

MODELS OF PEER SUPPORT FOR BOWEL CANCER PATIENTS

FINAL REPORT

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EXECUTIVE SUMMARY

Research has identified psychosocial support as an important component of multidisciplinary cancer care. In particular, peer support has become recognised as an effective strategy to meet the supportive care needs of people with cancer. Peer support refers to the emotional and practical support that can be offered to people with cancer by people who have had similar experiences to their own. Peer support has been shown to benefit people with cancer by increasing well being, improving adjustment and coping, reducing distress and most importantly providing people with an empathetic and accepting environment to share experiences.

Bowel cancer is the second most common cancer in Victoria with over 3,441 new diagnoses made in 2005. Although the number of people living with bowel cancer is substantial and a demand exists for peer support amongst this cancer group, the number of bowel cancer support groups is minimal. Currently there are only twelve bowel cancer survivor volunteers providing peer support through a Victorian telephone peer support program and no bowel cancer specific accredited Cancer Council Victoria peer support programs operating in either metropolitan or rural Victoria.

The Cancer Council Victoria received funding from the Australian Government, through Cancer Australia's Building Cancer Support Networks Grants Program, to conduct a project over four years commencing March 2006. The aim of the project was to examine the acceptability of peer support for people affected by bowel cancer in metropolitan and regional areas of Victoria. This was achieved by exploring peer support needs specific to this cancer group, enablers and barriers to peer support participation and preferred models of receiving peer support. Three studies were conducted as part of this research project.

First, a search of the national and international literature on support models for people living with cancer was undertaken. The review examined the published literature from 1980 to March 2006 to identify models of peer support, and evidence for the effectiveness of these models in helping people with cancer cope with their cancer experience. Five models of peer support for people with cancer were identified from the 58 papers included in the review: one-on-one face-to-face, one-on-one telephone, group face-to-face, group telephone and group Internet. Only three papers were specific to bowel cancer; they discussed programs that adopted the following models: one-on-one face-to-face, group face-to-face and group Internet. Overall, the quality of the studies included in the review was disappointing with few good quality studies published and no definite recommendations were made due to the lack of strong evidence for the effectiveness of any model of peer support.

With no clear recommendations arising from the systematic literature review, an investigative phase was undertaken. The aim of this phase of the project was to explore the needs of people with bowel cancer from metropolitan and

regional areas and their preferences with regards to the various peer support formats (e.g., one-on-one face-to-face, group internet), via quantitative (survey design, N=52) and qualitative (focus group and one-on-one phone interviews, N=29 people with bowel cancer, N=11 peer support group facilitators) studies. The findings from these studies suggested a strong interest in peer support from people with bowel cancer, with benefits reported to include: bond of common experience, normalisation of cancer journey, decreased sense of isolation and emotional and informational support. Perceived needs for people with bowel cancer were: greater promotion of support programs, increased public awareness of bowel cancer and, most notably, for peer support programs to be offered to them via their specialist or cancer care nurse. The main barriers to participation in peer support programs included: feeling unwell, stigma, sense of embarrassment, lack of bowel-cancer specific support programs and lack of knowledge and awareness regarding peer support programs, particularly noted by those in regional areas. Overall, the most preferred models of providing peer support to people with bowel cancer were a one-to-one telephone program or face-to-face group program.

The outcomes of this investigative phase informed the development of two models of peer support for people with bowel cancer: 1) a one-to-one telephone peer support program and 2) a face-to-face group peer support program. These models underwent pilot testing in the third study of the project. The aim of the pilot study was to examine the uptake, satisfaction and acceptability of the two peer support models. Support recipients (people with bowel cancer receiving support) were recruited through clinicians working in metropolitan Melbourne (Royal Melbourne Hospital, Western Health, The Peter MacCallum Cancer Centre) and regional areas (Barwon Health) of Victoria. Peers (support providers) were recruited through Cancer Council Victoria's Cancer Connect program and facilitators working with support groups accredited by Cancer Council Victoria. In total, 34 support recipients were recruited into the study (16 from metropolitan Melbourne and 18 from the Barwon region). Seventeen participants selected to participate in the telephone program and 17 in the group program. Twelve peers were recruited to provide support in the telephone program and 2 peers to facilitate the group program.

The peer support programs ran between June 2008 and December 2008. Support recipients in the telephone program received at least eight calls from their peers over a period of four to five months. More calls were made if felt necessary by the dyad. The group program ran two separate groups; one in Barwon region and one in metropolitan Melbourne. The Barwon group held eight meetings every three weeks and the metropolitan group held six meetings fortnightly. As well as participating in the programs, support recipients were asked to complete two surveys: one before the start of the peer support program and one at the end of the program. Peers were asked to complete contact forms after each contact with a support recipient or meeting and a survey at the end of the program. Results indicated that the two peer support models tested in this study were successful in terms of support recipients satisfaction and acceptability and met the peer support needs of people with bowel cancer. Therefore, it would be difficult to recommend only one model for people with bowel cancer. Rather, the findings suggest that

both models should be implemented into the wider community to cater for the differing peer support needs. For example, those wanting convenience, flexibility and tailored support to meet specific needs might be more interested and gain more satisfaction from joining the telephone program, whereas people looking to gain a variety of experiences and coping strategies and social support (i.e. a sense of belonging) might benefit from a group program.

In conclusion, peer support provided over the phone or in a group meeting can meet the support needs of people with bowel cancer and importantly it appears that people with bowel cancer were interested and receptive to receiving peer support. This research project is one of the few to investigate the specific peer support needs of people with bowel cancer and preferred models of delivery. Findings revealed that a one-to-one telephone and face-to-face group format were the most preferred manner to deliver peer support to people with bowel cancer, as seen from the high satisfaction rates reported by support recipients in the pilot study and the success of these models in meeting support recipients needs and peer support expectations.

The 'Models of peer support for bowel cancer patients' research project emphasized the value of peer support in cancer care for people with bowel cancer, as an additional form of support for this population. This project has identified preferred methods for delivering peer support to people with bowel cancer and barriers to uptake and retention of this type of support. In addition, this project has helped to highlight principles for effective peer support programs. This information will be useful to facilitate the development of effective peer support programs for people with bowel cancer in Australia.

INTRODUCTION

In Victoria, there are over 25,500 people diagnosed with cancer each year (excluding non-melanocytic skin cancers) and over 10,000 deaths caused by cancer (The Cancer Council Victoria, 2009a). In 2006, bowel cancer was the second most common cancer in Victoria with over 3,516 new diagnoses and had the second highest mortality, with 1,050 individuals dying (The Cancer Council Victoria, 2009a). Therefore the number of people living with bowel cancer in our community is great and prevalence is increasing due to improved survival and the aging population (The Cancer Council Victoria, 2009a).

For most individuals, a diagnosis of cancer is devastating and subsequent treatments can be traumatic and stressful. As a result, it is not surprising that many cancer patients experience a range of psychosocial difficulties following their diagnosis. These difficulties have been well documented in the literature and include a range of symptoms such as, increased negative mood (e.g., depression, anxiety, general distress), feelings of isolation, loneliness, uncertainty and loss of control, decreased self-esteem, disruptions to intimate, family and social relationships, and fears about cancer recurrence (Dunn, Steginga, Rosoman, & Millichap, 2003; Dunn, Steginga, Occhipinti, & Wilson, 1999; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; Steginga & Dunn, 2001; Van den Borne, Pruyn, & Van den Heuvel, 1987). Therefore, in addition to the medical support offered to cancer patients at diagnosis, services aimed at alleviating the negative psychosocial impact of cancer is an area of need. While the most recent data indicate that the number of people living with bowel cancer in Victoria is substantial, currently the number of specific supportive services for these patients is minimal.

Research has identified social support as an important contributor to general well-being and suggests that social support can buffer against the impact of stressful life experiences including those related to physical illness (Cohen & Wills, 1985; Cutrona, 1990; Schaefer, Coyne, & Lazarus, 1981). Social support is defined as a multidimensional construct that includes the provision of either emotional (empathetic, nurturing and reassuring support), informational (increasing knowledge and understanding about problem and coping skills), instrumental (practical and physical assistance) or esteem (enhance self-confidence and self-esteem) support (Cutrona, 1990; Schaefer et al., 1981). In light of evidence indicating that social support can positively influence health outcomes, it is increasingly recognised as an important component of psychosocial care of cancer patients.

