



Identification and Characterization of Peer Support for Cancer Prevention and Care: A Practice Review

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Abstract

Research across the cancer care continuum indicates peer support can improve patient outcomes, yet little is known about how cancer peer support programs are implemented in practice. This study aimed to describe cancer peer support programs in “real world” (i.e., non-research) settings. A web search identified 100 programs in a wide variety of settings and locations; 48 published contact information on their website and were invited to participate in semi-structured interviews. Twenty-nine program leaders participated. From the interviews, we observed eight primary themes, which centered on challenges and responses regarding training and content of peer support services as well as program organization and support. Obstacles include inconsistent funding, reliance on volunteers, and physician concerns about peer supporters’ advice to patients, while increasing diversity, reach, and accessibility are future priorities. Peer support should be recognized and funded as a routine part of cancer care in order to expand its reach and address priorities such as increasing the diversity of supporters and those they help.

Keywords Cancer peer support programs · Peer supporters · Support seekers · Cancer centers

Introduction

Peer support (PS) provided by “community health workers,” “lay health advisors,” “promotores,” “patient navigators,” “peer supporters,” and individuals with a number of other designations has been shown effective in enhancing linkages to care and attending to the dynamic conditions of real-world circumstances that influence health behavior [14, 15, 20]. Although medical care and self-management programs may help individuals understand what to do to stay healthy, individuals often find themselves disconnected from

resources and emotional support needed to initiate and sustain behavior change. PS addresses this gap by offering emotional, social, and practical assistance for achieving and sustaining complex disease management or lifestyle changes and for enhancing quality of life [6, 23]. PS can complement and enhance other health care services to improve patients’ adherence to treatment regimens, motivation, and ability to cope, and it can help them stay connected to their health care providers, often in a cost-effective manner [24, 25].

PS is recognized as a valuable strategy for the prevention and management of chronic illnesses including cancer [6, 18]. We and our colleagues published a scoping review [17] that examined peer-reviewed literature on PS across the cancer care continuum. Although there are types of cancer (e.g., lung) and phases of the continuum (e.g., survivorship, end-of-life care) in which research on PS is sparse, nevertheless, the scope is broad. Starting with prevention, peer supporters promote healthy behaviors such as smoking cessation [12] and provide education to promote screening for cancers like cervical and colorectal cancer [9]. Peer supporters assist with linkages to clinical care and community resources to help individuals cope with the challenges of diagnosis and treatment [9, 16]. Ongoing support may also contribute to survivorship, palliative, and end-of-life care [1, 2]. Beyond the research

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literature, however, little is known about how PS programs for cancer operate in ongoing clinical and community settings. Programs in “real world” (i.e., non-research) settings may experience unique challenges compared with those operating within a research protocol, particularly in regard to funding and personnel. The purpose of this study was to learn more about such cancer peer support programs and how they are organized, managed, and supported by their hosting organizations.

Methods

Participants

We conducted a web search to identify programs inside National Cancer Institute (NCI)–designated cancer centers as well as community-based programs. To do this, we first reviewed the websites of all 71 NCI-designated cancer centers for information about cancer PS programs available for cancer patients and/or survivors, including support groups and patient navigation services. To locate cancer PS programs outside of cancer centers, we utilized Google to search for “cancer peer support.” We identified 100 programs in total; of these, 48 had contact information available on their websites and were thus contacted for interviews. Twenty-nine individuals in program leadership roles, “program leaders,” responded and completed interviews. Two were unable to find a time to interview, one declined to be interviewed, and 16 did not respond. Because this was a program review and not a study of human subjects, informed consent was not required. The purpose of the study was to characterize the variety of ways in which cancer PS programs address prevention, care, and survivorship needs. It was *not* to enumerate and identify all such programs. Because the 29 interviews reached saturation (no new information emerging), we did not interview leaders of additional cancer PS programs.

