Implementing a One-on-One Peer Support Program for Cancer Survivors Using a Motivational Interviewing Approach: Results and Lessons Learned

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Abstract Peer Connect matches cancer survivors and care-givers (guides) with those currently experiencing cancer-related issues seeking support (partners). Motivational interviewing (MI)-based communication skills are taught to provide patient-centered support. There is little guidance about MI-based applications with cancer survivors who may have multiple coping needs. This paper addresses the results and lessons learned from implementing Peer Connect. Thirteen cancer survivors and two caregivers received a 2-day MI, DVD-based training along with six supplemental sessions. Nineteen partners were matched with guides and received telephone support. Evaluation included guide skill assessment (Motivational Interviewing Treatment Integrity Code) and 6-month follow-up surveys with guides and partners. Guides demonstrated MI proficiency and perceived their training as effective. Guides provided on average of five calls to each partner. Conversation topics included cancer fears, family support needs, coping and care issues, and cancer-related decisions. Partners reported that guides provided a listening ear, were supportive, and nonjudgmental. Limited time availability of some guides was a challenge. MI can provide support for cancer survivors and caregivers without specific behavioral concerns (e.g., weight and smoking). An MI support model was both feasible and effective and can provide additional support outside of the medical system.

Keywords Peer support · Cancer survivors · Telephone counseling · Motivational interviewing

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Background

Approximately 1 in every 25 Americans is a cancer survivor. With improvements in early detection and treatment of cancer, more than 68 % of cancer patients now survive more than 5 years [1]. Survivors and their families face psychosocial and quality of life issues at various stages, such as during active treatment and recovery, after recovery, during advanced cancer, and at end of life [2]. Projected limits in the healthcare provider workforce's capacity to serve the rising number of survivors [3, 4] suggest the need for additional resources to help survivors cope with the impact of cancer on their health and well-being.

Social support, including peer support, has been identified as a key resource that can buffer the impact of stressful experiences, such as cancer [5, 6]. Peer support programs have been developed to help patients at all stages of the cancer continuum [7] and have been shown to be effective in both

one-on-one and group support settings [8, 9]. Peer support programs help patients cope with diagnosis and treatment [10–12] and have been found to improve cancer patients' satisfaction with medical care, increase knowledge, improve coping strategies [10, 13], provide a sense of hope [10, 13], improve personal relationships, expand social support [11], foster a sense of belonging [10], and improve mood [14]. Peer support also can provide acceptance by others in a similar situation, a sense of normalcy, and diminished feelings of social isolation [9–15].

Motivational interviewing (MI) is an interpersonal counseling approach that has been applied to chronic disease management and health promotion behaviors [16]. In MI interventions, the counselor's role is to explore coping resources in a safe, nonconfrontational, and supportive way using communication skills like reflective listening as opposed to persuasion or advice-giving. Although the majority of MI applications have been implemented by healthcare professionals, MI-based communication also has been used in peer counseling interventions focusing on healthy eating [17], smoking cessation [18], and HIV-related behavior change [19]. Few studies have applied MI techniques to cancer care health behaviors and cancer survivors. Campbell et al. [20] tested the combined effectiveness of telephone MI counseling and a tailored print intervention for promoting healthy diet and physical activity in colorectal cancer survivors and healthy individuals ($n = 735$). Participants randomized to receive the MI plus tailored print interventions showed a significant increase in fruit and vegetable consumption ($p < 0.05$). Bennett et al. [21] randomly assigned 56 sedentary adult cancer survivors to either an MI intervention (one in-person MI counseling session followed by two MI telephone calls over 6 months) or a control group (two telephone calls without MI content). They found that the MI intervention explained significant group differences in regular physical activity. A third MI study [22] trained three masters-level interventionists to increase colorectal cancer screening in a primary care population ($n = 150$). Postintervention, 19.8 % of MI participants reported scheduling a screening test and 43 % credited the MI conversations with helping them overcome perceived screening barriers. Park et al. [18] trained adult survivors of childhood cancers to deliver up to six MI-based telephone calls to childhood cancer survivors who were current smokers, and found that MI calls led to better quit rates.