Various social support interventions have been developed to meet the needs of people living with cancer such as peer support, psychotherapeutic and educational programs (Hutchinson, Steginga & Dunn, 2006). The focus of this project is on the delivery of peer support. Peer support refers to support provided or exchanged amongst people who are facing similar challenges or problems (e.g. cancer diagnosis) (Gray, Fitch, Davis & Phillips, 1997a). Sharing experiences is the essence of peer support and it is thought that the opportunity to interact with cancer survivors and receive acceptance and empathetic and experiential support can be a valuable experience for current cancer patients (Gray, Fitch, Davis & Phillips, 1997b; Mastrovito, Moynihan, & Parsonnet, 1989). The benefits of peer support have been

well established in the literature, including: improved psychological adjustment (e.g. increased well being, improved coping and self-efficacy, reduced distress); reduced sense of isolation (e.g. normalising the experience, feeling a sense of belonging, improved relationships with family, friends and health care professionals); and feeling more informed about their disease and treatment (Ashbury et al., 1998; Dunn et al., 1999; Hutchinson et al., 2006; Ussher, Kirsten, Butow & Sandavol, 2006; Vos, Garssen, Visser, Duivenvoorden, & de Haes, 2004; Weber et al., 2004; Winzelberg et al., 2003). A range of different formats can be used to deliver peer support including face-to-face group, one-on-one face-to-face, one-on-one telephone, telephone groups and Internet groups.

Despite the lack of specific peer support services for people with bowel cancer in Victoria, there appears to be a high demand for these services from Victorians diagnosed with bowel cancer. For example, in 2008, approximately 8% of calls to the Cancer Council Victoria helpline were from bowel cancer patients requesting information regarding supportive services (The Cancer Council Victoria, 2009b). Forty percent of these calls discussed Cancer Connect, a one-on-one peer support service, and 22.5% discussed cancer support groups. Currently there are only twelve bowel cancer survivor volunteers providing peer support through Cancer Connect and no bowel cancer specific accredited Cancer Council Victoria peer support groups operating in either metropolitan or rural Victoria (The Cancer Council Victoria, 2009b). These figures indicate a mismatch between the number of bowel cancer patients seeking peer support and the number of supportive services being offered to this cohort. Further, an Australian study investigating salient psychosocial variables and dimensions of quality of life in bowel cancer patients (Dunn et al., 2006), found that informational, practical and support group contact was greatly appreciated by bowel cancer patients and that support from others with similar experiences was beneficial. These results supported an earlier study that found that for patients with bowel cancer the availability of emotional and instrumental support was associated with better mental and physical health (Sultan et al., 2004).

Project Aim

The project, funded by the Australian Government through Cancer Australia, aims to determine the acceptability and preferred models of peer support among people affected by bowel cancer via:

- Investigating the peer support needs of bowel cancer patients including their unmet needs, the factors that contribute to peer support uptake, barriers to participation, and preferred modes of peer support delivery
- Developing at least one model of peer support for bowel cancer patients
- Evaluating the acceptability of the model/s

To achieve this aim, the project undertook three separate studies: 1) A national and international literature review of peer support models for people living with cancer, with a particular focus on bowel cancer; 2) An investigative study of peer support needs, barriers and preferred formats using a mixed method design and; 3) A pilot study of two peer support formats.

STUDY ONE: SYSTEMATIC LITERATURE REVIEW

Aim

Peer support programs for cancer patients are offered via a range of methods including: face-to-face support groups; face-to-face one-to-one support; telephone support groups; one-to-one telephone support; and internet groups.

The objective of this study was to conduct a national and international literature review to: a) identify the different peer support models available to cancer patients; b) assess the quality of the research studies that have examined the effectiveness of the programs; and c) recommend at least one model of support that could be implemented in a trial to provide peer support for bowel cancer patients.

Method

The studies in this review were identified using two methods. First, an extensive search of the published literature was conducted using three electronic databases: CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE and PsychINFO. These three databases were searched using combinations of (cancer or neoplas\$ or oncology\$) and (peer or peer support or peer and support or support group\$ or support program\$ or group psychosocial support or self-help or visitor\$ or survivor support), where \$ represents other variations of the search term. The search was restricted to papers published from 1980 to week 3 in February 2006. A total of 3,442 published papers were found. Six hundred duplicate papers were eliminated, yielding a total of 2,842 papers. Second, key researchers in the field were contacted to identify additional publications that may have been missed in the electronic database search. A further six papers were recommended, producing a final count of 2,848 potential papers.

Paper Selection

To be included in the present review, papers had to be written in English and meet the following criteria:

- the paper described a specific program in which peers provided direct support to people with cancer
- the peer that provided support had been diagnosed and/or treated for cancer
- the primary purpose of the program was to provide support to the cancer patient

Papers only had to meet one of the following exclusion criteria to be eliminated from the review:

- the program described was not a specific peer support program
- the program focused on children and adolescents
- the program was an educational course

- the program was a therapeutic course run by professionals (including supportive expressive therapy)
- the program was not primarily focused on peer support – i.e., it was one of many components of the program
- the peer support was for someone other than the person with cancer (e.g., carer/friend/health professional)
- the peers were engaged in activities that were not directly providing support to the individual (e.g., fundraising)
- the paper did not describe the program in sufficient detail
- it could not be determined how the peer provided support to cancer patients
- it could not be determined if the person giving support had experienced cancer themselves
- the paper was an advertisement/commentary/letter about a program
- the paper was a first person account of an experience

Papers identified in the search results underwent a three -stage selection process: (1) title phase; (2) abstract phase; and (3) full paper phase. The titles and/or abstracts of all papers were read to determine if they met the selection criteria. Those clearly not matching the criteria were excluded and the papers were not read. If a paper did appear to meet the criteria on the basis of the abstract then the entire paper was read. If information provided in the title and/or abstract was not sufficient to determine if the paper met criteria, then it proceeded to the next phase.

- Title Phase: 2,418 potential papers retained.
- Abstract Phase: 171 papers retained.
- Full Paper Phase: 58 papers were rated as eligible for inclusion in the review.

Paper classification and data extraction

Eligible papers were classified into the following categories:

- *Commentary/service usage papers*: Theoretical papers or papers describing a proposed model or specific program. Papers that contained no data apart from service usage data (e.g., who uses the program, socio-economic status, disease status).
- *Descriptive*: Describing a program with data collected from members or participants on information such as quality of life, adjustment, satisfaction with service and needs assessment. Must not be an intervention of any experimental design and must only contain data from one group.
- *Comparative*: Comparing two groups but not randomised (e.g., users of a program compared with non users).
- *Randomised controlled trial*: Randomised with control or randomized between two groups with no control.

Data were extracted from each of the 58 papers using a Peer Support Review form developed by the researchers. Data extracted concerned the nature of research (e.g., design, sample size, age of participants, control or comparison group, type of data collected, measures, main outcomes and main findings) and information about the peer support program (e.g., mode of program delivery, peer or professional supervised, program members, cancer type, facilitator, program commencement date and country, the organization or institution running the program, the nature of peer support and the type of support provided, and specific information about the peers and support recipients if applicable).

Evaluation and assigning quality scores

The evaluation of full papers was a two-stage review process. In the first “Literature Overview” stage, commentary and descriptive papers were reviewed and rated as either ‘poor’, ‘fair’ or ‘good’ quality in terms of their description of the peer support program. In the second “Effectiveness Review” stage, papers that adopted one of four designs: (1) randomised controlled trial; (2) randomised clinical trial (no control group); (3) non-randomised controlled trial and; (4) non-randomised clinical trial (no control group), were reviewed and rated as either ‘poor’, ‘fair’ or ‘good’ quality, in terms of both their program description and research design.

Results

Paper selection and classification

Of the 58 papers rated as eligible for this review there were 15 commentary studies, 24 descriptive studies, 9 comparative studies, and 10 randomised controlled trials.

Literature overview

This review identified a substantial body of literature exploring models of peer support for cancer patients. From the papers, five different models were identified: one-on-one face-to-face, one-on-one telephone, group face-to-face, group telephone and group internet. These models delivered a number of different types of peer support to cancer patients including emotional, information, practical and social support. While the programs differed in terms of specific details (e.g., peer or professional facilitator, manual or no manual, or the length of support offered to cancer patients), they were all linked by the common aim of providing a program whereby former patients support current patients. Very few papers ($n = 3$) identified in the search focused on bowel cancer patients.

Overall, the quality of the papers was disappointing, with few receiving a good quality rating, and most receiving a fair or poor quality rating.

Effectiveness review

Two independent reviewers rated papers selected for the effectiveness review and an 80% inter-rater agreement on paper scores was achieved.

One-on-One Face-to-face

Six papers examined one-on-one, face-to-face peer support programs and included one good quality randomised controlled trial (Weber et al., 2004) and five fair quality comparative studies (Ashbury et al., 1998; Geiger et al., 2000; Rankin et al., 2004; Rogers et al., 1984, , 1985). Data from the good quality randomised controlled trial (Weber et al., 2004) indicated that a one-on-one face to face peer support model might reduce depression and increase self-efficacy among cancer patients.