Procedures

Using a deductive approach, we developed a phone interview guide (available as [online supplement](#)) based on prior work with peer support programs and topics included in the parallel scoping review [17]. KB conducted three initial interviews with program leaders. Based on detailed notes from these, the research team finalized the guide, which included items about the program model, eligibility criteria, peer supporter training, support from clinical staff and integration with other supportive services, funding and administrative information, diversity and inclusion, program evaluation, and challenges and barriers. KB

completed interviews with the remaining 26 programs. During the interviews, KB took detailed notes on leaders’ responses to each question, which were then entered into a spreadsheet. Due to privacy concerns, interviews were not recorded; as such, we do not report direct quotations. These responses were later checked against interview recordings for accuracy and summarized. The research team collaboratively reviewed the spreadsheet of program details and discussed cross-cutting themes. We used these themes as the basis for the characterization of programs and observations that follow.

Results

The 29 participating cancer PS programs came from NCI-designated cancer centers ($n=6$, 5 comprehensive), community-based programs ($n=10$), or were primarily online or telephonic ($n=13$) and ranged in longevity from 6 months to 40+ years. Thirteen of the 29 served individuals with any cancer type while six focused on breast/ovarian cancer. Others focused on prostate ($n=2$), colon ($n=1$), or pancreatic cancers ($n=1$); childhood brain tumors ($n=1$); and bone marrow transplants ($n=2$). Programs largely offered services for anyone touched by cancer ($n=13$), though some targeted women ($n=2$), young adults ($n=4$), young women ($n=2$), pregnant women ($n=1$), families ($n=1$), a specific ethnicity ($n=1$), or individuals in a particular location ($n=3$). All programs required peer supporters (PSers) to be cancer survivors, and eight required they be at least 1 year past active treatment. Eighteen offered programs for caregivers.

Below, we describe eight primary themes that center on challenges and responses regarding training and content of PS services as well as program organization and support. These are further detailed in Tables 1 and 2.

Recruitment, Training, and Ongoing Support for Peer Supporters

Allocating time and effort to recruit, train, track, and retain PSers was a constant challenge. Solutions included recruiting previous recipients to become PSers or incorporating PSers as paid staff. Most training shared similar content (e.g., empathic listening, role play) but varied considerably in duration (from none to 2 days, from no to required supplemental training), or format (in-person, online training). *All* programs, however, mentioned the importance of ongoing support and back-up for the PSers, given the difficult circumstances PSers face. For example, PSers may need support to handle situations outside of their competency, like mental health emergencies,

Table 1 Challenges and responses regarding training and content of peer support services**Challenge 1. Recruitment training and ongoing support for peer supporters***Challenges*

- Constant challenge of time, effort to recruit, train, track, and retain volunteers to maintain sufficient volunteers to support seekers with match
- Volunteer retention, especially if volunteers are not matched frequently
 - Volunteers eager to give back, so waiting for opportunity a challenge
 - Because treatments advance rapidly, volunteers may no longer be able to match well with treatments offered current patients facing same cancer
- Reality that peer supporters often face difficult circumstances
 - Emotional toll sometimes exacted on peer supporters
 - Especially if confronted with situation reminiscent of difficulties in own cancer
 - Most difficult may be death of supporter's mentee

Strategies for addressing challenges

- Recruit peer supporters from among those who received peer support in the past
- Use of paid staff as peer supporters
 - Reduced concerns around retention, recruitment, and training
 - Not able to provide as specific of a match between supporters and support seekers
 - Reported benefit to seekers from supporters' wealth of information and experience derived from working with many patients
- Training varied widely: No training to 2-day training with supplemental training required throughout year
 - Most programs focused training on empathetic listening or motivational interviewing skills, offering opportunities for role play
 - Some programs required in-person training; others offered training online through modules or program handbook
 - Most programs had one-time training, but handful offered continuing education opportunities, e.g., webinars, group meet-ups with other supporters
- Ongoing monitoring: Programs most actively involved in monitoring provided supervision/monitoring such as phone calls to check in about difficult cases
- Several programs address challenge of giving volunteers opportunities to serve through involving them in outreach efforts other than one-on-one matching, e.g., speaking at fundraising events, writing blogs, spreading information about cancer prevention or testing
- All programs discussed importance of support and back-up for peer supporters
 - Most programs specifically trained volunteers not to provide medical advice, but supervision of peer supporters used to ensure quality of information and support being provided, including, e.g., in answer to patients' questions
 - Keep them engaged and acknowledge they also face constant challenges as cancer survivors
 - Support opportunities varied, including mentor-to-mentor programs, support groups or phone meetings, "hangouts," retreats, opportunities to be involved in fundraising and marketing events, like walk-a-thons and survivorship panels
 - Some programs provided regular phone meetings for peer supporters to call in, discuss difficult cases, receiving support from program staff or other supporters
 - Program staff provided "back-up" for peer supporters facing situation outside their skill set, such as serious mental health concerns
 - Physician or other clinician to provide medical information for supporters to convey to their mentees or directly to those mentees

