered relationships with patients (9.6% parents, 14.4% children, 2% siblings or friends) and employed full time or part-time (66.4%). In addition, caregivers attended on average seven sessions in the clinic (range 1–39).

Several factors impeded referrals from leading to diagnostic visits, the most important of which was long wait-times (averaging 6 weeks to next available diagnostic visit) combined with caregivers' desire for immediate support. The clinic staff attempts to accommodate caregivers in urgent need of care and maintains an active waitlist through which an additional 25% of caregivers are offered sessions resulting from cancellations by existing patients. Yet, the inability to guarantee immediate support is the primary cause of attrition. Additional factors include the potentially prohibitive cost of care (care is covered by some insurance plans), caregivers enrolling in clinical trials providing psychosocial support (see below), and distress ameliorating on its own.

In addition to the professional support offered through the Caregivers Clinic, the Program is building on MSKCC's already existing successful patient-to-patient mentoring program with a caregiver-to-caregiver mentoring program. While professional support is invaluable, many caregivers benefit from connecting with others who have provided care in the past. Conversations with care mentors take place over the phone, email, or in person. All mentors first undergo a psychodiagnostic interview with the clinic director to determine their existing distress level and appropriateness to serve as a mentor, which is particularly important since the

majority are bereaved (at least 1 year). In addition, all mentors must complete a computer-based training of eight modules covering basic key concepts at MSKCC and participate in a daylong training session to learn about the Caregiver Volunteer Role. Confidentiality, boundaries, active listening skills, and red flag situations are a few of the many topics covered during the training. New mentors are also paired with “seasoned” caregiver volunteers and participate in an educational lecture series about topics such as identifying signs of distress, steps to take in emergency situations, and self-care. Finally, mentors participate in monthly group meetings led by a licensed social worker to discuss their cases and receive additional support to help them in this role. To date, 17 matches have been made through the mentoring program.

Research

A research component offers further supportive options for caregivers. There are on average three clinical trials of psychosocial support programs available at any one time free of charge. Such trials are investigating the unique emotional and practical issues for caregivers of patients with specific types of cancer or receiving certain treatments (e.g., brain tumors, bone marrow transplants), novel interventions for addressing existential distress, insomnia, and worry, and the feasibility, acceptability, and efficacy of tele-mental health approaches. Several such trials have fostered additional professional support for the Clinic from other hospital departments, such as Integrative Medicine where caregivers may receive services (e.g., acupuncture) that complement Clinic care.

The research component has been vital in addressing caregivers’ needs in a timely fashion. The distress level of caregivers seeking care at the Clinic is evaluated and those not in acute distress are informed of their potential eligibility to receive support via research studies. The ability to offer participation in clinical trials is a valuable mechanism to assist caregivers seeking care in the Clinic. Importantly, as a result of the magnitude of Clinic referrals and the desire of many caregivers in low distress to receive support, tension regarding generating clinical revenue and the competing demands of meeting study accrual goals does not exist. Moreover, the Clinic is one of the several sources of recruitment for the Program’s research studies that prevents a bias during the triage process in favor of referral to the Research Study Assistant.

Professional teaching and outreach

The Program is developing a training curriculum in a multidimensional approach to the care for caregivers and provides in-house training for faculty and staff in order to improve their skills in providing psychosocial care for cancer caregivers. Also, to reach caregivers nationally and internationally, the Program is involved in external collaboration and a

variety of outreach activities to extend information and services outside of MSKCC, including partnerships with American Psychosocial Oncology Society (APOS) and the American Cancer Society (ACS). As an example of extension beyond MSKCC, a web-based supportive care program that is self-administered over the Internet was developed and evaluated in a recently completed ACS funded study [25] and will eventually be made available nationwide via the ACS. Within MSKCC, the Program has partnered with the Social Work, Patient and Caregiver Education, and Volunteer Departments.

Challenges and future directions

The activities of the Program for the Study of Cancer Caregivers represent a multidisciplinary approach to supporting caregivers across the care trajectory in a comprehensive cancer center. Despite progress, a high proportion of caregivers remain underserved. In 2014, there were 115,836 active patients at MSKCC, with 78% having a caregiver. However, in 2014, only 76 caregivers received care through any of the Program’s modalities, due largely to challenges named above (e.g., long wait times) and limited advertising. Future efforts to refine the screening and referral process are needed to ensure that caregivers receive immediate services if necessary and that support is provided to others that fit their unique need for specific types or levels of care. The evaluation of a targeted screening process for caregivers of patients receiving care in one of the MSKCC’s outpatient surgical facilities is currently underway and, ideally, the results will generalize to other services and groups of caregivers.