Overall, results from the five fair quality comparative studies did not provide strong evidence for an effect of a one-on-one face-to-face peer support program on well-being outcomes. One study measured quality of life among users and non-users (Ashbury et al., 1998) and found users reported better social support and better relationships with their doctors. Evidence regarding satisfaction of program users indicated that this model can provide useful peer support and is worth being recommended to other patients.

One-on-One Telephone

Of the two papers that explored the efficacy of a one-on-one telephone intervention using randomised controlled trials, one was rated as good quality (Houts, Whitney, Mortel, & Bartholomew, 1986) and the other as fair quality (Rudy, Rosenfeld, Galassi, Parker, & Schanberg, 2001). The fair quality randomised controlled trial did not report sufficient data to comment on the efficacy of their peer support model.

The good quality randomised controlled trial (Houts et al., 1986) focused on gynaecological cancer patients. The results suggested that this intervention did not reduce patients' emotional distress levels, as there were no significant differences between participants in the experimental and control conditions. However, it is important to note that the control group in this study received a high level of social support from nurses and health professionals at the facility that the program was conducted.

Group face-to-face

There were four good quality randomised controlled trials (Helgeson, Cohen, Schulz, & Yasko, 1999, , 2001; Jacobs, Ross, Walker, & Stockdale, 1983; Vos et al., 2004), one fair quality randomised controlled trial (Helgeson et al., 2000) and one fair quality comparative study (McGovern, Heyman, & Resnick, 2002) exploring the effect of face-to-face group support programs for cancer patients. Overall, the results from these six studies suggest that none of the interventions can be recommended for improving psychosocial adjustment or functioning, or health related quality of life for cancer patients.

Group Internet

Five papers described internet support groups with two good quality randomised controlled trials (D. H. Gustafson et al., 2001; Winzelberg et al., 2003), one fair quality comparative (McTavish, Pingree, Hawkins, & Gustafson, 2003), and two poor quality comparative studies (P. Klemm et al., 1999; Sullivan, 2003). Overall, these papers provided some evidence that group internet programs may be an effective way to deliver peer support to cancer patients. Winzelberg (2003) reported that their internet based support program reduced depression, perceived stress and cancer-related

trauma among breast cancer patients. Although Gustafson (2001) did not find any significant differences in quality of life between the experimental and control group, cancer patients in the experimental group reported higher perceived support and involvement in their own health care stress and cancer-related trauma.

Discussion

This review identified four models that had been evaluated via randomised controlled trials and comparative studies: one-on-one face-to-face, one-on-one telephone, group face-to-face and group internet. Unfortunately, only tentative recommendations can be made due to the lack of good quality randomised controlled trials conducted in this area. Two models were found to have some evidence, suggesting they could be recommended for further investigation. The one-on-one face-to-face and group internet models were found to have some success in reducing psychological distress and improving coping resources for cancer patients. However, given that the vast majority of programs identified in the review did not focus on bowel cancer, it may be worthwhile investigating whether any of the models will assist bowel cancer patients adjust to and cope with their illness.

Overall, the quality of the studies included in the review was disappointing and no definite recommendations were made due to the lack of strong evidence for the effectiveness of any model of peer support and the very little research that has specifically explored effectiveness of peer support programs for improving psychological outcomes of bowel cancer patients. With no clear recommendations arising from the systematic literature review, an investigative phase was undertaken to explore preferences regarding peer support formats among people living with bowel cancer.

STUDY TWO: INVESTIGATIVE PHASE

Aim

The primary aim of this phase of the project was to determine preferred methods of delivering peer support to people with bowel cancer and develop at least one model of peer support to be examined in a pilot study. In achieving this aim, preferences regarding the various peer support formats identified in the systematic literature review (e.g., one-on-one face-to-face, group internet), factors that might facilitate the uptake of peer support programs and barriers that might prevent participation were explored through survey and focus group methodologies.

Method

Quantitative Study

Participants: Fifty people with bowel cancer recruited from outpatient clinics at Peter MacCallum Cancer Centre in East Melbourne (N= 32) and Border Medical Oncology in Albury/Wodonga (N= 21).

Data Collection Methods: Questionnaire assessed participation/awareness of existing peer support programs and/or resources, perceived helpful/unhelpful aspects of peer support programs, perceived barriers to peer support participation and preferences regarding peer support programs.

Qualitative Study

Participants: Thirty- four people with bowel cancer recruited from outpatient clinics at Peter MacCallum Cancer Centre in East Melbourne, Border Medical Oncology in Albury/Wodonga and Andrew Love Centre in Geelong and through support groups accredited with The Cancer Council Victoria.

Metropolitan (N = 7) and regional (N =5) support group facilitators recruited through support groups accredited with Cancer Council Victoria.

Data Collection Methods: Semi structured focus groups and one-on-one phone interviews. The focus groups/phone interviews explored the pros and cons of potential peer support models identified in Phase One of the project (systematic literature review) and participants' preferences regarding these models, content (e.g. informational versus emotional support) and structure (e.g. closed versus open groups) for peer support programs and explored benefits and barriers of peer support participation.

Two metropolitan and two regional focus groups and one metropolitan and nine regional one-on-one phone interviews were conducted with people diagnosed with

bowel cancer. One metropolitan focus group and one metropolitan and five regional one-on-one phone interviews were conducted with support group facilitators.

Results

The results of this study will be reported in two sections. The first section will present a summary of the main findings from the quantitative and qualitative study in terms of peer support needs and preferences and benefits and barriers of receiving peer support. The second section presents the rationale for the models recommended for the pilot study.

Peer support need and barriers to participation¹

Quantitative Study

Printed information was the most used resource (81.6%) and a majority of those who accessed support services and/or resources found them useful. Participants indicated that they would like peer support programs to include informational (e.g. information about bowel cancer, treatment, how to be involved in making decisions about treatment) practical (e.g. managing physical symptoms, exercise) and emotional (e.g. someone who understands me, can listen to me) support, with informational support considered to be the most useful (96.2%). As might be expected 'feeling unwell' was the main barrier to peer support participation (54.8%). Other barriers included: concern over accessing toilet facilities easily (37.7%), difficulty with transport (35.9%) and travel costs (35.8%); however, the majority of participants did not perceive these factors to be barriers.

Meeting with someone one-on-one (32.1% 'yes'; 35.8% 'don't mind') received somewhat more support than meeting with a group of people (28.3% 'yes'; 22.6% 'don't mind'). In terms of whether to receive peer support in person, over the phone or over the internet, receiving peer support in person was most preferred (32.1% 'yes'; 32.1% 'don't mind'), followed by telephone (15.1% 'yes'; 37.7% 'don't mind'). Support was shown for a health professional (47.2% 'yes'; 34% 'don't mind') or a volunteer with bowel cancer (41.5% 'yes'; 34% 'don't mind') to run the peer support program.

Qualitative Study

The findings from the qualitative study suggested a strong interest in peer support from people with bowel cancer, with benefits reported to include: bond of common experience, normalisation of cancer journey, decreased sense of isolation and emotional and informational support. Identified peer support needs for people with bowel cancer were: greater promotion of support programs, increased public awareness of bowel cancer and, most notably, for peer support programs to be offered to them via their specialist or cancer care nurse (preferably in the period between initial diagnosis and commencing treatment) rather than patients having to

¹ A more detailed presentation of the qualitative and quantitative results has been provided in previous reports to Cancer Australia.

seek out support themselves. The main barriers to participation in peer support programs included: feeling unwell, stigma, sense of embarrassment, lack of bowel-cancer specific support programs and lack of knowledge and awareness regarding peer support programs, particularly noted by those in regional areas.

Overall, the most preferred models of providing peer support to people with bowel cancer were one-on-one face-to-face or telephone peer support and face-to-face group peer support, with peer support thought to be important throughout the entire cancer trajectory (e.g. following diagnosis, during and after treatment and in the survivorship phase). Advantages of the one-on-one telephone format were flexibility, privacy and tailoring to individual needs. Advantages of the face-to-face group format included sharing experiences, modelling, increasing perceived sense of belonging and encouragement and the ability to provide support. Receiving peer support primarily via the internet was the least preferred option, however, partial support was given for an online bulletin board to run concurrently with a face-to-face format.

Development of Peer Support Models

Data from the investigative phase suggested that people with bowel cancer may prefer the following two models:

One-on- One Telephone Peer Support Program

Quantitative Findings

The telephone was suggested as an effective tool in overcoming many of the barriers reported. A specific barrier to peer support participation included feeling too unwell; 34% of participants indicated this would be 'very much' a barrier for them (options for responding were: 'not at all', 'somewhat', 'very much' or 'not applicable'). Travel costs (24.5% responded 'somewhat' and 11.3% responded 'very much') and concern about accessing toilet facilities easily (24.5% responded 'somewhat' and 13.2% responded 'very much') also appeared to be potential barriers for participation. Further, when asked to provide reasons for not attending a peer support program, responses most frequently concerned travel restraints (27.8%).