Challenge 2. Promoting program to support seekers*Challenges*

- How to connect inform patients, link with clinical care
- HIPAA: Extra hurdles because HIPAA compliance requires extra precautions when providing patient information to a peer supporter

Strategies for addressing challenge

- Myriad of ways that patients connect with programs
 - Many programs marketed via their website, social media, and in-hospital advertising
 - Some provide brochures in clinic waiting rooms
 - Some have seasoned peer supporters available in outpatient clinics to provide informal support, invite participation in peer support program
 - Some programs report mainly self-referrals
- Most programs receive referrals from clinical staff at cancer centers and hospitals
 - Clinical staff may provide resources and information to patients, who then follow through on the referral
 - For others, clinical staff can make direct referrals to the program if patient consents to be contacted. Program may then follow up directly with patient rather than waiting for patient to contact
- Programs outside cancer generally not required to be HIPAA-compliant. Still emphasize confidentiality and delicacy when handling patient information, but fewer barriers regarding confidentiality

Table 1 (continued)

	<ul style="list-style-type: none"> • Offer wide variety of opportunities for both recipients and peer supporters to meet, e.g., fundraisers like walk-a-thons or 5Ks, community forums, craft classes, large social gatherings or “meet-ups” <ul style="list-style-type: none"> ◦ Some programs sponsored these types of events instead of one-on-one peer matching, noting that one-on-one support often resulted informally from these community gatherings • Programs’ active web-based communities through which individuals connect and share stories via blogs, social media, video chat, and online forums. These observed to lead to informal matching and one-on-one support.
<p>Challenge 3. Matching</p> <p><i>Challenges</i></p> <ul style="list-style-type: none"> • Deciding on basis for match (i.e., cancer type vs. interests vs. life experience) • Should programs facilitate the match itself, or facilitate opportunities for matches to be made informally? 	<p><i>Strategies for addressing challenge</i></p> <p>Two broad approaches to organizing peer support and arranging for peer matching</p> <ul style="list-style-type: none"> • Quasi-clinical approach or “micro-matching” or “connection perfection”: focused on match specificity <ul style="list-style-type: none"> ◦ Match based on similar cancer experiences and characteristics, e.g., diagnosis, stage, treatment plan, age of patient, and gender ◦ Programs noted commitment to importance of matching so patients gain reassurance about their own prognosis through talking with someone with whom they can identify because they have a very similar clinical condition ◦ More specific matching focused on characteristics that matter most to patients, e.g., occupation or hobbies. ◦ Extent of concern about matching reflected in some programs referring to other programs unable to provide strong match. ◦ Emphasis on matching also corresponded to emphasis on individual support rather than through groups, etc. • Alternative approach—“community facilitation”—creating spaces and activities for peer support to occur naturally <ul style="list-style-type: none"> ◦ e.g., social outings or meet-ups, online video chat groups ◦ Staffing places like hospitality centers or outpatient clinics with peer supporters ◦ Example: programs for young adults less interested in match specificity; consistently noted that young adults often feel isolated, so receiving support from someone their own age may be more important than similar cancer diagnosis or treatment plan. ◦ Through activities, individuals and peer supporters may often become linked and grow into one-to-one supportive relationships, comparable to those among individuals more systematically matched
<p>Challenge 4. Domains and channels of support</p> <p><i>Challenges</i></p> <ul style="list-style-type: none"> • Whether, how to include social media, online channels • Whether, how to limit extent or duration of support 	<p><i>Strategies for addressing challenge</i></p> <ul style="list-style-type: none"> • Programs varied in ways peer support was delivered, including in-person meetings, phone, video chat, e-mail, social media <ul style="list-style-type: none"> ◦ One program allows cancer survivors to connect with their own supporter from other users’ website profiles • Social media and online support <ul style="list-style-type: none"> ◦ Several mentioned patients are receiving support informally from Facebook, other social media sites instead of seeking out a formal match; expect this mode of support-seeking to continue to grow ◦ Cohort effect: all programs for young adults mentioned importance of utilizing online modes of support for meeting patients where they are and finding ways to make peer support more convenient and accessible, especially since work and family commitments may constrain time ◦ Video chat between individuals ◦ Virtual peer-led support groups and activities (e.g., art as a creative outlet for stress) • Duration of contact differed based on support seeker’s preferences <ul style="list-style-type: none"> ◦ Most programs require peer supporters to make first contact ◦ Some require that peer supporters stay in touch for a minimum amount of time, from one phone call to duration of treatment ◦ Several indicated most people are only interested in one or two contacts (typically via phone or e-mail) with a peer supporter; they

