

Surviving & Thriving: Moving On After Treatment

Final Report 2010

**BUILDING CANCER SUPPORT NETWORKS GRANTS
PROGRAM
CANCER AUSTRALIA**



**This report was prepared by:
The Cancer Council Queensland
For
Cancer Australia**

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1. EXECUTIVE SUMMARY

Psychosocial, emotional, cognitive, physical, spiritual and practical impacts of cancer and its treatment can continue to affect a survivor's quality of life and wellbeing for months or even years following treatment. The transition from cancer patient to cancer survivor is a difficult time of adjustment, and the unique challenges that mark this period have drawn greater interest in cancer care and related research. While early detection, improved treatments and the ageing population has resulted in increasing numbers of cancer survivors, the support services available to post-treatment survivors has not necessarily paralleled this growth.

The Cancer Council Queensland (CCQ) is a community-based organisation dedicated to serving the community in cancer control. The *Surviving & Thriving: Moving On After Treatment* project was conducted to help address the gap in support services available to cancer survivors who have completed treatment in Queensland. The project was undertaken over two stages, including an investigative phase and pilot study. The aim of the investigative phase was to identify and examine unmet needs and challenges faced by cancer survivors upon completion of treatment, and their preferred options for the delivery of information and support. Outcomes were used to inform the development of the pilot program.

The pilot program consisted of six, weekly psychoeducational sessions delivered through a peer support group format to cancer survivors who had completed active treatment within the previous 18 months. Content covered throughout the program included common survivor concerns; social roles and relationships; psychosocial responses to cancer and useful coping strategies; stress and stress management strategies; dealing with physical changes after treatment; and making healthy lifestyle choices. An adjunct session was also delivered for the carers, partners or family of cancer survivors to facilitate sharing in a supportive environment and to introduce skills for dealing with the difficulties of caring for a cancer survivor.

The program was piloted through an exploratory study and the overall aim of the evaluation was to determine the appropriateness and impact of an education and peer support program designed to assist cancer survivors in their transition from cancer treatment to emotional and physical recovery. Data was collected to determine the feasibility of program content, format and delivery; and to gain consumer feedback in identifying what worked well, and areas in

need of improvement. This feedback informed the revision of the final program to ensure it is feasible, appropriate and sustainable for all post-treatment cancer survivors.

Findings

Overall, the findings suggest that the program was beneficial in facilitating peer support and allowing participants to share their experiences in a supportive environment; increasing knowledge and confidence in dealing with cancer challenges; providing practical tips and strategies for coping and stress management; and providing some education on nutrition and physical activity after cancer treatment. However, qualitative feedback showed that the program was not helpful in reducing feelings of uncertainty. Components of the program that required improvement as identified through the evaluation, included session timing, guest presenter choice, group diversity, and more information on nutrition and physical activity.

From the evaluation, several recommendations were made for the revision of the program including dedicating whole entire sessions to key content, including physical activity/rehabilitation, coping and stress management, nutrition; removing the homework activities, including journaling; removing the wellness plan and substituting this with practical activities, such as goal-setting and problem-solving throughout the program; delivering education and practical activities for communicating with health professionals and establishing follow-up care; revising program content to be applicable to both cancer survivors and their carers; and offering flexible delivery of the program.

The *Surviving & Thriving: Moving On After Treatment* project demonstrated that cancer survivors who have completed treatment, and their carers, experience ongoing concerns and identified a number of unmet needs in this population. It also demonstrated that the opportunity to access an education and support program provided cancer survivors with a helpful step to move forward to physical and emotional recovery. The findings of this project informed the development of a support and education program entitled “*Moving Forward*” which can be adopted through a variety of settings, including community organisations, cancer care centres, and other health care providers across Queensland.

2. BACKGROUND

Whilst cancer research and clinical trials strive to find the most effective cancer treatments with minimal toxicity, interdisciplinary care and management is now also recognised as an important component of treatment. Early detection and improved treatments, coupled with an ageing population have resulted in increasing numbers of cancer survivors worldwide^[1]. The complexities and challenges of survivorship, including psychosocial, emotional, cognitive, physical, spiritual and economic issues faced by survivors, have drawn greater attention in cancer care and related research^[2, 3]. As such, the provision of well-targeted supportive care for cancer survivors who have completed cancer treatment and their families is a high priority. Cancer survivorship research has emerged as a specialist area with studies being conducted to identify the physical^[4-6], psychosocial^[7, 8] and practical issues^[6, 9] faced by survivors of various cancer types following treatment and beyond. Attention has been given to late effects of treatment, psychosocial impacts of cancer, and to evaluating the benefits of psychological and behavioural interventions, and supportive care programs designed to have a positive impact on quality of life and survival^[10].