Qualitative Findings

For the majority of people with bowel cancer who attended both the regional and metropolitan focus groups, a one-on-one format was reported as being most likely to meet the needs of people with bowel cancer. It was reported that as individuals differ in their support needs (e.g. informational, practical, emotional support) and the amount of support they would like to receive (e.g. weekly versus fortnightly contact), a one-to-one format would allow these differences to be catered for. A one-to-one format was also perceived to be a "safer" and "less daunting" method of receiving peer support, as many participants indicated that they would find it too confronting to talk about their cancer journey in front of a group of people, particularly in the period immediately after diagnosis. Further, some participants indicated that they preferred to discuss their personal concerns about cancer in a more private context.

I think it's more personal, and rather than in a group, and I find it hard to express myself in a group, whereas if I can maybe just talk one to one with somebody who's been through it.

Providing peer support over the telephone was suggested to have many advantages, in particular, overcoming the limitations of a face-to-face format, such as travel difficulties due to geographical constraints, scheduling difficulties or their physical condition (e.g. feeling too unwell).

....when I was sick I couldn't even make it out of my house. After surgery I couldn't even walk to my local shops. So unless they came to my house, which I might have felt uncomfortable about because it was messy because I was sick....

...It's probably more convenient, like you can have a phone conversation any time of the day, whereas it might be harder to meet up for people. So if someone is not well they don't have to get dressed and go out, they can still be in bed on the phone... It's the getting dressed and getting ready that was a hard thing. It would have been a huge thing to do when you are having chemo.

Anonymity and the privacy and the comfort of speaking in their own home were also important considerations for the people with bowel cancer who participated in the focus groups, and again, could be accommodated in a telephone peer support program.

...you're home in your own backyard, and they're [peer] in the same position, or in their office, or wherever they're doing it. So you're not strangers sort of meeting, you're in your own environment, and I think it's easiest to communicate when you're in your own environment.

Interestingly, a participant who attended a metropolitan focus group and who is currently providing peer support through Cancer Connect, also noted that a telephone peer support program has the advantage of overcoming the problems that may arise from difficulties establishing firm boundaries when meeting face-to-face in a one-to-one context. For example, the dyad becoming too emotionally involved.

If I meet you face to face and it doesn't work out the way we both hope and pray it will, I am going to go through another pretty traumatic experience and disappointment. That is why I believe that the telephone one is a much better one because at that point if you start to be drawn too closely to that person you can back away and ask for somebody else....If we get emotionally involved with everybody that we are talking to, to the point where you know so much intimately about them, and you do learn lots of intimate things....If you get too close to them it could hurt and I make that point again.

Overall, discussions from the focus groups indicated that many people with bowel cancer strongly support a one-on-one telephone format as a way of receiving peer support as it offers flexibility, privacy and can be tailored to an individual needs, while overcoming travel and scheduling issues.

Face-to-Face Support Group

Quantitative Findings

When asked to indicate their preferences regarding peer support formats, more than half of the people with bowel cancer who participated in the survey study expressed interest in a face-to-face support group format². Twenty-eight percent indicated that they would like to meet with a group of people and 22.6% responded 'don't mind.' Further, 54.7% of the participants responded that 'not wanting to participate in group situations' would 'not at all' be a barrier to them participating in a peer support program. When asked to provide reasons for why they would attend a peer support program, the most common responses were: to share common experiences with others (47.4%) and to provide support and advice to others (26.3%); these needs are more likely to be achieved by attending a face-to-face peer support group program.

Qualitative Findings

The face-to-face group peer support format was strongly supported by people with bowel cancer who attended the focus groups. From the four patient focus groups, a consensus was reached in three focus groups that a face-to-face group program would be the most preferred method of receiving peer support. The main advantage participants offered for a group format as opposed to one-on-one was the opportunity to share their illness experience with others, as well as hear about the experiences of others with bowel cancer. Participants felt that being able to share issues such as personal feelings, experiences with treatments, and family reactions to their illness, with a group of people going through the same or similar experience was very beneficial.

We can talk to each other.... share different survivor experiences.

It is the sharing that is huge.

....and just hearing someone say, "I have had this problem too, it is okay" was such a good thing.

We present and bring to the whole of this thing something that all of the professionals in the majority of cases don't have, which is the very fact that we have been there, done that and we know the reality of it all and the empathy that we get from you guys [referring to medical/health professionals] is good but you still haven't been there.

As well as sharing personal stories, the ability to exchange information regarding cancer resources, coping strategies and treatments with a number of people was seen as a further advantage of a group format. Whereas one-on-one support only allows the expression of one opinion, the participants felt it would be more valuable to hear a variety of viewpoints and strategies that others had used to cope with similar challenges, for example, learning to live with a colostomy bag.

² Please note this was a multiple response question (i.e. participants could tick all that apply).

Talking to someone that has a bag, sharing where you have problems, and it is very helpful. A lot of people have strategies how they cope with the stress, some will tell you they exercise or some will say I go shopping. All those strategies are important to hear.

I think by getting into the group we can learn different things...

That's what does happen a lot within face to face support groups. I've just been to one today that meets every Monday, and people take and leave what they hear, different things suit different people, but there is a lot of that sharing and taking books along, or cuttings out of a newspaper.

Providing a sense of belonging and encouragement was also reported to be an advantage of a face-to-face group format. Participants felt that the idea of being bonded by a very similar experience and receiving complete empathy would provide a sense of normality, strength and belonging.

...it seems to me it is an automatic human need for someone to belong to something... You go there, you have a common language, it is a common thing and the rest is independent... To me, I think it is a great idea.

It's the fellowship of, of where we've been. You know, we've, a lot of us have been to hell and back several times and so I think the fellowship with that and the contact is very important.

I was quite looking forward to coming [to the focus group] today because it's probably the first time I've been in a room with similar people that have had similar experiences.

You see it here now. We can talk to each other and you come a bit closer about the whole thing.

The main perceived advantage of a face-to-face format over a telephone or internet format was the ability to share nonverbal expressions such as hugs, tears and smiles and for these 'unspoken' cues to be understood without explanation. Further, for many, the hope that could only be instilled from seeing others with bowel cancer doing well and surviving was invaluable.

The biggest advantage of face to face multi group, of several people, you can laugh at each other and you can laugh at yourself. And if you want to have a cry you can have a cry and you've got a dozen people who will be with you straight away, or if you tell them to go away, they'll leave you alone.

...and you don't know what a hug can do, when you're feeling really bad and it goes between men and women. So they come into the room, they say hello, the men give you a hug or the women give you a kiss and it's just so lovely.

...I see them, I see their body language.... That is important for me.

..see a survivor... I think I also needed to see the hope of a survivor.

I would have liked to have had that human contact of seeing someone.... I don't know, there is a difference between human contact and the phone.

Principles behind the models recommended for the pilot study

Type of support

Ninety-six percent of the people with bowel cancer who participated in the quantitative study reported that informational support about bowel cancer in general, and treatments for bowel cancer would be useful. Practical support, for example, assistance with decision-making (92.5%) and managing physical symptoms (86.8%), was also considered useful. Further, emotional support, for example, ‘someone who understands how you are feeling (88.7%) and ‘someone who can comfort you when you are upset’ (81.1%) was identified as a useful component of a peer support program. These results were supported by participants’ discussions in the patient focus groups, and in addition, support for family members and social support (e.g. organising outing as part of peer support program) were identified as peer support needs.

Format of models

Focus group participants were asked to discuss whether they would prefer the peer support program to be closed and structured (e.g. discussion topics sets, 8-week program, one contact per week etc) or open-ended and semi-structured in terms of topics discussed. A general consensus was reached among participants across the four patient focus groups for the latter option.

Unstructured as far as I’m concerned I think...we’re all seeking different things - There’s really not a hard, fast set of rules as to what each individual wants to understand or know about. So I think if it’s already put down in black and white and your counsellor [support provider] follows the book, perhaps what you were really seeking out of it never eventuates anyway.

I think probably open-ended because otherwise you would have to hang around and wait. Otherwise too you can get the opportunity of various experiences along the journey because if everybody in October starts in November everyone is doing the same bit at the same time, whereas this way we get, like you were diagnosed five years ago and I was diagnosed in October. That is such a difference. You have had a secondary cancer and that different experience is making it more valuable.

Participants felt that support recipients should be allowed to determine the amount of support they received to ensure their individual needs were met. Therefore, in terms of a face-to-face group format, it was preferred that the group be open-ended, that is, the group be ongoing, so that people can join the group at any time during their cancer journey and do not have to attend each meeting if they did not feel the need. For the telephone format, it was felt that the number of contacts should be negotiated between the peer and support recipient, with limits set to avoid abuse of support (e.g. one contact per week).

