

Cancer Survivorship: Does One Size Fit All?

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Research Article

ABSTRACT

Due to successes in early detection and disease management of cancer, there are increasing numbers of cancer survivors in the US and Australia. Cancer survivors are a vulnerable population who face numerous physical, psychological, social, spiritual and financial issues. Empirical evidence suggests that survivors and their providers are not adequately prepared for the experiences after initial treatment highlighting the need to create or improve existing strategies for survivors. Guided by the Australian National Service Improvement Framework for Cancer and the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, this paper presents the findings of an evaluation of "Moving on...Living Well" (MO...LW), a multidisciplinary patient education program, based in Australia, designed to provide transitional support in the immediate timeframe following completion of active cancer treatment. An observational, non-equivalent group comparison design, utilizing post-program evaluations of participants (n=105) and a retrospective survey of all eligible participants (n=196) provided data for this study over a three-year time period. Findings suggest that the majority of patients transitioning to survivorship had either felt supported by their health care team or indicated they were self-sufficient in their need for support. Participants in MO...LW were highly satisfied although there were not differences between them and non-attendees. One reason for the lack of statistical difference could be that cancer survivors have differing preferences and levels of needs. This indicates that one size does not fit all when implementing survivorship care in a post-treatment setting. Suggested recommendations for providers are discussed.

Keywords: Cancer, Psychosocial care, Survivorship

INTRODUCTION

While cancer is a worldwide concern with an estimated 19.3 million cases expected by 2025, technological advances in cancer screening, diagnosis and treatment have resulted in unprecedented high numbers of cancer survivors. Worldwide, there are 32.6 million five year cancer survivors including Australia ^[1,2]. Approximately 144,000 individuals were diagnosed with cancer in Australia/New Zealand ^[3]. Furthermore, in Australia, more the 66% of cancer patients will survive at least five years after diagnosis. The most recent data indicates that there are approximately 800,000 cancer survivors in Australia representing about 3-4% of the total population ^[4]. Cancer survivors face numerous physical, psychological, social, spiritual and financial concerns during and after the cessation of active treatment ^[5-7]. Being diagnosed with cancer is a new, generally negative experience, perhaps filled with false notions, which may elicit fear and emotional distress. The period of time after a patient completes active treatment for cancer poses comparable but different challenges ^[8]. There are persistent gaps in the research that assess strategies to prevent or diminish the physiological or psychosocial sequelae and studies designed to measure the efficacy of a specific intervention ^[9].

The Moving On...Living Well (MO...LW) program, a multidisciplinary patient education program designed to facilitate the transition from initial cancer treatment in the adjuvant setting to survivorship was developed to fill a recognized gap in service provision in the Sunshine Coast regional cancer care center. This paper presents findings from an assessment of the survivor's experience of the MO...LW program.

CONCEPTUAL FRAMEWORK

Guided by an integrated conceptual framework of the Australian National Service Improvement Framework for Cancer and Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, the purpose of the study reported here is to present findings about whether attendance at MO...LW contributed to meeting the needs of cancer survivors. The Australian National Service Improvement Framework for Cancer suggests that "people making that transition reflect on the fact that it is a time of anxiety and uncertainty after a period or relatively intense support" ^[10]. The framework also states that initiatives must place people affected by cancer at the center of their care. The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer suggests that psycho-educational programs should have psychological/supportive and skills/knowledge-building components, provided on a group basis and offer information on cancer and coping strategies, which have been found to decrease anxiety and depression, and increase knowledge ^[8]. Utilizing the concepts from these frameworks, the MO...LW program was designed to increase patient satisfaction and wellbeing, improved patient follow up and increased efficacy of transition from a hospital to community basis of care.

Moving on Living Well Program

The goals of the MO...LW program are to facilitate the transfer of cancer patients from hospital based care to a community based or self-care model and to support the patients and their caregivers in their educational needs and psychological readjustments required in this transition. The MO...LW program is a multidisciplinary initiative of Sunshine Coast Cancer Care Centre (SCCCS). The impetus for the program came about with the appointment of a cancer care coordinator position specifically tasked to implement systemic service improvements to improve patient outcomes across the disease trajectory. The cancer coordinator identified a gap in service and a multidisciplinary allied health and nursing team was formed to investigate the best way to provide transitional support in the immediate period following completion of active treatment. The components of the MO...LW program included 14 sessions. Patients with any types of cancers or treatments streams with a curative intent in the adjuvant setting as opposed to palliative patients could participate to support the goal of a transition to wellness program. The sessions consisted of short presentations from each specialty field (oncology nursing staff, dieticians, clinical psychology, social work, occupational therapy and physiotherapy), followed by a short question and answer session. Take home information packs included the presentation summaries, community and published cancer resources that were identified by the participating health professionals as potentially useful to cancer survivors. The number of participants for the sessions was limited to eight in addition to caregivers. Institutional Review Board approval was obtained for this study.