CANCERSUPPORTSOURCE®-CAREGIVER: AN ONLINE PLATFORM FOR CAREGIVER DISTRESS SCREENING AND REFERRAL DEVELOPED BY THE CANCER SUPPORT COMMUNITY

Relevance to NCI/NINR priority: maximizing the impact of technology on informal cancer caregiving

Overview of the online tool

While caregiver burden measures exist, caregiver needs are frequently overlooked and go unrecognized. There is a need for innovative tools or programs to screen for distress among cancer caregivers and provide appropriate referrals to services that meet their needs. Moreover, despite greater awareness of the dyadic impact of patient-to-caregiver or caregiver-to-patient interplay with respect to the emotional response to cancer, there is no distress screening and referral platform that addresses both the patient and his or her caregiver simultaneously. Finally, few if any distress screening and referral tools are web based and designed to allow an individual to complete screening at a location desired by the caregiver (e.g., home or work). Convenience is important to this population that experiences many time and energy constraints.

As an international nonprofit organization that provides supportive programming for those affected by cancer, the CSC sought to address this gap by developing an online platform for distress screening and referral for caregivers (i.e., CancerSupportSource[®]-Caregiver). The intent was for this online tool to be used in tandem with the already implemented patient version (i.e., CancerSupportSource[®]). The organization wanted to support all those served via CSC affiliates (i.e., individual community-based entities), which included informal caregivers, and to expand use to broader clinical care networks.

Program content and delivery method

The CSC's patient distress screening and referral online tool, CancerSupportSource[®], provided the foundation for the development of the caregiver version. CancerSupportSource[®] allows patients to identify areas of top concern by rating their concern per item from 0 (not at all) to 4 (very seriously). The program includes a highly sensitive depression subscale to identify those at risk for depression [26]. Patients are also prompted to indicate how they would like to receive help (speak with a staff member; receive written or online information; or do nothing at all). The development of this 25-item patient distress screening online tool was guided by the Institute of Medicine's recommendations to address psychosocial well-being in a standardized manner, including patient/doctor communication, assessment of psychosocial needs, referral for assistance (as needed) and follow-up [27].

Focus groups and cognitive interviews were conducted with caregivers at CSC affiliates to understand the cancer caregiver experience and specifically to assess the relevance of the previously developed CancerSupportSource[®] patient items to the caregiving context, and to add new areas that needed to be addressed via CancerSupportSource[®]-Caregiver. Focus group findings led to (a) clarifying directions; (b) clarifying wording of items; (c) deleting items; and (d) adding new items (e.g., "feeling guilty," "feeling unappreciated"). The resulting CancerSupportSource[®]-Caregiver included 47-items designed to understand caregiver concern in three areas: (a) *self-care and emotional response* (e.g., feeling sad or depressed, communicating with one's own doctor); (b) *caregiving tasks* (e.g., communicating with the patient's doctor); and (c) *patient function and well-being* (e.g., patient's cognitive decline, patient's eating or nutrition). Parallel to the patient version, all items were based on a 5-point scale to assess level of concern (0 = not at all to 4 = very seriously). Caregivers could indicate how they would like to receive help if at all. Subsequently, 10 cognitive interviews [28] were conducted among caregivers identified from CSC affiliates throughout the USA to further clarify instructions and confirm the relevance and meaning of the individual items. During the interviews,

caregivers were invited to "talk aloud" in response to the screening and referral tool (i.e., instructions, concern items, and associated referral questions) and to explore caregiver understanding and relevance of the questions.

Program testing and implementation

A multisite validation study was conducted between August, 2015 and May, 2016 to assess the psychometric properties of CancerSupportSource[®]-Caregiver and correlate it to standardized measures (i.e., CES-D, the Distress Thermometer, SF-12 mental and physical component scores, the Zarit Burden Interview, and the Caregiver Reaction Assessment). Ten geographically diverse CSC affiliates (Chicago, Quad Cities, Greater St. Louis, Kansas City, Central Ohio, Madison, Louisville, Delaware, San Francisco Bay Area, and Greater Philadelphia) were tasked with recruiting approximately 25–30 caregivers each to reach an overall sample of 250 caregivers. CancerSupportSource[®]-Caregiver was delivered via a web-based platform similar to the patient version. However, a caregiver unable to use an Internet program could complete the distress screening and referral program by paper.