Support providers

Forty-seven percent of the people with bowel cancer who participated in the quantitative study indicated that they would like a health professional to run the peer support group and 34% indicated they did not mind. When asked if they would prefer a peer (someone who has bowel cancer) to run the peer support program, 41.5% said 'yes' and 28.3% said 'don't mind.' When given the opportunity to further explore this issue in the focus groups, participants felt it would be beneficial for both a peer and health professional to be involved in the group. They felt that the peer should be the main provider of support or act as the facilitator but that a health professional should be present or available to ensure that the information being provided is current and accurate and as a resource for information.

I still believe people that should be leading should have been there and done that... We present and bring to the whole of this thing something that all of the professionals in the majority of cases don't have, which is the very fact that we have been there, done that and we know the reality of it all and the empathy that we get from you guys is good but you still haven't been there."

"I'll say the cancer survivor is very important, as well as professional

You want someone [referring to professional] who knows what they're talking about.

While focus group participants did agree that peers should be the main provider of support, there was also strong agreement that peers should be trained, especially regarding effective listening and communications skills. For one-on-one formats, matching was also considered important, particularly in terms of gender, type of bowel cancer and treatment.

Duration of peer support program

Findings from the systematic literature review suggested that improved psychosocial outcomes were associated with programs that continued for a longer time-period (e.g. 12 weeks to 6 months). Therefore, an extended period of time may be required for people to develop relationships and build sufficient rapport to enable them to gain psychosocial benefits from peer support. Certainly, this suggestion was supported by findings from a recent review of professionally facilitated support groups for cancer patients, which also concluded that groups lasting for a longer time-period were more efficacious (Gottlieb & Wachala, 2006).

Discussion

People with bowel cancer have an interest in peer support and their low participation levels may stem, at least partially, from a lack of availability and awareness of services. One-on-one telephone and face-to-face group support programs are preferred models of gaining peer support and patients' satisfaction with these models will be evaluated in a pilot study.

STUDY THREE: PILOT STUDY

Aim

To determine the experiences and responses of people with bowel cancer to two different ways of delivering peer support.

Study objectives:

- Trial two models of delivering peer support, suggested from the investigative study, to people affected by bowel cancer in two geographical locations (metropolitan Melbourne and Barwon South West Region) over a six month period:
 1. One-on-one telephone peer support program
 2. Face-to-face support group peer support program
- Evaluate the models in terms of uptake of the different models, sustainability (retention of participants in the different models), satisfaction with the different programs and successfulness of the program in meeting participants' expectations.

Method

Design

Pre-post study of people with bowel cancer interested in participating in a peer support program.

Participants

Support Recipients

Support recipients had a diagnosis of bowel cancer and were within 24 months of receiving their cancer diagnosis; were aged between 18 and 80 years; were considered physically and mentally capable of participating in the study by their clinician; had sufficient understanding of written and spoken English; and did not have advanced or metastatic bowel cancer.

Peers (Support providers)

Peers were eligible to act as support providers if they were diagnosed with bowel cancer more than 18 months ago; were aged 18 years and older; were considered physically and mentally capable of providing support and participating in the study and could fluently read and converse in English.

Recruitment*Support Recipients*

Clinicians working in metropolitan and regional areas of Victoria contacted people with bowel cancer (who met the above eligibility criteria) concerning the study by letter. A Participant Information Sheet and Consent Form was attached to these letters. Interested people returned a consent form to Cancer Council Victoria and were then contacted by the project co-ordinator from Cancer Council Victoria. People who were not interested in participating in the study were asked to indicate this on the consent form.

Reminder letters were sent to participants who did not return their consent form within three weeks.

Assignment to different peer support models

As the aim of the pilot study was to examine satisfaction and participant rates for the different models of peer support, it was preferable to let support recipients choose the peer support program they wished to participate in. Therefore the project co-ordinator informed support recipients of the two different peer support programs and asked them to select the one they wished to participate in.

All participants received a letter confirming the peer support program they selected to participate in. People receiving the telephone support were informed of the name of their peer and to expect a call in the next 5 days. People attending the support group were given details regarding their support group (e.g. venue, dates, name of support group facilitator etc), and advised that this person would call to introduce themselves and confirm attendance.

Peers

Peer volunteers were recruited from current Cancer Connect volunteers who had been diagnosed with bowel cancer and support group facilitators diagnosed with bowel cancer who had been accredited by Cancer Council Victoria. Volunteers were sent an invitation letter to participate in the study and information pamphlet that described the recruitment process and study. Volunteers indicated whether or not they were interested in becoming a peer by returning a form to the project co-ordinator.

The project co-ordinator contacted interested peer applicants by phone to discuss the study further and determine whether or not they were suitable to be support providers (e.g. availability, ability to commitment to requirements of the program etc). If suitable, peers were invited to participate in training according to the program for

which they were providing support. Participant information and consent forms were distributed at the completion of the training.

Peer Support Programs

One-on-one telephone peer support program

In this program, support recipients were matched to a peer who was similar in gender, age and treatment and, where possible, family situation (e.g. how many children, separated etc). Peers were notified of the match and asked to contact their support recipient within five days. In the first phone call, peers introduced themselves and explained that they were from the Cancer Council Victoria's peer support program. They then explained the purpose of the peer support program and their role (i.e. to normalise responses and experiences, provide support and provide information on their own cancer experiences). Content of the each phone call was dependent on the individual needs of the support recipient. Peers were expected to make at least eight contacts over a four to six month period. While the timing of the contacts could be negotiated between the dyad, the default contact was every two weeks and thus peers called participants at this interval if no other arrangement was made. Peers were given the choice whether or not they wanted to provide their telephone numbers to support recipients.

Face-to-face peer support group program

This program was based on the structure and format of support groups that are run in the community. The program was co-facilitated by a professional facilitator (i.e. social worker, nurse) and a peer facilitator. The Cancer Information and Support Service (CISS) at Cancer Council Victoria has procedures in place for developing support groups and these were followed for this study. Support groups had between six and ten participants, and meetings were to be held at two or three week intervals over a four to five month period. Meetings were held at a convenient local setting and ran for one and a half hours. The format/content of the meetings were derived from the peer support needs of the group participants but generally were a mixture of information provision and sharing of experiences. Two support groups were formed; one in the Barwon region and one in metropolitan Melbourne.

Data Collection Methods³

Support Recipients

Support recipients completed two surveys: one before the start of the peer support program (baseline), and one at the end of the program (post program). Questionnaires were mailed to participants.

³ Data collection resources (e.g. questionnaires and contact forms) are available on request to the authors if interested

Baseline questionnaire: Included standard demographic questions (e.g. individuals' age, sex, marital status, level of education, number and age of children, occupation and disease information) and questions assessing use of other peer support programs and participants' expectations regarding the program.

Post program questionnaire: A series of questions assessing participants' experience with the program, whether they felt their expectations had been met, satisfaction with the program (e.g. aspects of the program that participants were satisfied with and aspects that participants did not like, whether they felt they needed to access other sources of support during the program) and their thoughts regarding their peer.

Peers

Peers were asked to complete a contact form after each phone call with their support recipient or after each support group session and a questionnaire survey at the end of the program.

Contact Forms: For the one-on-one program, peers were asked to record the length of their contact with each of their support recipients, topics and strategies discussed, any difficulties experienced and their satisfaction with the phone call. For the face-to-face group program, peers were asked to record how many participants attended the group, general outline of topics discussed, any difficulties experienced and their satisfaction running the group.

Questionnaire content: Where possible similar questions were asked of peers participating in the differing support programs. The questionnaire included questions assessing: demographics, prior experience providing support and involvement with support programs, experience and satisfaction with the program (e.g. satisfaction with peer-support recipient match (if applicable), co-facilitation with health professional (if applicable), issues discussed with support recipients, emotions experienced prior to providing peer support, challenges experienced, opportunities for self-growth and suggestions for improvement) and how supported they felt (e.g. peers' satisfaction with the level of support they received from Cancer Council Victoria and other resources that could have been provided to increase they perceived sense of feeling supported).

Process Indicators

One-on-one telephone program: Contact sheets were monitored to assess the number of calls between the peer and support recipient and topics discussed between the dyad. Peers were asked to continue completing contact sheets for any contacts made after program completion, to assess whether support continued in the two-month period following the pilot program.

Face-to-face group program: Facilitators were asked to record attendance at each group meeting to determine retention rates. Additionally, facilitators indicated whether they believed the group would continue running after the five to six month study period had lapsed.