Based on these findings, we developed an MI training program for cancer survivors (anyone who has ever had a cancer diagnosis) and cancer caregivers (guides) to provide nonbehaviorally specific emotional support to other cancer survivors and caregivers (partners). This paper reports the role of guides, perceived program efficacy, program satisfaction, and partners' perceptions about the support actually meeting their needs. We also share lessons learned about program implementation.

Methods

Study Design

We developed the MI-based Peer Connect program to train post-treatment volunteer cancer survivors and caregivers (guides) to serve cancer survivors and caregivers (partners) currently facing cancer-related issues. Volunteer guides were trained over a 6-month period to deliver support to partners, primarily by telephone but occasionally in person. Details on the Peer Connect study design and MI training are available elsewhere [23]. A program coordinator was responsible for managing study recruitment, program logistics, matching guides and partners, and maintaining contact with guides and partners. Study approval was received from the University of North Carolina at Chapel Hill's Institutional Review Board and the Lineberger Comprehensive Cancer Center's Protocol Committee.

Sample and Recruitment

Recruitment took place from July to December 2010 through Cornucopia Cancer Support Center, cancer support group listservs, area hospitals, and community organizations. Eligibility criteria for guides stipulated that participants be over 18 years old, English speaking, and either a cancer survivor (at least 1 year post-treatment) or experienced in caregiving for someone diagnosed with cancer. Participants were eligible to be partners if they had a cancer diagnosis or were a caregiver of someone with cancer, over 18 years old, and English speaking. Consent was obtained prior to any data collection. Small financial incentives ($25 gift cards) were provided to guides and partners at the completion of the evaluation questionnaires.

Intervention Development

To develop the MI-based DVD training and overall program structure, we conducted a 2-day pilot training (unpublished data) with cancer survivors and caregivers. The training included video clips and content adapted from previous work training peers [24, 25]. Content and delivery adjustments (e.g., more training time) were made to the guide training protocol based on the pilot testing.

Guide Training

Guides completed a 2-day DVD training in MI-based communication skills including: asking open questions, reflective listening, building motivation, moving toward change, and goal setting. Additionally, because this was a telephone support program and not face-to-face support, the training included specific tips for staying engaged with partners via the telephone

(e.g., using the Conversation Road Map and avoidance of prolonged silences). The DVD along with guide manual are described in greater detail elsewhere [23]. Guides recorded practice conversations that were assessed for MI adherence [23]. Guides attended monthly 90-min supplemental sessions (guide gatherings) for 6 months to reinforce MI skills, gain additional practice, problem–solve issues partners raised, provide feedback about content needed in future trainings, and obtain support. The guide gatherings occurred concomitantly with the matches although most of the guides were matched by month 3. Two guide gatherings were offered each month covering the same topic to address scheduling issues.

Matching Process

Partners self-referred to the program after getting recruitment materials. Partners were fully informed about the program parameters, asked about any guide preferences (gender, cancer type, age, or other concerns) they had for being matched to a guide and their reason for signing up for the program. A guide was usually assigned to each partner based on cancer type, gender, age, availability, etc. When no guide had a specific cancer type requested, partners were asked about their willingness to speak with someone with a different cancer type. Guides were expected to initiate contact with partners within 1–3 days of receiving a match with a partner. Guides were provided with information about the partner (name, phone number, cancer type, gender, best time to contact, and reason for requesting a guide). Additionally, guides as part of their training were given "roadmap" script to help them make the calls and as a reminder of the MI communication skills to use. All parties signed a confidentiality form. In the event of an unsatisfactory match, both guides and partners were instructed to notify the coordinator so that another match could be made. Within 3–5 days of initiating the match, the coordinator contacted the guide to see if contact had been made, elicit any concerns, assess the quality of the match, and offer support. The coordinator contacted all guides on a monthly basis to continue monitoring each match and address any questions or concerns.