A total of 246 caregivers completed the survey. This represents a 52.6% response rate, as an additional 221 surveys were released via the online platform but expired. Automatic expiration occurred if a survey was not initiated within 2 weeks of receiving access to the platform. The first 115 respondents participated in the test-retest reliability substudy by completing the screening items a second time. Participants were predominately female (68%), the spouse/partner of the patient (58%), and White (88.7%). The top concerns (% moderately to very seriously concerned) included "Worry about the future" (71%) followed by "Disruption in home life" (59%), "Patient's pain or physical discomfort" (59%), "Patient's eating and nutrition" (57%), and "Changes in patient's mood or behavior" (57%). The top concerns in which caregivers indicated their preference to speak with someone included "Changes in patient's mood and/or behavior" (22%), "Worry about the future" (22%), "Feeling sad or depressed" (20%), "Relationship problems with the person for whom I am caring" (19%), and "Disruption in home life" (17%).

The screening tool demonstrated high internal consistency (Cronbach's alpha = .96). Test-retest reliability was excellent (intraclass correlation coefficient [ICC] \geq .75) for 28 of the items, and 18 items demonstrated good reliability (ICC = .60–.74) [29]. CancerSupportSource[®]-Caregiver demonstrated concurrent validity; it was associated with greater distress as measured by the NCCN Distress Thermometer, more depressive symptoms (CES-D), more caregiver burden (ZBI), lower caregiver esteem (CRA), and lower mental and physical

Table 2 | Correlations with validated measures

Validated measure	Pearson's <i>r</i>	<i>p</i>
NCCN Distress Thermometer	.54	<.01
CES-D	.64	<.01
Zarit Burden Interview	.54	<.01
Caregiver Reaction Assessment		
Health problems	.46	<.01
Disrupted schedule	.42	<.01
Financial problems	.37	<.01
Lack of family support	.27	<.01
Caregiver esteem	-.27	<.01
General Health Survey, SF-12		
Mental Component Summary Score	-.52	<.01
Physical Component Summary Score	-.24	<.01

well-being (SF-12; see [Table 2](#)) [30]. The distress screener demonstrated moderate to strong psychometric properties and is a valuable online tool that can be used to screen for caregiver psychosocial distress and provide them with desired resources. CSC affiliates began using CancerSupportSource[®]-Caregiver in March, 2017 across its network of over 40 sites, reaching diverse communities in the USA.

Challenges and future directions

Development of CancerSupportSource[®]-Caregivers was based on the recognition that it was essential to first explore the specific needs and experiences of cancer caregivers to develop an online distress screening and referral tool that was most relevant to them. A primary limitation of recruitment reported by CSC-affiliated PDs was caregivers lacking time or energy to participate. Thus, it is possible that some caregivers with even higher distress did not participate in the research. However, these PDs did mention that it opened the door for further conversation with these caregivers. Work going forward will evaluate reducing the number of items in the scale to decrease participant burden. Furthermore, 15% of participants were from rural areas and 22% less than 40 years of age. These findings suggest that the web-based format for screening can be useful for accessing more difficult-to-reach populations, especially people living in rural regions and those of younger ages who might prefer web-based technology. Further research on implementing distress screening and referral for caregivers is needed not only among diverse populations of caregivers but also in diverse contexts (e.g., hospital, health clinics). This work to date provides an important step forward toward understanding the concerns of cancer caregivers and identifying those at greater risk for adverse outcomes. Ultimately, the goal of CancerSupportSource[®]-Caregivers will be to provide initial support tailored to individual caregiver need, to offer follow-up support as needed, and to

explore effect on caregiver and patient quality of life outcomes and health care service use.

DISCUSSION

Each program provides a unique approach to meeting the psychosocial needs of caregivers and addresses one of the priority areas outlined in the NCI/NINR report (see [Table 3](#)) [7]. Although distinct, when considered together, the programs provide a variety of opportunities and coverage to support caregivers. Specifically, these approaches provide interventions that can be used at different time points along the cancer trajectory and in different settings and modalities. With multiple access and time points at which to deliver evidenced-based support, including via community organizations, hospitals, comprehensive cancer centers, and virtually using the web, more caregivers can be served. Furthermore, such variety of services can address caregiver readiness for engaging support and preferences, as caregiver burden can ebb and flow throughout the trajectory of providing care (including survivorship). To serve caregivers more effectively, we will need an increasingly diversified menu of evidenced-based options in clinic, community, and virtually. Thus, going forward, it is recommended to initiate implementation studies of each of these approaches so that one can clearly understand barriers to broader use and generalization.