Table 1 (continued)

<p>Challenge 5. Diversity, inclusion, and access</p> <p><i>Challenges</i></p> <ul style="list-style-type: none"> • White, older women are most likely to use services of nearly every program (excluding those specifically focused on men or young adults) • Based on observations of program leaders; most programs do not collect data on race, ethnicity, or income of support seekers or peer supporters <ul style="list-style-type: none"> • True regardless of program size, location, or mode of communication • A few programs reported volunteers who speak Spanish; these volunteers frequently overloaded with matches • Most programs not able to match non-English-speakers with peer supporters and do not offer training in languages other than English • General: cancer peer support opportunities for men and ethnic/racial/language minorities seem to be severely lacking 	<p>simply want to know someone else had a similar disease and prognosis and is still living and made it through treatment</p> <ul style="list-style-type: none"> ◦ All programs also had stories of individuals who developed lifelong relationships after being matched <ul style="list-style-type: none"> • For some, simply contact information is enough. Knowing there are “others like me” is helpful; actual contact or conversation unnecessary. <p><i>Strategies for addressing challenge</i></p> <ul style="list-style-type: none"> • A few programs specifically target men, socially or economically disadvantaged groups, or ethnic minorities who are so often “hardly reached” by health care <ul style="list-style-type: none"> ◦ Challenges in this include stigma and difficulty recruiting peer supporters from these communities • One program that focuses on predominantly low-income, racial-minority area described extra support and flexibility it tries to provide peer supporters <ul style="list-style-type: none"> ◦ Peer supporters, who come from same community the program serves, may encounter their own struggles with homelessness, family illness, unemployment, or other issues. Consequently, may not always be able to be present as a volunteer and source of support in another patient’s life. • Many programs are facilitated online and advertised via social media, limiting reach to individuals with internet access
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or may need staff support to cope with difficult experiences like the death of their supportee.

Quality control tended to be linked with ongoing training, monitoring, and supervision/consultation for the PSers. Notably, a common concern about PS is the possibility of misinformation. Most programs specifically trained volunteers not to provide medical advice. Ongoing supervision of peer supporters ensured quality of information and support being provided such as in answering patients’ questions, though programs differed greatly in the amount of supervision provided. Most programs required participation in some type of formal training at least once per year and had staff members available to provide support to PSers on an as-needed basis, while a few programs reported more frequent oversight, such as monthly conference calls.

Promoting Cancer PS Programs to Support Seekers

Patients connected with programs in many ways. In addition to one-to-one peer support were a variety of channels, e.g., web-based communities, blogs, social media, video chat, and online forums, which sometimes lead to informal, one-to-one support.

HIPAA compliance may limit the ability of PSers to directly contact individuals who have not consented. Programs outside cancer centers noted that they are generally not required to be HIPAA-compliant, lessening confidentiality-related barriers.

The Match

Careful matching (aka “micro-matching”) pairs those seeking support with PSers based on diagnosis, stage, treatment, age, gender, and, sometimes, occupation, interests, or hobbies. Providing individuals reassurance about their own prognoses through talking with someone in a similar clinical situation was a prime motive for many seeking support and, thus, for careful matching. Some programs even referred to other cancer PS programs if they could not provide a close match. Some PSers also look forward to matching and the opportunity to help someone going through what they have endured.