STUDY DESIGN AND METHODS

Utilizing an observational non-equivalent group comparison design, this paper investigated whether attendance at the MO...LW program transition to survivorship patient education program has contributed to meeting the needs of cancer survivors.

Sample

Convenience sampling was used to recruit patients. Nursing staff identified eligible patients as they approached the completion of planned treatment. All eligible patients were either handed or posted an invitation that outlined the purpose of the program and advised of RSVP details. Both the patient and their caregiver were invited to attend. An excel spread sheet was maintained to document all invitations and responses for both quality improvement and data management purposes.

Over the course of three years, 275 patients were identified as being eligible for the program. Of the 275 eligible patients, 105 participated (69 were patients and 36 were caregivers). No caregivers attended alone. Of the 105 participants, 36 were patient/caregiver dyads and 33 were unaccompanied patients. All 275 patients and their caregivers who had been invited to participate in the MO...LW program as part of usual care were eligible to participate in the retrospective analysis of this quality improvement project. Of these, 79 patients were excluded from participation in the February 2011 survey as they were deceased, too unwell, or had no contact address, leaving a total of 196 eligible patients for the retrospective evaluation survey.

Data Sources

The source of data to understand whether attendance at the MO...LW program transition to survivorship patient education program has contributed to meeting the needs of cancer survivors was a retrospective survey of all eligible patients who had completed cancer treatment and who been invited to attend the MO...LW program in the period from March 2007 to March 2010, whether they had attended the program or not. The two instruments utilized to collect data were the MO...LW retrospective feedback and the Cancer Survivors Unmet Needs (CaSUN).

RESULTS

The MO...LW Retrospective feedback survey was distributed to all previously identified cancer survivors from the SCCCS, whether they had participated in the program or not. A total of 89 surveys (45% of 196 eligible patients) were returned. The survey was developed to facilitate understanding of the overall experience of the time of transition from active treatment for cancer. Survivors were requested to share how they had perceived the overall support they had received as they transitioned from active treatment into survivorship, and were asked if they had felt supported by their health care providers, and if they had, which health care providers they had found particularly helpful. A total of 93% (n=83) expressed satisfaction or self-sufficiency, with 3.4% (n=3) identifying as being unsure about their level of perceived support. Further, three respondents (3.4%) stated they had not felt supported after the completion of their active treatment. The patients who chose to attend MO...LW were asked if they felt that the program had assisted in their transition to survivorship following treatment for active cancer. Of the 38 patients who had identified as attending the program, 76% (N=29) agreed that it had, 6% felt that the program hadn't helped, and 16% were unsure as to its helpfulness. Six caregivers whom attended the program reported that it assisted the transition, four were unsure.

Cancer Survivors' Unmet Needs Survey

A total of 79 cancer survivors returned their Cancer Survivors Unmet Needs (CaSUN) questionnaire. This Australian developed self-reporting measure is designed to facilitate the evaluation of supportive care services and generate service delivery recommendations for cancer survivors [11]. The measure incorporates 35 unmet need items, 6 positive change items and an open ended question. The CaSUN data were scored per the guidelines. The total identified needs were calculated, as were total met needs and total unmet needs. This resulted in three scores for each participant ranging from 0-35. The results were then compared between the group of patients who had attended the MO...LW program, and those that did not. The scores for patients who had experienced recurrence were calculated separately, as those with a recurrence are likely to experience a range of unique health and psychosocial concerns [8,12,13] that may confound interpretation of the results in this study.

As seen in **Table 1**, on average cancer survivors who attended the MO...LW program identified a mean of 10.74 areas of total need, with a mean of 5.8 of those areas described as met, and a mean of 4.93 described as unmet. Patients who did not attend the program described a mean of 11.89 areas of total need, with a mean of 5.75 of those meet, and a mean of 6.07 unmet. Cancer survivors who had experienced recurrence had higher total need (M=12.14) and higher met need (M=7.71), but lower unmet need (M=4.42).

Table 1. Cancer survivors total need scores.