Data Collection and Measures

We collected outcome and process data for guides and partners at baseline and 6 months. Additionally, guides evaluated the guide gatherings immediately after each session.

Demographics

Guides and partners provided demographic information (age, race, gender, marital status, and occupation) as well as cancer type at baseline.

Guide Evaluations

Six months after their first match, guides were contacted via telephone by research assistants. All evaluations were tape-recorded and double-coded for accuracy. Evaluations assessed perceived efficacy of the training, match experience, and benefits and challenges of participating. Responses were rated using a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5).

Perceived Efficacy of Training and Guide Gatherings Guides answered nine questions rating their training experience: the 2-day training, guide gatherings, time commitment, extent that role expectations were clearly communicated, adequacy of resources and materials, and sense of competency in guide role.

Match Experience Questions assessed guides' comfort level in initiating contact with partner(s), number and quality of the match(es), number of conversations with each partner, general content of the conversations, ability to address partner needs, and perceived support from the program team.

Benefits and Challenges of Participating Guides rated their overall experience, feelings of support and connection to the survivor community, and whether they would recommend the program. Open-ended questions assessed personal impact of program participation, positive and challenging experiences, and recommendations for program enhancement.

Guide Gathering Evaluations At the end of each monthly gathering, guides evaluated meeting materials (poor–excellent), effectiveness of training (yes/no), activities liked (most/least), and thoughts about improving future trainings (open-ended).

Partner Evaluations

Telephone interviews with partners 6 months after the initial match with a guide were tape recorded and double-coded to ensure accuracy. Responses were rated using a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5), unless otherwise stated.

Match Process Five questions assessed ease of enrollment, adequacy of time taken to be matched, and quality of match.

Match Experience Questions evaluated if partners' needs were met, and how important/relevant the conversations were (not at all=1 to completely=5). Additional questions assessed number and quality of conversations and conversational balance (whether the partner perceived the guide to talk more/less/equally than him/herself). Partners' also evaluated guides' MI skills, perceived listening and supportive tone, as

well as, if guides asked for permission before giving advice (not at all true=1 to very true=4).

Perceived Efficacy Seven questions assessed the partner's overall experience. Specifically, confidence to make healthcare decisions, feelings of optimism, acceptance about the future, and connectedness to community.

Analysis

Qualitative data (telephone interviews) were audiotaped and transcribed. Two team members summarized responses and conducted thematic analyses to identify recurring themes. During data coding, team members compared codes and resolved any differences through discussion with project team members. Categorical variables from interviews and guide gathering evaluations were summarized by frequency and percentage.

Results

Twenty volunteer guides completed the training, with five dropping out due to relocation ($n=1$), lack of time ($n=3$), or loss of interest ($n=1$). Fifteen guides completed the program and were matched to a partner. Nineteen partners were enrolled and matched. Two partners who were matched and talked with a guide died during the study period. Table 1 provides descriptive information for guides and partners.

Guide Evaluations

Guide Gatherings Typically four participants (range, 2–6) attended the monthly guide gatherings. Guides rated the meeting materials favorably (good or excellent). All participants reported that the role plays and targeted content discussions were effective in enhancing newly acquired MI skills through confidence building, active participation, and peer feedback. Table 2 describes the benefits and challenges of participation.

Guide Participation and Evaluation of the Program Eleven of the 15 guides who completed the program completed 6-month telephone evaluations (four relocated or did not respond to phone calls). As a group, guides were highly satisfied with the program and reported that the training components were effective (Table 3).