Matching raised a number of other issues for programs. Closely tied to emphasis on matching was a focus on one-to-one peer support. Some managers noted, however, that young adults who feel isolated may benefit from a PSer with common age or interests more than a similar diagnosis or treatment plan. Rapid developments in treatment may also provide challenges to matching based on diagnosis and treatment. Some PSers may no longer match current patients facing the same cancer but with newer, very different treatments. Several programs found continued roles for these PSers through additional opportunities, such as speaking at fundraising events, writing blogs, or helping spread information about cancer prevention or testing. Community-based activities created spaces for PS to occur naturally, whether through social outings, online chat groups, or by PSers staffing hospitality centers or outpatient clinics. These may lead to one-to-one relationships comparable to those among individuals systematically matched.

Table 2 Challenges and responses regarding program organization and support**Challenge 1. Program promotion and buy-in from clinical staff***Challenges*

- Although nearly all programs reported strong buy-in/support from social workers, nurses, and nurse navigators, programs varied substantially in reporting buy-in/support from physicians
 - Most programs expressed neutral feelings about support from physicians; while not the best champions, they still supported it
 - These programs explained that physicians are typically focused on the biomedical side of treatment, and leave the psychosocial issues to other clinical staff members
 - Consequently, vast majority of referrals seem to come from nurses and social workers
- A few programs mentioned some physicians are actively unsupportive or openly antagonistic toward their programs; a few respondents even laughed or audibly sighed in response to the question about physician support
 - Variety of reasons for this, including concerns about losing control over whom the patients speak with about their diagnosis
 - Worry that peer supporters may encourage patients to question their treatment plans or not trust their clinician or may encourage patients to seek other opinions or alternative remedies
- Respondents noted that physicians are not opposed to idea of peer support generally
 - Some physicians make their own informal matches between current and former patients
 - Although well intentioned, respondents reported this undermines peer support program

Challenge 2. Program evaluation*Challenges*

- Most programs had completed no formal program evaluation
- Nearly all collect some information on patient satisfaction, but not on psychosocial or health outcomes
- Consistent in explaining they would like to do formal evaluation and publish results, but lacked staff time, resources, and/or knowledge to do this
 - Consensus that procuring funding and other resources is major obstacle to conducting formal evaluation

Challenge 3. Funding models*Challenges*

- Funding is major obstacle for many programs, especially for those based outside of cancer centers

Strategies for addressing challenge

- A few programs mentioned physicians who serve as champions for the program
 - Invited physicians to be part of programs, e.g., “ask-the-expert” panels, community meetings, serving as board members
 - Three programs noted some of their strongest support comes from surgeons
- Some programs are members of cancer coalition in their area
 - These programs generally expressed more buy-in from clinical staff
 - Described how cancer coalition facilitated resource and information sharing
 - For some, cancer coalition seemed to be a stamp of approval that encouraged other cancer organizations and clinical teams to utilize services
- All programs mentioned networking as among biggest challenges
 - Slow and constant effort to build rapport and marketing
 - Major obstacle is staff turnover: If a champion at a hospital who regularly refers patients leaves, program may have no further link with that facility
 - Programs reported advantage of having a relationship with an outside institution rather than being dependent on an individual at the institution.
- A few programs mentioned it would be helpful if they could receive some sort of certification as an officially recognized peer support program and indicated approval from an outside certifying agency would improve buy-in from clinicians

Strategies for addressing challenge

- Only a few programs had conducted an evaluation and published their data or had plans to do so
- Usually these programs had relationships with research team at a university or academic medical center
- Academics, however, may be an unreliable resource for program evaluation; one described researchers having collected data from program participants, but failing to share findings with the program

Strategies for Addressing Challenge

- Programs described variety of funding models
 - In cancer centers, funding typically through social work, psychosocial support programs, survivorship programs, or volunteer services
 - In some cases, programs also funded through foundation grants (e.g., Ovarian Cancer Research Fund’s Woman-to-Woman program)
 - A number of the NCI-designated cancer centers represented have budget and staff allocated for the program
 - Some received grants and private donations
 - Others part of a larger non-profit whose primary goal was to raise money for research or various supportive services for cancer patients
 - One program described the “NPR/PBS model,” in which patients start providing donations as they feel appropriate to their use of the program’s time and resources
 - A few programs receive some funding or in-kind donations like office space from cancer centers for which they provided peer supporters
 - Some provide fee-based services (e.g., patient navigation) to cancer patients or hospitals with the income funding the peer support program.
- In general, programs agreed on the importance of creative and diverse funding strategies.