Although each initiative is different in approach, collaboration—either within an organization or across organizations—was a defining characteristic of each. For example, the Program for the Study of Cancer Caregivers at MSKCC relies on collaboration among departments (e.g., Social Work) and providers to effectively support caregivers at MSKCC. There is also the need to collaborate effectively with external organizations for broader dissemination. Similarly, the development and implementation of CancerSupportSource[®]-Caregiver was dependent on a foundation of collaboration between CSC National headquarters (i.e., Research and Training Institute) and multiple CSC affiliates and included ongoing and consistent communication. The development of FOCUS-CSC required collaboration across institutions; namely among academic and the nonprofit community sectors. This collaboration too required ongoing communication and problem-solving as evidenced by program modifications. Thus, collaboration is central to developing, implementing, and disseminating programs to reach caregivers regionally and nationwide. As the health system is increasingly integrated, so too must be efforts to provide support for caregivers, and efforts must involve broad internal and external collaboration rather than replicating historical siloed approaches.

Furthermore, given the reality of finite resources, each program faces the challenge of not only

Table 3 | Comparisons of example initiatives for cancer caregivers

Program and goals	Setting	Participants	Implementation strategies	Results	Challenges and lessons learned
<p>FOCUS Program: To provide education and support to cancer survivors and family caregivers, as unit of care</p>	<p>Cancer Support Community sites in USA (Michigan, Ohio, California)</p>	<p>Patient-caregiver dyads (i.e., pairs)</p> <p>Survivor with any type or stage of cancer</p> <p>Caregiver who is patient's spouse, partner, adult child, other relative, or friend</p>	<p>Agency clinician participates in training sessions to insure FOCUS is implemented with fidelity</p> <p>Clinician completes initial assessment to ensure appropriateness and eligibility</p> <p>Clinician follows a structured FOCUS protocol checklist to implement program with fidelity</p> <p>FOCUS is delivered in weekly small group format (3–4 dyads per group) by agency clinician</p> <p>Initial implementation study: 6 weekly sessions; 2 hr per session</p> <p>Second implementation study: 5 weekly sessions; 2 hr per session</p> <p>Agency clinician meets regularly with experienced FOCUS supervisor to discuss group process and potential problems</p>	<p>Significant improvements in outcomes for dyads:</p> <p>Quality of life</p> <p>Emotional well-being</p> <p>Functional well-being</p> <p>Benefits of illness;</p> <p>Self-efficacy</p> <p>Agency staff implemented program with high fidelity</p>	<p>Challenges:</p> <p>Recruiting dyads who are available at same time for weekly group sessions</p> <p>Obtaining demographic diversity among participants</p> <p>Reaching large numbers of caregivers with face-to-face program delivery</p> <p>Lessons learned:</p> <p>Collaboration is essential among agency clinicians and program developers to implement program within agency culture/horns</p> <p>Regular monthly supervision/consultation is needed between the agency clinicians who are implementing the program and an experienced FOCUS leader to address group process issues and facilitate intervention fidelity</p>
<p>Program for the Study of Cancer Caregivers</p>	<p>Memorial Sloan Kettering Cancer Center (MSKCC, New York and Regional Sites)</p>	<p>Caregivers of patients diagnosed with any site or stage of cancer</p>	<p>Caregiver Clinic, appointments for psychotherapy or medication management, individual/family/group sessions</p> <p>Enrolment in clinical trials providing psychosocial support to caregivers</p>	<p>114 diagnostic visits, 462 follow-up visits, 3 time-limited groups, 21 couples/family therapy sessions, 103 caregivers receiving medication management</p> <p>118 caregivers consented to clinical trials</p>	<p>Challenges:</p> <p>Accommodating the needs of all distressed caregivers in need of timely support</p>

Table 3 | Continued

Program and goals	Setting	Participants	Implementation strategies	Results	Challenges and lessons learned
			Support through the Caregiver-to-Caregiver Mentoring Program	17 matches	<p>The potentially prohibitive cost of care in the Clinic</p> <p>Lessons learned: Enrolment of caregivers in clinical trials offsets both the long wait time for sessions in the clinic and the financial burden associated with care</p> <p>The use of volunteer caregiver mentors provides additional support that is free of charge and delivered flexibly. Concurrently, providing mentorship assists bereaved caregivers with a continued sense of meaning and purpose</p>
CancerSupportSource® - Caregiver: Online platform for distress screening and referral for cancer caregivers	Cancer Support Community National and Affiliate Network	Caregivers providing active care to cancer patients	Web-based delivery among CSC affiliates. Expand use of broader care networks.	Currently implemented across the CSC organizational network of over 40 affiliates across the USA (caregiver version implemented March, 2017)	<p>Challenges:</p> <p>In future will evaluate reducing the number of items on the scale to decrease participant burden</p> <p>Lessons learned: Can assist in reaching hard-to-reach populations or those who prefer Internet-based technology (e.g., rural and younger populations)</p> <p>Network of collaboration among affiliates is invaluable to the success of implementation</p>