Match experience All 15 guides were matched to a partner. Of the 11 guides who completed evaluations, two had 3 matches over the 6-month period, five had 2 matches, and four had 1 match. Nine partners were matched with guides of a different cancer type. Two of the 15 guides were caregivers and were matched with partners who were caring for someone with a

Table 1 Characteristics of guides and partners

	Guides $N=15$ n (%)	Partners $N=19$ n (%)
Gender		
Male	5 (34)	3 (16)
Female	10 (66)	16 (84)
Age (M, SD)	56 (12.99)	60.7 (9.21)
Race		
African American	3 (20)	3 (16)
Caucasian	11 (73)	15(79)
Other	1 (7)	1 (5)
Guide volunteer type		
Caregiver	4 (27)	3 (16)
Cancer survivor	11 (73)	16 (84)
Cancer type[a]		
Breast	7 (46)	6 (32)
Leukemia	1 (7)	2 (11)
Nasopharyngeal	1 (7)	0 (0)
Prostate	1 (7)	1 (5)
Rectal	1 (7)	1 (5)
Multiple myeloma	0 (0)	2(11)
Brain	0 (0)	1 (5)
Oral/neck squamous	0 (0)	1 (5)
Hodgkin's lymphoma	0 (0)	1 (5)
Colon	0 (0)	1 (5)
Brain cancer caregiver	0 (0)	1 (5)
Ovarian cancer caregiver	0 (0)	1 (5)
Other	0 (0)	1 (5)
Prostate cancer caregiver	1 (7)	0 (0)
Lung cancer caregiver	1 (7)	0 (0)
Brain cancer caregiver	1 (7)	1 (5)
Ovarian cancer caregiver	0 (0)	1 (5)
Melanoma cancer caregiver	0 (0)	1 (5)
Leukemia cancer caregiver	1 (7)	
Marital status		
Married/partnered	9 (60)	7 (37)
Single	3 (20)	7 (37)
Divorced/separated	1 (7)	1 (5)
Widowed	2 (13)	2 (11)
Missing	0 (0)	2 (11)
Occupation		
Self-employed	3 (20)	
Employed	6 (40)	
Retired	6 (40)	
Stage of diagnosis at enrollment	n=9*	n=16*
Newly diagnosed		
1–6 months	0 (0)	6 (38)
6–12 months	0 (0)	3 (19)
>12 months	0 (0)	1 (6)
Unknown or missing	15 (100)	2 (13)
	0 (0)	4 (25)

Percentages for partner data have been rounded up so totals may exceed 100 %

[a] Caregivers excluded

Table 2 Benefits and challenges of program participation

	Guides	Partners
Benefits	•An opportunity to give back • Improved communication and listening skills • Provided valuable support rather than "typically speaking more of my own experience" • Helped deal with their own cancer experience • Meet and engage with more cancer survivors • Boosted confidence about helping in meaningful way • Supportive environment to serve in	• Rated positively • Felt supported • Conversations focused on their needs • Able to share their hopes, fears, and concerns about cancer and/or caregiving • Received coping resources • Suggest matching on cancer type was not a priority
Challenges	• Though telephone support ok; some expressed preference for face-to-face contact • Sense of loss in cases when assigned Partners died and no contact with their families to share grief • Some experienced a wait time for a partner	• Wanted more frequent contacts • Interest in face-to-face contact • Some experienced a wait time between match confirmation and first contact with Partner • Some felt challenged finding a balance between listening and sharing their own cancer experiences

similar cancer type. On average, guides and partners had five conversations (range, 1–13) about topics including fears arising from a recent diagnosis, physical and mental cancer-related coping needs, coping resources, family and spousal concerns, treatment decisions, negative feelings about care received during treatment, and self-perceptions after treatment. Ten of the 11 guides strongly agreed that they were comfortable initiating contact with their partners, had adequate training to address partners' expressed needs, that they were a good match for the partner, and that adequate resources were available if any issues arose. The one guide who reported not being a good match cited differences in age and life situation as reasons.

Partner Evaluations

Fifteen of the 19 (one was ill, one was unavailable, and two died after being matched) enrolled partners who completed the 6-month telephone interview were highly pleased with the program, the experience, and the support received.

Match Process Most partners strongly agreed that the intake and matching process was easy (80 %), the match process and procedures were clearly explained (73 %), and a match was made within a reasonable amount of time (87 %). After a match had been made, all but one partner reported being contacted by a guide in a reasonable amount of time. Nearly

all guides (94 %) agreed that they had a good match for their cancer type.