Additionally, programs reported making efforts to bring PSers and supportees together through meet-ups and activities, which encouraged individuals to stay involved over time.

Domains, Channels, and Patterns of Support

Because many already seek support through web and social media sources, programs incorporated these as well as in-person meetings or phone support. In perhaps a cohort effect, all the programs for young adults mentioned the importance of online support. Length of support varied from one contact to the duration of treatment. Several leaders indicated that many seeking support are interested in just one or two contacts, sufficient to learn that someone else had a similar disease and prognosis, made it through treatment, and is still living. Indeed, for some patients, simply having someone's contact information and knowing there are "others like me" was adequate with little or no actual contact. Nevertheless, all programs had stories of individuals who developed lifelong relationships after being matched. Program leaders suggested women are more likely to stay in touch and to seek emotional support, while men primarily use PS for information.

Diversity, Inclusion, and Access

Most cancer PS programs do not collect data on race, ethnicity, or income. Except for those focused on men or young adults, however, nearly every program reported that older, white women are most likely to use their services, regardless of program size, location, or mode of communication. Most programs were not able to match non-English-speakers and did not offer training in languages other than English. Leaders reported that Spanish-speaking PSers are frequently overloaded with matches. Challenges reaching men, racial/ethnic minorities subject to discrimination, or socially/economically disadvantaged groups include stigma and difficulty recruiting PSers from these communities [22]. One program serving a predominantly low-income, racial-minority area explained that their PSers may themselves encounter struggles with homelessness, family illness, unemployment, or other stressors, compromising their ability to be present as a PSer.

Buy-in from Clinicians

Programs reported strong buy-in and support from social workers, nurses, and nurse navigators, but variable buy-in and support from physicians. Some engaged physicians as champions through activities like "ask-the-expert" panels, community meetings, or board membership. Most reported that physicians focus on biomedical treatment, leave psychosocial issues to other staff, and support the programs, but are

not programs' best champions. Most referrals are reported to come from nurses and social workers.

A few programs mentioned lack of support or even antagonism from some physicians, which was attributed to concerns about losing control over patients' care and worry that PSers may encourage patients to question their treatment plans, not to trust their medical provider, and to seek other opinions or alternative remedies. Reports indicated physicians are not opposed to the idea of PS but prefer to maintain control over with whom patients are matched; for example, some physicians reportedly informally match their own current and former patients. Program leaders indicated this may undermine the cancer PS program. Participation in local cancer coalitions may gain credibility among and cooperation from physicians as well as facilitating use of services by other organizations and clinical teams and sharing resources and information. Several also mentioned the desirability of independent certification of programs [21] to improve buy-in from physicians. Turnover of champions within cooperating organizations complicated networking. Developing relationships with institutions rather than individual champions was recommended.

Program Evaluation

Nearly all programs collected some information about patient satisfaction but did not assess psychosocial or health outcomes or maintain formal program evaluation. Reasons were lack of staff time, resources, funding, and/or knowledge. Planning, conducting, or publishing an evaluation was more likely for programs connected with a university or academic medical center. One respondent mentioned researchers collecting participant data but failing to share findings with the program.

Funding Model

Managers reported a need for creative and diverse funding strategies. Within NCI-designated cancer centers, cancer PS programs were allocated budgets and staff and funded through social work, psychosocial support programs, survivorship programs, volunteer services, or foundation grants. Outside of cancer centers, funding presented a major obstacle. Sources included grants, private donations, in-kind donations like office space from cancer centers for which programs provide services, or being part of a non-profit. One respondent noted the "NPR/PBS model" in which grateful patients donate as they judge appropriate to their use of the program. Some provide fee-based services (e.g., patient navigation) to cancer patients or hospitals. Several programs noted difficulties in funding ongoing monitoring and quality control that require appreciable staff time.