The most commonly cited and accepted definition of a cancer survivor comes from the National Coalition for Cancer Survivorship (NCCS), which states that anyone who has been diagnosed with cancer is considered a survivor from time of diagnosis, through to end of life^[11]. In Australia, and for the purpose of this review, the term ‘cancer survivor’ refers to people who have completed initial cancer treatments and are considered cancer-free^[12].

Psychological, social, and spiritual impacts continue to affect a cancer survivor’s quality of life and well-being for months and even years following treatment^[13]. Little work has been done in the ‘post-treatment’ transitional phase of cancer survivorship; however, qualitative research with survivors suggests this period remains a difficult time of adjustment and that survivors express the need for greater levels of support, information and follow-up after treatment^[14, 15].

In addition to coping with lingering treatment related effects, uncertainty about the future and fears of recurrence, for many survivors this period is made worse by a decline in available support. Upon completion of treatment, survivors often feel overwhelmed or anxious^[15] and even “abandoned” through reduced contact and engagement with their health care team^[1].

For many, support from family and friends also declines, as those around them assume with the completion of treatment, they are “back to normal”. Many describe difficulties as they search for meaning related to what they have been through, and try and resume previous roles and responsibilities. Furthermore they may face a variety of practical issues in relation to finances, work and insurance, and struggle to find information about how to stay healthy and prevent recurrence^[16].

A number of approaches to group intervention can benefit cancer survivors, and since psychosocial needs remain high after treatment, a variety of psychosocial support options may provide critical assistance to survivors at a time when other supports (i.e medical and social support) typically decline^[1]

One increasingly popular model of supportive care utilised in cancer care and community support settings is psychoeducation. Psychoeducational interventions are structured, time-limited and involve delivery of health education, enhancement of problem-solving and coping skills, stress management techniques and psychological support.

Evidence shows that psychoeducational interventions are the most beneficial for cancer survivors as they provide both informational and psychological support. A comprehensive meta-analysis of 56 interventions in breast cancer survivors, compared the effect of four methods: psychoeducational, cognitive-behavioural therapy, supportive and relaxation^[17]. Results showed that psychoeducational interventions had the most positive effect on survivors.

There is a growing body of evidence regarding the effectiveness and benefits of lifestyle interventions for cancer survivors which focus on healthy lifestyle recommendations during treatment and beyond. Speck et al. conducted a comprehensive meta-analysis of physical activity interventions both during and after active treatment and found that physical activity interventions have a large effect on upper and lower body strength and a moderate effect on fatigue in post-treatment cancer survivors^[18].

Anderson et al. (2009) developed and piloted a lifestyle intervention that aimed to improve diet, physical activity and weight management in post-treatment colorectal cancer survivors^[19]. Participants showed a significant increase in quality of life and moderate-

intensity physical activity, a decrease in saturated fat intake and waist circumference and a non-significant weight loss (-1.2kg). One limitation of this study was that there was no control condition. What can be concluded, however, is that this sort of intervention is feasible in promoting healthy lifestyle behaviours with cancer survivors and that more randomised-controlled trials are needed.

Interventions can be delivered individually or in a group format. Substantial evidence exists regarding the benefits of peer support in a number of settings including peer based telephone support, peer support groups, and peer led education sessions. Herron (2005) defines peer support as the emotional, social and practical support provided to people affected by cancer and is based on the premise that shared experience is a valuable coping resource^[20]. Ussher et al. (2006) found that the majority of people affected by cancer who attend support groups have an improved sense of empowerment and psychological wellbeing and benefitted from the opportunity and freedom support groups provide to discuss issues considered taboo or a burden on family; a decreased sense of isolation; and increased confidence in communicating with health professionals^[21].

A review of the effectiveness of peer based cancer support groups revealed consistent positive benefits; however authors noted that methodological issues make it difficult to draw clear conclusions^[22]. Helgeson (2003) reviewed the support group intervention literature and concluded that there is little evidence for the effectiveness of peer group interventions alone^[23]. It can be recognised that psychoeducational interventions delivered in a group format will, as a consequence, include an aspect of peer support^[20].