Results

Sample Characteristics

Thirty-four people with bowel cancer agreed to participate in the peer support programs as support recipients (yielding a participation rate of 42.5%); sixteen were recruited from hospitals within metropolitan Melbourne and eighteen from the Barwon South West region. The mean age of support recipients was 61.3 years, with a range of 45 – 78 years. Table 1 and 2 shows the demographic and disease information of the support recipients. Table 1 shows that the majority of support recipients were married (67.6%) and not working (55.9%) at the time they participated in the programs. In relation to cancer diagnosis, the majority were diagnosed with colon cancer (64.7%) and were diagnosed approximately 14 months (range 2 – 33 months) prior to entering the program (see Table 2). Twenty percent (N = 7) of support recipients were either still undergoing treatment when participating in the program or had finished treatment one month before starting the program.

Support recipients were asked to indicate whether they had looked for support before participating in the programs. Nine percent (N = 3) indicated they had looked for peer support through Cancer Council Victoria's Cancer Connect Program. Thirty eight percent (N = 18) indicated that they had looked for informational support regarding their diagnosis from health professionals (50.0%), written resources (41.7%), Internet (33.3%), The Cancer Council Victoria (25%) and family and friends (8.3%).

Uptake of the Programs⁴

Seventeen support recipients, seven males and ten females, chose to participate in the one-on-one telephone program rather than the face-to-face group program. Travel constraints were the main reason for this preference (75%), followed by the convenience of receiving support over the phone (18.8%) and other commitments (e.g. family, medical appointment, work; 12.6%). Consistent responses were provided in the post questionnaire in addition to feeling more comfortable talking about cancer over the phone than face-to-face (21.4%).

Seventeen support recipients chose to participate in the face-to-face group program rather than the one-on-one telephone program. More males (N = 10) had a preference for the face-to-face peer support than females (N = 7). The opportunity to listen and share a variety of experiences (31.3%), the impersonal nature of receiving support via the telephone (31.3%) and receiving social support (12.5%) were the main reasons cited for selecting the group program. Similar responses were given after program completion, as well as, the ability to see and share nonverbal expressions (20%), perception of gaining greater benefits discussing problems face-to-face (20%) and the opportunity to both receive and provide support (6.7%).

⁴ All open-ended questions were coded into categories after data collection was completed and allowed for multiple responses.

Table 1
Demographic characteristics of Support Recipients

		One-on-One Telephone Group (N = 17)	Face-to-Face Support Group (N=17)
		N (%)	N (%)
Location	Metro	9	7
	Regional	8	10
Age	Range	45 – 78	49 –78
	Mean	60.18	62.41
Gender	Male	7 (41.2)	10 (58.8)
	Female	10 (58.8)	7 (41.2)
Country of Birth	Australia	15 (88.2)	10 (58.8)
	Other	2 (11.8)	7 (41.2)
Marital Status	Married	12 (70.6)	11 (64.7)
	Defacto/ Live with partner	1 (5.9)	1 (5.9)
	Separated/divorced	2 (11.8)	2 (11.8)
	Widowed	2 (11.8)	2 (11.8)
	Single/never married	0	1 (5.9)
Current Employment	Full-time	1 (5.9)	2 (11.8)
	Part-time	4 (23.5)	3 (17.6)
	Casual	2 (11.8)	3 (17.6)
	Not working	10 (58.8)	9 (52.9)
Employment Prior to Cancer Diagnosis	Full-time	5 (29.4)	7 (41.2)
	Part-time	6 (35.3)	0
	Casual	1 (5.9)	2 (11.8)
	Not in labour force	5 (29.5)	8 (47.1)

Table 2
Disease Information of Support Recipients

		One-on-One Telephone Group (N = 17)	Face-to-Face Support Group (N = 17)
		N (%)	N (%)
Bowel Cancer Diagnosis	Colon	12 (70.6)	10 (58.8)
	Rectal	5 (29.4)	6 (35.3) ^a
Time since diagnosis (months)	Range	3 – 30	2 – 33
	Mean	12.82	16.35
Treatments received	Surgery	17 (100)	14 (82.4)
	Chemotherapy	13 (76.5)	10 (58.8)
	Radiotherapy	8 (47.1)	7 (41.2)

^aOne participant did not specify their diagnosis in this program.

Retention of Support Recipients in the programs

One-on-One Telephone Program

One support recipient withdrew after the first contact call with their peer. This support recipient was diagnosed with cancer 24 months prior to entering the program and did not feel they needed peer support at this point in their journey. The support recipient reported that this program would have been more beneficial in meeting their peer support needs if offered to them earlier in their cancer journey.

Seven support recipients did not feel a need to remain in the program for the complete duration. Two support recipients completed the program after three calls; three completed the program after four calls and two after five calls. All seven support recipients were between 15 to 24 months post their diagnosis and did not feel that they needed further peer support in this stage of their journey.

Seven support recipients remained in the program for the entire duration. These support recipients were 3 to 10 months post their diagnosis. One support recipient was 22 months post diagnosis but had just completed treatment 8 months before entering the program.

Three support recipients remained in the program longer than the required contacts; 9, 10 and 11 calls respectively. These support recipients were 6 to 10 months post diagnosis and were still undergoing treatment or had very recently completed their treatment.

Face-to-Face group program

Barwon support group: All ten support recipients attended the first meeting, however attendance for the next seven meetings ranged from six to nine. Reasons for not attending included illness, travel, family commitments and medical appointments. All ten participants continued to program completion.

Metro: One support recipient withdrew just before the first meeting due to a change in work commitments. Another support recipient was only able to attend one meeting also due to work commitments. Attendance at meetings was generally four to five, with six in one meeting. The main reason for not attending was side effects of treatment and medical appointments.

Expectations of the Program

One-on-One Telephone Program

Prior to entering the program, support recipients were asked about their expectations of the telephone program. Six participants indicated that they were not sure what to expect or had no specific expectations regarding the program. The remaining 11 participants reported the following expectations: opportunity to share similar experiences (18.8%), receive informational support (18.8%), receive emotional support and reassurance (12.6%), gain better understanding of their cancer experience (6.3%), compare experiences (6.3%) and feel less isolated in their cancer

experience (6.3%). Support recipients were also asked to indicate what they hoped to gain from their contact with their peers. Responses included knowledge and experience (26.7%), mutual understanding (20%), reciprocal exchange of support (20%), expectations for post treatment and survivorship (20%), and general improvement in their psychological functioning (e.g. less distressed/anxious, 6.7%).

On program completion, all support recipients who returned their post questionnaire (N = 14), reported that the one-to-one telephone peer support program had met their expectations. Functions of the telephone program that assisted in meeting their expectations could be summarised in three main categories: 1) exchanging information (e.g. asking for information, providing information to others, sharing views and gaining advice); 2) sharing the illness experience (e.g. similar experiences, personal feelings at various stages of the journey, family reactions) and; 3) improving psychosocial functioning (e.g. reassured/encouraged, increased confidence and self-acceptance, elicited positive thinking, reduced distress, normalised the experience and reduced sense of isolation). Further, quantitative responses showed that support recipients 'strongly agreed' that contacts with their peer made them feel they weren't alone (93%), made them hopeful (93%) and reassured them that their reactions were normal (79%). Overall, the most helpful/important aspect to all these functions was that some one who had bowel cancer, and therefore could be completely empathetic, was delivering the support.

Surprised we could talk so easily and discuss things so well

It gave me the knowledge that other people have been through what I was going through.

Program met my expectations much more...now feel at ease

As she has experienced what I was going through I found her to be a good and understanding listener. To share my ups, downs and worries.

It was just easier talking to someone with the same condition because they know what you are going through than someone that doesn't.

Made me more comfortable with my condition

Generally made me feel less anxious about treatments and outcomes

Reassured my feelings were normal

Even though everyone handles things differently you can understand each other's feelings when you have both been through a similar experience.

Made me feel I was not alone

It just relaxed me knowing what I was thinking and feeling was normal.

It gave me a better outlook into the future.

Face-to-Face group program

Similar to support recipients in the telephone program, support recipients who elected to participate in the group program were asked about their expectations prior to entering the program. Expectations included sharing of ideas and experiences (43.8%); reciprocal exchange of support (i.e. providing and receiving support; 37.6%); sharing of coping strategies (18.8%); discussions regarding the impact of cancer on relationships and lifestyle (12.5%); knowledge (12.5%) and to receive emotional support (6.3 %) and reassurance (6.3%). Additionally, support recipients were asked to comment on what they hoped to gain from having contact with others who had been diagnosed with bowel cancer. Responses included a better understanding of the cancer experiences through gaining advice, knowledge and sharing experiences (37.6%); opportunity to give support (31.3%); better quality of life (18.8%); empathy and mutual understanding (12.5); decreased sense of loneliness or isolation (12.5%) and general support (6.3%).