Discussion

Cancer peer support programs are popular and valued across many cancer centers recognized by the National Cancer Institute as well as across clinical, community, and other treatment and support settings. Services ranged widely, including matched one-to-one PS and support groups, as well as broader activities within which important PS often emerges, such as advocacy or fund-raising activities. Strategic challenges include training and quality control, matching patients with PSers, increasing diversity, gaining support from otherwise skeptical or cautious physicians, and funding. More practice-oriented issues include building community around PS, contacting and engaging patients, recognizing the value of the simple availability of support, and diversifying modes of support.

Strategic Challenges

PSer Training: Need for Standardization? Program training varies greatly. A standardized curriculum for PS in cancer care might have substantial appeal as a step toward legitimacy. However, the variety of approaches and PSers, from full-time employees to volunteers offering PS a few hours a week, suggests standardizing training and qualifications might constrain the range, vitality, and flexibility of PS to meet the needs of different patient groups, settings, and communities. Peers for Progress has promoted standardization not around specific program details but around five key functions: (i) being there, (ii) assistance in daily management, (iii) social and emotional support, (iv) linkage to clinical care and community resources, and (v) ongoing support since problems may last “the rest of your life” [7, 10]. Training, protocols, supervision, etc. can be organized around how such functions may be applied to the objectives and resources of a particular program. That is, emphasizing functions may enable a compromise between standardization and adaptation to local circumstances.

Flexibility might also be enhanced by credentialing programs as meeting quality standards and qualifying for funding. Once reviewed and approved, a program might then be able to recruit, train, and deploy PSers without each individual having to gain certification, a barrier to many such as retired volunteers and an administrative burden for programs. Amidst the variety of approaches and providers of PS in cancer, such recognition of programs may be more nimble than certifying individuals, although pursuing both approaches is surely feasible as suggested in guidelines developed by Peers for Progress with several collaborating groups [4].

Match Specificity The ability of a cancer PS program to provide specific matches is largely dependent on its number of PSers. Programs with national or international reach through

telephone or online support can provide PSers with a wide range of experiences. Smaller, community- or hospital-based programs may provide a local sense of community and spaces for peer support to occur naturally, obviating the need for a large number of PSers to facilitate specific matches. The availability of both might be ideal—a remote PSer with similar diagnosis and treatment but also a local PSer or support group that could provide more varied forms of support. Needs vary and, with them, the importance of matching. For young adults who often feel isolated, receiving PS from someone their own age may be most critical.

Concerns Related to Diversity, Access, and Inclusion Program leaders noted that older, white women were both most likely to use PS and most likely to serve as PSers. A challenge is recruiting PSers from groups that are underrepresented: those with cancers other than breast, ovarian, and gynecological; males; and racial/ethnic minority and socially/economically disadvantaged groups, some of whom may need extra support and flexibility to participate. Stigma surrounding cancer may also reduce participation in some communities.

From the perspective of social networks, programs led by and serving a particular group will be less likely to engage those outside the group, creating a vicious circle of lack of diversity. Inclusion efforts should prioritize recruiting diverse PSers and program leaders. Challenges to diversity reflect resource constraints. Those with greater social privilege and economic resources may be more able to volunteer time while resources for transportation, telephone access, etc. are particularly critical when recruiting socially/economically disadvantaged PSers. The success of programs such as the Sisters Network [19], a mutual support program for African American women with breast cancer, makes clear that PS may be welcomed in diverse communities. The problem is resources.

Gaining Support from Physicians Reports of lack of support especially from some physicians raise concern. Amidst the myriad of alternative remedies, physicians treating cancer may feel especially a need to protect patients from frivolous or harmful approaches. Some may fear PSers will lead their patients to “bogus” treatments or encourage patients to question their physician’s judgment. Program leaders reported success in gaining physician support through inviting them to learn about PS, the match process, and PSer training, and to serve on advisory committees. Additionally, by providing more comprehensive training and ongoing monitoring of PSers, and conducting regular program evaluations, cancer PS programs may secure greater confidence in program quality and support among physicians.