In light of this evidence, the Cancer Council Queensland developed the *Surviving & Thriving: Moving On After Treatment* program which included:

- A psychoeducational focus; including the delivery of information around post-treatment issues, coping strategies, stress management and relaxation, communicating with health professionals and utilising available resources.
- A lifestyle intervention component. Promotion of healthy lifestyle recommendations and the delivery of education in regards to physical activity, healthy eating, a healthy weight, tobacco cessation, alcohol intake and sun protection practices.
- A peer support setting to facilitate normalisation of issues and a shared understanding.

3. AIMS AND OBJECTIVES

The aim of the project was to develop an appropriate and targeted supportive care program to assist cancer survivors in the transition from treatment to emotional and physical recovery; addressing the gap in post-treatment support services in Queensland. The objectives of the *Surviving & Thriving: Moving On After Treatment* project included:

1. Identify a range of initiatives that are effective in assisting cancer survivors to cope with the transition from completion of treatment to emotional and physical recovery after cancer;
2. Provide relatives/and or partners with support through the delivery of a session or sessions on survivorship and relationship issues to assist them to gain greater understanding of survivorship issues and to strengthen the support for relatives;
3. Ensure consumer input at all stages of project development and evaluation;
4. Ensure stakeholder involvement in the development of project initiatives to reduce duplication of services;
5. Identify the need for and establish ongoing networks of support for cancer survivors.

To address these objectives and achieve the overall aim, the project was undertaken over two separate stages, the investigative phase and pilot study.

4. INVESTIGATIVE PHASE

Three activities were undertaken to inform the development of the *Surviving & Thriving: Moving On After Treatment* program. A comprehensive review of the scientific literature was undertaken to identify the issues related to post-treatment survivorship and the types of interventions which assist survivors during this period. A scoping exercise was also undertaken to identify current services and resources available locally, nationally and internationally specifically for cancer survivors who have completed treatment. Finally, qualitative research was conducted through focus groups with Queensland cancer survivors, and carers, partners or family members to explore common survivorship issues and preferences for the delivery of information and support.

In addition to these activities, one of the key aims of the Cancer Council Queensland was the involvement of stakeholders during all phases of the project to continually provide feedback on the materials and program and also reduce duplication of services. A reference group of fourteen key stakeholders including consumers and carers, medical oncologists, allied health professionals, oncology nurses (paediatric and blood related cancers) and representatives from the Cancer Council Queensland's Community Services department, Cancer Counselling Service and Viertel Centre for Research in Cancer Control was established. Terms of reference were established and ratified and regular communication between the project team and stakeholders was undertaken. Ongoing collaboration continued with key stakeholders (i.e. health professionals, internal and external partners) to seek input into program content, format, evaluation and revision.

4.1 LITERATURE REVIEW

A comprehensive review of the literature was undertaken with the aim of answering the following questions:

- What are the unmet supportive care needs of cancer survivors who are at least one year post-diagnosis and who do not have advanced disease?
- What types of interventions improve adjustment outcomes in cancer survivors who are at least one year post diagnosis and who do not have advanced disease?

Databases searched included Sciencedirect, Cochrane, Wiley, WebMD, Springer, Trip data base (Evidence based Medicine), Access Medicine, and NCBI PubMed) using a range of terms (cancer; survivorship; post-treatment; quality of life; unmet supportive care needs;

programs; interventions). The search was limited to systematic reviews, Cochrane reviews, or randomised controlled trials. The literature review (provided to Cancer Australia separately) was used to inform the focus group topic guides and development of the pilot program.

Results from this literature review showed that little research has been done into the unmet supportive care needs of cancer survivors who have completed treatment. Furthermore, it is difficult to isolate studies that focus specifically on the 'post-treatment' phase of cancer survivorship. Comparing the benefits of different types of interventions has been hindered by the lack of agreed definitions on these different types.

Despite these limitations, the review identified that cancer survivors experience ongoing physical, psychosocial and practical needs following treatment and beyond. It showed that psychoeducation interventions are the most beneficial for cancer survivors as they provide both informational and psychological support. Additionally, peer support groups are beneficial in improving psychological wellbeing based on the premise that shared experience is a valuable coping tool. Delivering psychoeducational interventions through a group format will be more effective as there is the added benefit of peer support.