Cancer Survivors Total Need Scores (CaSUN Data) (n=79; range 0-35)			
	Attended MO...LW	Did not attend MO...LW	Experienced Recurrence
	Mean (Range)	Mean (Range)	Mean (Range)
Total Need	10.74 (0-30)	11.89 (0-35)	12.14 (8-22)
Met Need	5.80 (0-21)	5.75 (0-29)	7.71 (2-21)
Unmet Need	4.93 (0-22)	6.07 (0-35)	4.42 (1-13)

Although the cohorts were not randomized, we conducted independent t-tests to compare average number of needs by attendance at the program, excluding the seven participants who had reported experiencing recurrence. The analysis revealed no significant differences between the two groups in terms of their self-identified needs. Therefore the hypothesis that those participants who attended the MO...LW had significantly improved outcomes in terms of level of survivorship need was unsupported.

Five domains within the 35 unmet need items of CaSUN were further analyzed. The domains were: existential survivorship; comprehensive cancer care; information; relationships; and quality of life. For the purposes of this paper, findings for existential survivorship and comprehensive cancer care are presented. Data were grouped into the identified domains as per the CaSUN Scoring Manual. Domains are scored by summing all the items in that domain. As domains contain different numbers of items, the average number of needs in that domain is reported. Results were differentiated by attendance/non-attendance at the Moving On...Living Well program and the self-reported presence of recurrence.

Existential Survivorship and Comprehensive Cancer Care

Table 2 shows that scores for existential survivorship and comprehensive cancer care. For existential survivorship, those who had attended the MO...LW program were less for all items in this domain when compared to those who had not attended the program. Independent t-tests however revealed no significant differences between the two groups in terms of existential survivorship needs ($t(70)=0.85, p=0.40$). When the patients who had self-identified recurrence were assessed independently, their level of existential need was uniformly lower. For comprehensive cancer care, patients who had attended MO...LW also reported a slightly lower unmet need in the comprehensive cancer care domain in comparison to patients who had not attended the program. However independent t-tests revealed no significant differences between the two groups in terms of comprehensive cancer needs ($t(70)=-0.29, p=0.77$).

Table 2. Results for the existential survivorship and comprehensive cancer care domains.

Domain: Existential Survivorship (Range 0-3); $t(70)=0.85, p=0.40$			
Items	No MO...LW	MO...LW	Recurrence
	Mean (n=47)	Mean (n=32)	Mean (n=7)
10. Reduce stress in my life	0.738	0.419	0.5
19. Concerns about cancer coming back	1.024	0.0387	0.333
20: emotional support for me	0.738	0.194	0.333
29: move on with my life	1.024	0.097	0
31: acknowledging the impact	1.024	0.419	0.167
32: survivor expectations	1.119	0.29	0.167
33: decisions about my life	1.071	0.194	0.167
34: spiritual beliefs	1.048	0.065	0
35: make my life count	1.19	0.161	0
Domain: Comprehensive Cancer Care (Range 0-3); $t(70)=-0.29, p=0.77$			
Items	No MO...LW	MO...LW	Recurrence
	Mean (n=47)	Mean (n=32)	Mean (n=7)
4: best medical care	0.476	0.355	0.833
5: local health care services	0.381	0.452	0.167
6: manage health care with team	0.524	0.452	0.833
7: doctors talk to each other	0.643	0.484	1.167
8: complaints addressed	0.595	0.323	0.833

Accessing Survivorship Information Needs

Participants in the retrospective survey were also asked to identify ways they had accessed survivorship information. A total of 74 cancer survivors provided a response. The most common source of survivorship information was the general practitioner, identified by 57% of respondents, followed by a written information pack or survivorship brochure. 4% of respondents recalled receiving a personalized survivorship care plan, a figure that reflected a pilot trial done in our regional cancer center in 2009. Relatively low utilization of the internet, cancer specific support groups and community

support organizations was recorded. The retrospective survey also asked if cancer survivors could identify what their preferred method for receiving survivorship information would have been.

The majority of respondents identified they would prefer the opportunity of a one-on-one discussion with a cancer doctor or cancer nurse. Although 57% of respondents had received survivorship information from their general practitioner (GP), only 40% would list it as their option of choice. The MO...LW program rated relatively consistent as an important source of information for around one third of participants. While 30% had accessed it, 34% expressed a preference for it. The provision of a Survivorship Information pack was identified as being preferred by 47% of participants, rating second highest of all the offered methods of service delivery. Only a quarter of respondents expressed preference for a Survivorship Care Plan, which is promoted in the survivorship literature as an intervention^[14].