Eighty percent of support recipients who returned their post questionnaires (N = 15 who returned completed questionnaires) felt their expectations of the group program were met. Three support recipients (20%) felt their expectations were only partially met. One support recipient felt the issues and topics were not explored as well as they would have liked. The second support recipient felt that a gender-specific, as well as cancer-specific (i.e. colon versus rectal), support group would have more satisfactorily met their needs. The third support recipient felt their needs and expectations would have been met if the program was offered to them closer to diagnosis.

Functions of the group program that emerged from support recipients' responses and assisted in meeting their expectations could be summarised in five main categories: 1) exchanging information (e.g. learning about different treatments, sharing strategies to deal with side effects); 2) sharing the illness experience (e.g. similar experiences, different experiences, personal feelings, family reactions and relationships); 3) providing strength and a sense of belonging (e.g. 'family' atmosphere, normalising the experience, not alone, being there for each other, empowering); 4) mutual exchange of support (e.g. opportunity not only to receive but also provide support) and; 5) improving psychosocial functioning (e.g. increased confidence to cope with cancer experience, elicited positive thinking, reduced distress and fears). Interestingly, a few participants did report that at times meetings elicited negative emotions for them (e.g. brought back bad memories, concern/worry when hearing experiences of others). Quantitative responses reinforced that support recipients' contact with their peers during group meetings met their expectations. Support recipients 'strongly agreed' that contact with their peers made them feel they were not alone (80%), hopeful about the future (73.3%), provided them with practical advice (80%), reassured them that their reactions were normal (86.7%) and made them feel understood (80%).

It exceeded my expectations – meeting people with similar difficulties.

Now I feel that I have been helped and I have helped other people.

I found it very reassuring to hear that others in the group were experiencing similar thoughts. The fact that you are not alone in your thinking gives you strength

They all felt the same. I did not have to convince anyone.

I knew the group members understood. Sometimes feel I don't want to burden friends and family with too much and the realization that they can't fully know what one is going through.

Sharing my thoughts with them was helpful, it was like they all gave me their hands to make my problems smaller.

Whilst I have always had a positive attitude to my situation, I found I was even more positive about my future and the possible hurdles or challenges I may face.

The whole experience was very positive for me. I came away feeling I could cope with whatever came along on the future.

It makes you feel like you are not alone going through these ups and downs.

Despite the difficulty in getting to the group sometimes, although this challenge can be beneficial as well (you get out and you are doing something different), the cheerfulness of the group, the human element and the support, left me always feeling uplifted.

You find the support you need in moments like this.

Satisfaction with the program

One-on-One Telephone Program

Eighty-six percent of support recipients indicated that they were 'very satisfied' with the telephone program and 14% indicated that they were 'satisfied'. Further, all reported that they felt that their needs were met by the support received. Ninety-three percent of support recipients also indicated they did not need to look for support or information elsewhere whilst participating in the telephone program. The main topic areas discussed with peers included personal experiences and feelings (100%), getting better (85.7%), access to services (84.6%), lifestyle (83.3%) and family issues (71.4%).

Eighty-six percent of support recipients also indicated that they were 'very satisfied' with the match with their peer and 14% reported that they were 'satisfied'. One support recipient commented "I was extremely satisfied with my peer, I think we were perfectly matched." Experience with chemotherapy (50%) and family situation (28.6%) were rated as the most important factors to be taken into consideration when matching a peer with a support recipient. All support recipients reported that they were 'mostly' comfortable talking about their cancer with their peer, and 78.6% reported that they were 'very satisfied' with the contacts they had with their peer. All support recipients felt listened to and felt it was very helpful to share their thoughts with their peer. Peers were described as 'extremely' friendly (71.4%), not judgemental (85.7%), helpful (71.4%), caring (71.4%), easy to talk to (92.9%) and compassionate (78.6%).

Face-to-Face group program

Sixty-seven percent of participants indicated that they were 'very satisfied' with the program, 27% 'satisfied' and 6% 'neither satisfied nor dissatisfied.' Ninety three percent felt that their peer support needs were met by attending the group, found it helpful to share their thoughts with group members, were 'mostly comfortable' talking about their cancer experience with their group and indicated that they did not need to look for support elsewhere while participating in the program. Further, all support recipients felt they had enough opportunity to talk during the sessions and that group members listened to them. The main topics discussed within the groups were personal feelings and experiences (86.7%); side effects (86.7%); nutrition (73.3%); getting better (86.7%); family issues (80%) and spirituality (71.4%).

The peer-professional co-facilitation was received very favourably by support recipients. Ninety-three percent indicated that they were 'very satisfied' with this model and 86% thought the facilitators worked 'very well' together and 14% 'well'. The peer facilitators were described as helpful (80%), friendly (93.3%), non-judgemental (80%), helpful (86.7%), sympathetic (100%), caring (93.3%), responsive (93.3%), easy to talk to (93.3%), compassionate (93.3%) and sensitive (80%).

Peer Satisfaction

Fourteen peers provided support for this study. Twelve peers through the one-to-one telephone program and two support group facilitators.

Fifty percent of peers in the telephone program reported that they were 'very satisfied', 25% 'satisfied' and 25% 'neither satisfied or dissatisfied' with their experience of being a peer in the one-on-one telephone program. Dissatisfaction mainly derived from peers supporting support recipients who were significantly past their initial diagnosis and therefore had no or few needs. The majority of peers (83.4%) were satisfied with the support they received from Cancer Council Victoria during the program and thought the training adequately prepared them for their role (91.6%). Further, 50% indicated that their role as a peer helped them cope with their own cancer experience. These peers commented that they felt 'lucky' in their experience with bowel cancer (e.g. support recipients' experiences were more challenging) and that providing support assisted in their adjustment to their diagnosis and increasing their knowledge.

Both peer facilitators in the face-to-face group program were 'very satisfied' with their experience in the program. In addition, the peer facilitators reported that they were 'very satisfied' with the structure of meetings, guest speakers, the peer-professional co-facilitation model, support received from staff at The Cancer Council Victoria and the professional facilitator and the training provided. The peer facilitators commented that this experience was empowering for them (e.g. reinforced they were survivors) and made them realise that positive outcomes can come from having cancer, for example, being a source of support to others with cancer and helping them through their journey.

Acceptability of the Programs

One-on-One Telephone Program

All support recipients indicated that they would recommend the telephone peer support program to others diagnosed with bowel cancer. The main reason the support recipients recommended the program was for the 'special' type of support, understanding and bond gained by receiving support from someone who shared a common experience with them (54.5%). In addition, the support recipients reported that receiving peer support helped to reduce distress and provide a sense of empowerment and hope and positive future outlook (45.5%). Other reasons included the flexibility and convenience of receiving support over the phone and the opportunity to talk about their cancer without having to burden their family.

The only recommendation for improvement was that the program should be offered closer to diagnosis or during treatment, as this is when the need for peer support is most significant. Many support recipients felt they were offered the program too late in their cancer journey.

Face-to-Face group program

Ninety-four percent of support recipients indicated that they would recommend the group program to other people diagnosed with bowel cancer. Support recipients reported many reasons for recommending the group program, including: a sense of belonging or being part of a 'family' atmosphere, where you feel supported and accepted and not alone (36.4%); receiving unique empathy and understanding that can only be gained by meeting people with bowel cancer and sharing experiences (18.2%); the ability to talk freely about your fears and worries without burdening your family (18.2%); feeling positive and uplifted by attending the groups (18.2%). Support recipients also reported that learning and gaining information from others in the group was more beneficial than receiving information through the internet or pamphlets (18.2%). One participant indicated that they would definitely recommend peer support however would recommend a one-on-one format rather than group-to-group. This support recipient felt a one-on-one format had the benefit of offering tailored and individualised peer support to meet the specific peer needs of the support recipient.

Recommendations for improvement included gender sub-groups and bowel cancer type sub-groups (e.g. rectal specific and colon specific) for some meetings, male and female facilitator partnership, more time for personal sharing/discussion within meetings, less frequent meetings, after hours meetings and for the meetings to be offered closer to diagnosis.

Discussion

This pilot study examined the uptake, satisfaction and acceptability of two peer support models: one-to-one telephone program and face-to-face group program. Thirty-four people with bowel cancer agreed to participate in the study as support recipients with 17 electing to participate in the telephone program and 17 in the group program.

Indications from the investigative study were that uptake of a support program is likely to be related to how well informed or aware people are about the program and referral to a program by a health professional, namely their clinician. Support recipients in this study were invited into the program by a letter from their clinician with an information sheet attached and, where possible, referring clinicians discussed the programs with their patients. Discussions with support recipients indicated that the opportunity to talk with their clinicians about the program and the function of peer support contributed to uptake of the program. Recruitment into the program also suggested that timing of referral to a support program in relation to a person's cancer journey is important. The most common reason reported for not participating in the study, despite being interested in receiving peer support, was that the program had been offered too late in their cancer journey. Many people felt peer support would have been more beneficial and more applicable if offered closer to their diagnosis. Discussion and comments from support recipients who participated in the study indicated that people with cancer should be made aware of support programs after diagnosis and before treatment by their clinicians, as this is the time peer support is most needed.