Match Experience Overall, partners rated their program experience positively. Partners who completed evaluations reported that the conversations focused on their needs (80 %), the information they received was personally relevant (67 %), the number of conversations was "just right" (73 %), and the conversations were balanced (87 %) as well as supportive and encouraging (80 %). Over half (53 %) recalled their guides asking for permission before giving advice or information (33 % did not recall). Most partners (93 %) felt listened to, that their guide was easy to talk to (80 %), and that their guide allowed them to share their hopes, fears, and concerns about cancer and/or caregiving (80 %).

Perceived Efficacy As a result of having talked with a guide, most partners reported having increased feelings of optimism or acceptance about the future (60 %) and feeling more confident about their ability to make healthcare decisions (40 %). Most (73 %) partners reported that participating in the program had had a positive impact on their quality of life.

Discussion

Peer support has been shown to be effective for disease conditions including cancer [8, 9]. Peer Connect provides evidence that MI techniques can be successfully taught to nonprofessionals and used to provide support to cancer survivors and caregivers. Our study confirms the feasibility of implementing such a program. Overall, both guides and partners reported positive experiences and a high level of satisfaction. Participants on both sides underscored the need for such a program.

Table 3 Perceived efficacy of 2-day training and guide gatherings

	SA-1 (n)	A-2 (n)	N-3 (n)	D-4 (n)	SD-5 (n)	N/A (n)	Overall mean (SD)
Two-day training							
Adequate training	7	4	0	0	0	0	1.36 (0.5)
Clear expectations	5	6	0	0	0	0	1.5 (0.5)
Guide gatherings							
Sufficient number of meetings	2	8	1	0	0	0	1.9 (0.5)
Useful for MI skill refinement	5	5	0	0	0	1	1.36 (0.67)
Provision of adequate resources	8	3	0	0	0	0	1.27 (0.47)

Scoring based on Likert scale from 1 to 5

SA strongly agree, *A* agree, *N* neutral, *D* disagree, *SD* strongly disagree

Lessons Learned

We identified practice implications critical to the successful development and implementation of Peer Connect.

Peer Support Culture Many support programs for cancer survivors pair their participants with someone with a similar cancer experience and expect the support provider to share their own story. Peer Connect, on the other hand, is grounded in MI and focuses on meeting the needs of the partner and deemphasizes the guide's sharing of their cancer story/ experiences. Given this emphasis on partners, we needed to provide ongoing training to support the learning curve of guides whose baseline expectations were that they would be sharing their cancer story. Initial training, therefore, covered the rationale for shifting the focus totally to the partner and sought to obtain buy-in from the guides through a variety of skill-building activities (including video examples), role playing, and discussion. The training also focused on the development of both expertise and self-confidence in using MI skills effectively.

Iterative Process Guide gathering lesson plans reinforced the need to keep the focus on partners and also worked to develop guides' confidence in dealing with potentially uncomfortable issues such as partners seeking medical advice or asking intrusive personal questions. Guides' questions and concerns played an important role in shaping ongoing training sessions and provided opportunities to demonstrate MI skills.

Program Expectations and Feasibility Peer Connect is a time-intensive program for both the supporting organization(s) and the volunteer guides, which has implications for the feasibility of program implementation. The successes reported by both guides and partners in our study suggest that the level of required training and the time commitment for volunteers are worthwhile. During recruitment, we made the training requirements very clear but—to increase program flexibility— provided little guidance about the amount of contact needed with partners. Instead, guides and partners could determine what arrangement was best based on needs and availability. Partners' timing and availability sometimes conflicted with guides' availability, and some partners expressed the need for more contact and quicker responses. Partners' contact needs and guides' limitations might be better determined during the intake and matching processes.

Match Criteria Contrary to our assumptions prior to program implementation, matches may not need to be cancer-specific to be successful. Most partners calling for support did request a cancer-specific match; however, 9 of the 15 partners did not end up with a similar cancer match, particularly for the rarer cancer types. In these cases, the coordinator matched the partner with a guide of similar demographics [age, gender, family role (caregiver or patient), occupation, or time since diagnosis]. These characteristics appeared to be more important than a cancer-specific match in helping partners relate to their guide.