Funding Priorities The Affordable Care Act has spurred accountable care organizations (ACOs), development of an oncology-focused medical home model (COME HOME project), value-based payments, health homes that provide ongoing

support for those with multiple chronic conditions, and bundled and episode-based payment initiatives in specialty care (Oncology Care Model) [3]. These population- and performance-based payment reforms can utilize PS in varied ways such as care navigation, patient education, enhancing access, service integration including palliative care, home care, and caregiver engagement. As much as PS may play an important role, stronger advocacy efforts are needed to direct a portion of these funding streams for PS within both clinical and community settings.

Practice-Oriented Issues

Building Community From interviews, the more a program worked to create community among its recipients and PSers, the longer individuals stayed involved. Support from staff as well as other PSers creates a sense of community that extends then to other issues such as helping cancer survivors make meaning of their experience by helping others. However, PSers who are several years out of treatment may not be able to be matched because their experience is different from current patients. This may discourage PSers, so programs may offer alternative ways for PSers to be involved. PSers also need staff support for situations beyond their skills (e.g., mental health emergencies). They may also need emotional support from staff or other PSers to cope with situations like the death of their supportee. Across all of these support needs, programs that create a strong sense of community among PSers, staff, and supportees may increase both their reach and sustainability.

Making Contact HIPAA and other constraints may complicate PSers linking with those they might help. In several studies [5, 13], providing descriptions of PS programs and then inviting individuals to participate does not result in high recruitment. On the other hand, if PSers are able to contact individuals directly, they are able to reach and engage large proportions of populations including those too often “hardly reached” [22]. Continuous quality improvement efforts might explore varied strategies, including arranging for PSers to meet patients in the clinical setting. Another approach might be for clinicians simply to inform patients that a PSer will contact them as a routine part of clinical care and to suggest they consider carefully the services offered. Outside the context of rushed clinical encounters, PSers might have more time to describe the potential benefits of PS to the patient and encourage them to participate.

Knowing There Are “Others Like Me” Versus Actual Contact Striking were reports that patients knowing they could contact “others like me” is helpful in and of itself, even without actual contact. A study of telephone support for high risk groups (e.g., veterans, police) identified the value just of voicemails as conveying “presence,” interest, support, and availability of help [8, 11]. This underscores the importance of simply “being

there” and the importance of emphasizing to PSers that they do not necessarily have to solve problems to be helpful.

Need for Diversifying Mode of Support Managers mentioned that people receive PS informally from social media sites and that they expect this mode of support-seeking to continue to grow. This may imply a need to diversify modes of support available to patients. Suggesting a cohort effect, all the programs focusing on young adults mentioned the importance of utilizing online modes of support. Online support may also make PS more convenient and accessible, especially amidst time constraints of work and family commitments and following experience with COVID-19 in which many have learned to connect through digital channels.

Strengths and Limitations

This study offers insight on challenges for cancer PS programs. Interviews included program leaders representing a wide range of “on-the-ground” programs that actively work with patients every day. This information expands on our scoping review of research literature [17] by providing real-world examples of issues commonly faced by cancer PS programs. Limitations however include a convenience sample and possible selection bias arising from inclusion only of those responding to emails and agreeing to participate. Findings were based on detailed interviewer notes that were checked against audio recordings. Interpretations of those notes were refined through detailed discussion and consensus among the research team comprised of the present authors, with recourse again to audio recordings as needed.

Conclusions

Programs offered through cancer centers, hospitals, and other clinical and community settings provide a wide range of PS for cancer prevention and care. Clearly, those directly involved in assisting and supporting individuals with cancer view PS as valuable in the continuum of cancer care from primary prevention and detection to end-of-life care. The field is robust. However, a number of challenges have prevented the extension of PS to all those affected by cancer who might benefit from it. Critical for future growth will be recognition of PS as a routine part of cancer care and support and, with it, sufficient funding to meet important challenges such as increasing diversity, standardization and evaluation, and development of a shared state-of-the-art in the field.

Authors’ Contributions All authors contributed to the study conception and design. Kaitlyn E. Brodar performed material preparation, data collection and analysis. Identification of themes from interviews was discussed with all authors and revised by consensus. All authors contributed to the first draft of the manuscript and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data Availability Not applicable; study data were interview notes.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Ethics Approval Because this was a program review and not a study of human subjects, informed consent was not required.

Consent to Participate Not applicable.

Consent for Publication Not applicable.

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