Retention into the programs was more successful for the group program than the telephone program. Fifty percent of support recipients in the telephone program ended their contact with the peers prior to program completion (eight contact calls). These support recipients were 15 to 24 months post diagnosis and reported that a lack of peer support needs at this stage in their cancer journey was the main reason for completing the program early. All of these participants reported that they would have liked to be offered this program closer to diagnosis and during treatment. While support recipients in the group program also consisted of people greater than one year post diagnosis, especially in the regional group, all support recipients remained in the program until program completion. Two factors may have been working here. First, receiving peer support via a group format provides support recipients with the opportunity to not only receive support but also provide support. Therefore, while many of the support recipients who were one year post diagnosis may not have come to a group with many peer support needs the ability for mutual encouragement and support may have been an added benefit and provided them with a sense of empowerment, confidence and hope. Second, as indicated by the support recipients in this study, joining the support group provided them with a sense of belonging and a 'cancer family' which assisted in reducing their sense of isolation and feeling alone. This may be particularly important for people with bowel cancer who, as noted in the investigative study, feel there is a stigma associated with having bowel cancer.

Satisfaction rates were favourable for both programs with the majority of participants indicating they were 'very satisfied.' Satisfaction was achieved in terms of both program format (e.g. fortnightly contact calls, peer-professional facilitation for group program etc) and experience with peers (e.g. peer-support recipient match, peer qualities). In addition, all support recipients who participated in the telephone program and 80% of support recipients in the group program felt their expectations had been

met. Twenty percent of support recipients in the group program did not feel their expectations were completely met for the following reasons: issues and topics were not explored as well as they would have liked, felt that a gender-specific group would have more satisfactorily met their needs and would have preferred the program to be offered to them closer to diagnosis. In this respect the telephone program may have been more successful in meeting the expectations of these support recipients as it allowed for individually tailored support and for recipients to be matched to peers by gender.

There was a general acceptance among people with bowel cancer for peer support and the peer support programs pilot tested in the study. All support recipients in the telephone program would recommend this to people with bowel cancer and all but one support recipient in the group program reported that they would recommend the group program. Further, the findings suggested that support recipients experienced many benefits from participating in the program including exchanging information, sharing the illness experience with someone who completely understood, and benefits to psychosocial functioning (e.g. empowerment, hope, confidence, reduced distress and sense of isolation and normalised the experience). The group program appeared to provide additional benefits, providing a sense of belonging and meaningful opportunities for patients to help others facing similar opportunities through mutual exchange of support.

The two peer support models tested in this study were successful in terms of support recipients' satisfaction and acceptability and meeting the peer support needs of people with bowel cancer. Therefore, it would be difficult to recommend one model over the other for people with bowel cancer. Rather, the findings suggest a need for both models to be implemented into the wider community to cater for the differing peer support needs. For example those wanting convenience, flexibility and tailored support to meet specific needs might gain more satisfaction from joining the telephone program. Whereas people wanting to hear about a variety of experiences and coping strategies as well as gain social support (i.e. a sense of belonging). might benefit from a group program.

CONCLUSION

The 'Models of Peer Support for Bowel Cancer Patients' research project aimed to determine the acceptability of peer support for people with bowel cancer by examining the needs of peer support among this cancer group, enablers and barriers to support program uptake, preferred models of delivering peer support to people with bowel cancer and acceptability of two different peer support models.

The project demonstrated that people with bowel cancer are interested in peer support. In addition, calls to the Cancer Council Victoria's Helpline from people with bowel cancer suggest continued interest in peer support programs. The literature reports that the opportunity to share experiences with people facing similar challenges is the essence of peer support (Gray et al 1997b; Mastrovito et al, 1989). Results from both the investigative study and pilot study support this principle as shared experiences and information were the predominant reasons people with bowel cancer sought peer support. Sharing experiences may be a distinctive service that peer support programs can meet.

As reported in previous literature (Dunn et al., 1999; Hutchinson et al., 2006; Weber et al., 2004; Winzelberg et al., 2003; Ashbury et al., 1998; Vos, Garssen, Visser, Duivenvoorden, & de Haes, 2004; Ussher, J; Kirsten, L, Butow, P & Sandavol, M., 2006) this project found that peer support programs benefit people with bowel cancer, namely by offering them the opportunity to receive unconditional acceptance and empathy through the bond of common experience. Perceived benefits included improved psychological adjustment (e.g. increased well being, improved coping and self-efficacy, reduced distress); reduced sense of isolation (e.g. normalising the experience, feeling a sense of belonging, receiving social support), and feeling more informed about their diagnosis through informational and practical support. An important finding is that peer support should not be offered only to those experiencing difficulties. Rather, it appears that people with cancer appreciate peer support, regardless of whether they were adjusting well to their diagnosis prior to entering the peer support programs or experiencing some distress. Therefore the opportunity to participate in peer support programs should be offered to all people diagnosed with bowel cancer early in their illness, as it appears that peer support can be valuable for all individuals.

While this project demonstrated that people with bowel cancer have an interest in peer support, it also revealed that the majority of participants, both in the investigative study and pilot study, were not engaged with peer support programs. The project has assisted in answering the important question of why peer support participation rates are low among people with bowel cancer and what are the barriers prohibiting uptake. The barriers reported by the participants in this project included lack of awareness of peer support programs, tentativeness to self refer to peer support programs, embarrassment and stigma associated with a bowel cancer diagnosis, lack of bowel cancer specific programs, and delayed referral to the programs. This provides useful information about what can be done to enable participation in peer support programs. Greater promotion of peer support programs is needed from clinicians and other health professionals. Patients considered it appropriate for clinicians to refer patients to peer support programs and discuss the idea of peer support rather than patients having to seek out support themselves. The timing of the referral to a program is important, as it appears to strongly determine relevancy,

satisfaction, uptake and retention in the programs. Some people with bowel cancer elected not to participate in the pilot study, despite being interested in receiving peer support, because they felt the programs had been offered to them too late in their cancer journey. Similarly, others who had been diagnosed six to twelve months prior did participate but withdrew from the program before completion, reporting that peer support would have been more beneficial if offered closer to diagnosis. Therefore, it appears that the period in between initial diagnosis and treatment completion is the optimal time for people with bowel cancer to receive peer support and suggests that clinicians should be offering peer support throughout treatment. Lastly, greater awareness of bowel cancer in the community and bowel cancer specific peer support programs were reported to be necessary to overcome the barrier to peer support participation related to stigma and embarrassment.

Well-designed peer support programs are therefore necessary to ensure that the needs of people receiving the support are being met. This research project is one of the few to investigate the specific peer support needs of people with cancer and preferred models of delivery. Findings revealed that a one-to-one telephone and face-to-face group format were the most preferred modes of delivering peer support to people with bowel cancer. Further, outcomes from the pilot study confirmed this recommendation, judging by the high satisfaction rates reported by support recipients and the success of these models in meeting support recipients needs and peer support expectations. As the literature review indicated that very little research has specifically explored the effectiveness of peer support programs for people with bowel cancer, it appears that further investigation of these models with people diagnosed with bowel cancer is warranted, particularly via a well designed randomised control trial.

The 'Models of Peer Support for Bowel Cancer Patients' research project emphasised the value of peer support in cancer care for people with bowel cancer as part of an additional form of support for this population. This project has identified preferred methods for delivering peer support to people with bowel cancer and barriers to uptake and retention of this type of support. In addition, this project has helped highlight factors that need to be considered when developing peer support programs including: developing the program and program structure in response to the needs of people receiving the support (e.g. matching criteria, frequency of contacts or meetings, structured versus unstructured, topics addressed), creating the opportunity for sharing of experiences and talking, opportunity for social support and humour as well as emotional and informational support, well trained support providers and facilitators, involvement of health professionals, collaboration with cancer services and supervision and support for peers. All this information can be used to facilitate the development of peer support programs for people with bowel cancer in Australia.

Recent outcomes of project

Two face-to-face peer support group programs have been formed in the Barwon region as a result of the pilot study. One will be a continuation of the original Geelong group formed for the pilot study and the second group has been set up in the Warrnambool region. The Barwon South Western Regional Integrated Cancer Service is providing support for the peer support groups and assisting to promote the programs (e.g. brochures, raising awareness among clinicians). Staff from the Andrew Love Cancer Centre have agreed to refer newly diagnosed patients to the programs.

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