4.2 SCOPING EXERCISE

Scoping of existing interventions or services and resources that address the needs of cancer survivors was undertaken to identify the range and types of support services available. Key findings revealed that resources and services offered to cancer survivors varied from survivorship fact sheets to telephone or face to face support groups to short workshops. There were internet-based information and support groups, however the majority of these resources were internationally based.

In relation to post-treatment services in Queensland, several findings were drawn from the scoping exercise which concluded that:

- 1) There are currently no psychoeducational group support programs available in Queensland, for cancer survivors or carers, partners or family members;
- 2) Limited regional services are available, with one single-day, post-treatment education program offered through a regional hospital;

- 3) There are no Queensland internet-based support groups or online options specific to post-treatment survivorship; and
- 4) The Cancer Council Queensland's website lacks services/resources for people completing active treatment.

4.3 FOCUS GROUPS

Focus groups with cancer survivors were conducted to identify needs and difficulties faced by cancer survivors and preferred sources of information and psychosocial support to ensure consumer input into the development of an appropriate program. Five focus groups were conducted with 56 participants including survivors, carers, partners and family and health professionals. The focus groups were held at the CCQ Brisbane office and run by a facilitator and note-taker.

Just over half the sample (55%) identified as a 'cancer survivor'; 38% identified as a 'support person' and 7% identified as both. Participants reported a range of cancer types including prostate, breast, colorectal, melanoma, brain tumour, throat and head and neck cancer. Over 60% reported they had been diagnosed within the past five years. One of the five focus groups was comprised of only partners of men with prostate cancer, however all other groups included a mix of both survivors and carers. The carer specific group was included to gain insight into the needs of this population and to inform the adjunct information session.

Participants were asked to rate how supported they felt after treatment on a 7 point likert scale, with 1 being "Completely isolated" to 7 being "I had lots of support available". Similarly, they were asked to rate the psychosocial support they had available to them at this time from 1 "not at all helpful" to 7 "very helpful". Of those responding (71%), two-thirds (67.5%) rated their support as ≤ 4 , with a 27.5% saying they felt "completely isolated" (mean score 3.5). In relation to the helpfulness of this support, the majority (61%) rated helpfulness as ≤ 4 , and a quarter (26.8%) reported that it was not at all helpful (mean score 3.8).

The focus group topic guide included the following five questions:

1. Think about your experience as a cancer survivor or support person in the early days following completion of treatment. What were the things most difficult for you?
2. What things make it even harder to deal with these difficulties?

3. What things have you found helpful in dealing with these difficulties?
4. What would you have liked to receive more support with?
5. CCQ with support from Cancer Australia is aiming to provide support to cancer survivors in the early stages following completion of treatment. In what format would you like to receive this support/ information?

Focus group findings highlighted that participants (both survivor and carers) with mixed cancer types felt that they had limited psychosocial support available to them at the completion of cancer treatment. An extensive range of difficulties were experienced by participants after completing treatment, which were summarised using thematic analysis into key themes and included:

- Anxiety (fear of recurrence, feelings of uncertainty)
- Expectations of others to return to 'normal'
- Communicating with significant others
- Feelings of isolation
- Coping with changes to self-identity and adapting to a new 'normal'
- Sexuality (low body confidence, sexual dysfunction, impact on relationships)
- Feelings of guilt about the impact on significant others
- Physical functioning (ability to do everyday tasks and roles, changes to body)
- Fatigue
- Lack of information (late and long-term effects of treatment, what to expect, lifestyle changes)
- Communicating with health professionals

In addition to these issues, the partner focus group identified specific difficulties in coping with both their own and their partner's emotions; sadness over loss in previous aspects of the relationship (including sexual); adjusting to the role of carer and feelings of guilt for not being able to understand.

In relation to what was helpful in dealing with difficulties, participants reported a variety of sources and approaches including:

- Keeping busy (learning new skills, participating in activities, planning holidays)
- Peer support (sharing and talking to others in similar situation, normalisation of feelings)

- Information seeking (reading, internet, researching)
- Skills development (goal-setting, planning, coping)
- Family and friends
- Healthcare team
- Relaxation
- Positive attitude
- Time

Unmet informational needs became very apparent through discussion of what participants would have liked more support with when completing their cancer treatment. Information was the most prominent theme, particularly information around available support services; what to expect upon completion of treatment; prevention; nutrition and exercise during recovery; potential side, late or long term effects; and dealing with physical changes. In addition to this, participants reported that they would have liked more practical support and peer support.