implementing but also sustaining programing. As evidenced by all programs, the process from development to implementation to program sustainment to date was characterized by three essential factors: (a) an organizational mission or priority to support caregivers; (b) diversified financing with internal and external support; and (c) commitment to cost analyses. Support for sustaining each of these interventions may be aided by examining the effect on patients' use of health services (e.g., hospital readmission). Important questions that remain to be answered are whether integrated screening and psychosocial support for caregivers has a positive impact on caregivers' quality of life and health outcomes as well as on patients' related outcomes, use of health care services, and cost of care. Such analyses are vital to decision-making about public and private financing of support to caregivers. Without such data, institutions and organizations lack clear incentives to support initiatives, which is a tremendous barrier to implementation of these activities especially in today's world where costs for programing often must be weighed competitively.

CONCLUSION

Providing a broad array of programing for cancer caregivers is essential as a growing number of Americans will face the demands of providing care for patients with cancer in coming decades [5]. These initiatives demonstrate diverse approaches to supporting caregivers and, together, have the potential to reach many caregivers. Going forward, cost-effective programs and tools that are accessible are needed to address the multiple concerns of a large number of caregivers at a reasonable cost.

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Compliance with Ethical Standards Statements

Conflict of Interest: The authors report no conflicts of interest.

Disclaimer: All statements and recommendations made in this manuscript are solely those of the authors and do not necessarily represent the views of the National Cancer Institute or National Institutes of Health.

Previous Reporting of Data: Aspects of this article were presented at the American Psychosocial Oncology Symposium; San Diego, CA; March 5, 2016, but all initiatives as presented here are updated in content. An abstract on the CancerSupportSource[®]-Caregiver validation data was recently accepted for poster presentation at the Society of Behavioral Medicine Conference in March, 2017. Information on the Program for the Study of Cancer Caregivers at Memorial Sloan Kettering Cancer Center (MSKCC) has not been previously reported in manuscript form. The FOCUS/CSC exemplar as written in this manuscript is a summary of work with FOCUS from initial development to RCTs and then implementation in a community setting. This process toward implementation has not been reported previously in manuscript form. However, as referenced in this manuscript, data related to the FOCUS Program and implementation were previously published (Cancer Nursing as well as at the Association of Oncology Social Work National Conference in May, 2014), but, again, this manuscript takes a different form and focus. This manuscript is not being simultaneously submitted elsewhere.

Statement Indicating That the Authors Have Full Control of All Primary Data and That They Agree to Allow the Journal to Review Their Data If Requested: The Cancer Support Community has full control of data related to CancerSupportSource[®]-Caregiver and would allow the journal to review the data if necessary. The "data" (diagnostic data, etc.) for the Program for the Study of Cancer Caregivers MSKCC is from medical records of which Dr. Applebaum does not have full control in terms granting access to such records per privacy. Researchers involved with FOCUS implementation (L.N.; B.D.) have full control over the primary data and are willing to let the journal to review data if believed necessary to do so.

Ethical Disclosures Regarding Treatment of Human and Animal Experimental Subjects and Informed Consent: The CSC research to develop and validate CancerSupportSource[®]-Caregiver was reviewed and approved by an independent IRB (Ethical and Independent Review Services) and involved participants' informed consent. No IRB was involved in terms of building the Program for the Study of Cancer Caregivers MSKCC, but IRB was involved in the Program's research arm (although data from these studies are not presented in this manuscript). The University of Michigan/CSC FOCUS project was approved by the University of Michigan (UM) IRB. Other studies (RCTs) that tested the efficacy of FOCUS also were reviewed by IRB at UM and by the IRBs of all the cancer centers where we obtained patients. All participants in each of the FOCUS studies completed written consent forms prior to the start of the study. In addition, the RCTs are registered on ClinicalTrials.gov. Thus, as appropriate, those research initiatives abide by Helsinki declaration to ensure for human subjects protection.

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