Relationship Parameters As with any helping relationship, creating relationship parameters is both important and challenging. Although our guides participated in a very comprehensive MI training program [23], it was nonetheless difficult to plan up front for all situations the guides might encounter. Thus, it was also important to create a protocol for handling situations beyond the scope of their training, skill level, and role, such as detection of severe emotional distress in partners, suicidal suspicions, issues of confidentiality, and grief.

Guides as Survivors In addition to the contacts with partners, the guides' participation in guide gatherings was a key contributor to the program's success. The monthly meetings fostered continued skill development, answered questions, provided ongoing feedback, and allowed guides to get to know and support each other. This was especially critical for guides who had an extended wait period between the initial Peer Connect training and their first partner match, helping guides remain motivated and minimizing potential frustration while waiting for a match. Once matched, guides repeatedly reported feeling satisfied that they were able to give back and learn new skills.

Program Sustainability Peer Connect program materials were specifically designed to provide standardized training to other organizations post study completion in an effort to promote easy dissemination and sustainability of the program in the future. For example, the DVD [23] was designed to be the primary training tool with the coordinator's manual acting as a step-by-step guide, including instructions for program implementation, training strategies, and support information for program coordinators. For sustainability purposes, the program was implemented in partnership with a local cancer support community organization whose mission is to provide outreach services to cancer survivors and caregivers and to whom developing peer support was a priority. Further, the same partnership organization staff that participated in the evaluation study now continue the program on their own without researcher involvement. To date, over 100 guides have been trained including guides recruited post study. Additionally, volunteers trained to be guides may choose to continue to be matched with partners and be involved in the ongoing guide gatherings as long as they are able to do so. Finally, because partners suggested that face-to-face interactions would be essential and some may require more frequent contact, this is an option that future programs need to consider in order to plan accordingly.

Limitations

Studies that incorporate MI-based skills to address specific behaviors (e.g., healthy eating and smoking), baseline, and follow-up measures can assess behavioral effect [20–22]. In Peer Connect, partners participated because of the impact of cancer on their lives, families, work, and sense of self rather than because of a specific behavioral focus. This design provides fewer guideposts for guides to use in discerning what has led a partner to request a guide. Moreover, reasons for enrollment may be based on amorphous behavioral concepts such as "inability to cope" or "ongoing fear of recurrence." Guides, therefore, needed to have the ability to work with less specific needs by providing support through listening and reflecting to help partners think through their feelings, fears, and concerns and assess coping strategies that fit their life and resources. One way to evaluate the effectiveness of this type of support is to examine statements from partners over time that may point to increased confidence or increased use of resources perceived to be useful and relevant. One implication is that it is important for guides to have ongoing organizational support to ensure that they get feedback that their work is effective and meaningful. A potential drawback of the program may have been the use of telephone-based support alone. Some partners in their evaluation interviews expressed an interest in also having face-to-face interactions with their guide. However, no challenges were noted by the partners or guides regarding the inability to make contact via telephone. Future studies should offer both face-to-face and telephone-based support as options if possible. Additionally, this was a pilot study with mainly White participants; therefore, our findings may not be generalizable to other populations.

Conclusion

It is feasible to implement a peer-to-peer support program among cancer survivors and caregivers using an MI approach. Survivors at all stages along the cancer continuum require varying support, and our approach can be useful for understanding and helping to address different needs. Our results confirm that cancer survivors want to give back in a way that feels meaningful and, incidentally, show that participating in Peer Connect can be beneficial to their own survivorship journey. Because the Peer Connect model is time-intensive, guides need to have dedicated time for initial and ongoing training along with the flexibility to determine number of contacts to meet each partner's needs.

Cancer survivors and caregivers need additional forms of support outside of the medical system to navigate other aspects of their cancer journey. Given the growing cancer survivor population, translational models like Peer Connect are needed to support the health and well-being of those affected by cancer in various community settings.

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