Information Needs of Survivors

Cancer survivors were asked to provide some insight into their experience of survivorship, and the informational needs they encountered as they transitioned to wellness following cancer care. These needs are listed in **Table 3**. This cohort of cancer survivors identified that their greatest informational need arose from requiring an understanding of the follow up plan, including doctor's visits and tests required. They reported a need to feel that there is a planned approach to their on-going care, and they wanted to be aware of what that planned on-going care will mean for them. They identified that if they know there is such a plan for follow up, they will feel less 'deserted' on completion of their active treatment phase.

Table 3. Survivors self-identified information needs after completion of active treatment (n=83).

	% (n)		% (n)
Follow Up Plan (including doctors' visits and tests required)	59 (49)	Long term side effects of treatment	53 (44)
Fatigue management	47 (39)	Living with possibility of recurrence	40 (33)
Managing emotions	35 (29)	Diet and exercise guidance	33 (27)
Getting back to 'normal'	28 (23)	Treatment Summary	25 (21)
Role of the GP	24 (20)	Sexuality Issues	15 (12)
Pain	13 (11)	Return to work	13 (11)
Social Support	10 (8)	Fertility Issues	6 (5)
Relationship difficulties-partner	5 (4)	Relationship difficulties- child	4 (3)
Smoking cessation	3 (2)		

DISCUSSION

The purpose of the investigation was to present findings from an assessment of the cancer survivor's experience and in particular, of the MO...LW program. Overall, the majority of patients transitioning to survivorship felt supported by their health care team or indicated they were self-sufficient in their need for support.

Participants in MO...LW were highly satisfied although there were not differences between them and non-attendees. The hypothesis that those participants who attended the MO...LW had significantly improved outcomes in terms of level of survivorship need was unsupported. There are several possible reasons for the insignificance. First, there may be an issue of selection bias. The patients who participated in the MO...LW felt they needed such an intervention and those who did not may have felt they did not need to participate. In addition, because cancer survivors have differing preferences and levels of needs, there was possibly too much variation in their responses. Despite the lack of statistically significant differences in needs between those who attended and those who did not attend the MO...LW program, some notable findings emerged from the CaSUN data. In terms of the self-identified area of most need, analysis revealed that some of the unmet needs that were common across both groups of cancer survivors were information on alternative and complementary therapies, knowing that their doctors were talking to each other, access to a case manager, managing the fear of recurrence and decision-making in the context of uncertainty. Survivors did have preferences for how to receive materials that included: individual sessions with a cancer care professional to learn coping mechanisms; Web based resources; provision of a regular survivorship newsletters or email updates; cancer specific support groups; and survivorship care plans.

In addition, information needs differed by length of survivorship time. Specifically, issues of fatigue and managing emotions are most important in the early phases, while concerns about long term effects, follow up care and recurrence

are more common for those who were more than two years following completion of treatment. Interestingly, when respondents were asked about the timing of an intervention, the most popular choice was two weeks prior to the completion of active treatment, which was selected by 38% of survivors. The majority of participants (91%) identified a preference for receiving survivorship information in the six week window from two weeks prior to the completion of active therapy to one month after that point.

LIMITATIONS

There are several limitations to this study. While a conceptual framework guided the development, consistency in how topics were presented were not considered. Furthermore, there is not an ability to identify confounding factors in the responses provided by the persons living after cancer. Future research will include further developing the MO...LW program so that the model that can be replicated by others. In addition, future research includes testing the efficacy of specific survivorship care interventions and identifying accurate ways to triage cancer survivors to receive the level of service that suits their particular needs.

CONCLUSION AND IMPLICATIONS

Despite the limitations, this investigation provides formative data to develop empirically based guidelines to support care delivery. By more clearly understanding the benefits of a specific survivorship program, more tailored and effective interventions may be planned. This can serve to improve equity of access to survivorship information and support for patients completing cancer treatment in the adjuvant setting. It can also inform the further utilization of health resources in a cost efficient and effective manner. Furthermore, the investigation supports the concept that a supported transition to survivorship from an active treatment component of cancer care impacts positively on the on-going health and well-being of cancer survivors; survivorship care must become part of an integrated and seamless approach to cancer care; and post-treatment survivorship care is an increasing focus for program development and clinical research in both Australia and internationally.

Survivorship care cannot consist of a 'one size fits all' approach. Participants in this investigation wanted access to information in a way that is pertinent and practical, and responsive to their needs and circumstances. Giving patients choices in settings can enable a sense of control and empowerment that is often, by necessity, lacking in the active treatment phase. A range of services should be considered that respects the choice of the majority of survivors to not engage in further scheduled interaction, but supports those survivors that require a higher level of intervention to progress them safely through this phase with a minimum of physical and psychological distress.

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