Participants suggested a variety of formats for the delivery of information and support. Print (brochures, booklets) and media resources (DVD) were the most commonly suggested format when finishing treatment. Other suggestions included both one-on-one and group support sessions, online support groups and information, and suburban, regional and remote options.

As CCQ has existing one-to-one support services such as CancerConnect and the Helpline, the group format was adopted for the pilot program. The Cancer Council New South Wales has an established online support network, which has a forum specific to cancer survivors who have completed treatment (<http://cancerconnections.com.au/survivors>). Therefore, to avoid duplication of services, participants are made aware of this service throughout the program. In addition, the resources unique to this program have been made available online through the CCQ website (http://www.cancerqld.org.au/page/information_resources/resources_and_brochures/Moving_forward_resources/). To improve the reach of the program to regional and remote survivors, a comprehensive facilitator manual was developed to guide other organisations in Queensland through the delivery of the program.

The following limitations should be considered when interpreting the focus group data. The majority of the sample were older (79% were aged over 50), and were not in the paid workforce (63%) therefore may not represent the needs of younger or employed cancer survivors. However, as cancer is significantly more common in those over the age of 50 years (about 80% of cancer patients are 50+ years), the sample is representative of the cancer population. Participants were sourced through established peer support groups and other CCQ networks therefore would already be aware of or have existing links to available support services. In addition, due to time restrictions, Indigenous survivors, young adults and regional (rural and remote) survivors were not sampled therefore data cannot be generalisable to these groups.

Furthermore, during the focus group sessions it was difficult to keep participants focussed on post-treatment needs and challenges. Many wanted to discuss unmet needs and difficulties that occurred during treatment including barriers to communicating with their treating health professionals. It is proposed that the opportunity for participants to discuss these issues and ‘debrief’ around their treatment experience may assist in emotional recovery post treatment and therefore should be included in the program. Despite these limitations, consistent themes emerged from the data ensuring theoretical saturation was achieved.

5. PILOT STUDY

5.1 AIM & OBJECTIVES

The aim of the project was to determine the feasibility and appropriateness of an education and support program for cancer survivors who have completed treatment.

Prior to commencement, program objectives were set which included:

1. Provide participants with an opportunity to gain understanding of common issues affecting survivors of cancer and to normalise their experience in a supportive group environment.
2. Provide participants with the opportunity to gain support through sharing and learning from each other in a supportive and collaborative environment.
3. Provide participants with an opportunity to gain skills in coping with the social and emotional issues affecting their lives.
4. Provide participants with an opportunity to gain knowledge about lifestyle behaviours to enhance wellbeing and reduce the risk of further cancer.
5. Provide participants with the opportunity to develop a wellness plan outlining future goals to assist in their emotional and physical recovery.
6. Provide participants with an understanding of resources available in the community to assist in meeting their support and information needs.
7. Provide relatives and/or partners of cancer survivors with support through the delivery of a session or sessions on survivorship and relationship issues to assist them to gain greater understanding of survivorship issues and to strengthen the support for relatives.

5.2 PROGRAM OVERVIEW

The *Surviving & Thriving: Moving On After Treatment* program was developed to provide support and education to cancer survivors in the transition period from treatment to physical

and emotional recovery after treatment. The Cancer Council Queensland's Brisbane office was chosen as the venue as it is easily accessible by public transport, it has disability access, and parking is available. The program was scheduled after business hours to enable survivors who work to attend.

Participants were recruited through existing CCQ Networks (CCQ's consumer newsletter "Perspectives"; local support groups; allied health contacts; radiation departments and medical oncologists); Cancer Helpline and Counselling Service referrals; and through media (flyers and posters). The project reference group were also asked to promote the program through their networks.

Eligibility criteria included: completed potentially curative treatment in the previous 18 months; treatment for any cancer incidence (primary, secondary or recurrence); ability to participate in a six week program; have no co-morbid conditions or significant concurrent emotional or physical stresses. Prior to inclusion into the study potential participants were interviewed and screened for eligibility and distress. CCQ has existing protocols for dealing with highly distressed people and the facilitator was trained in these protocols. Participants who expressed distress were referred to the Helpline, and, if required, the Cancer Counselling Service.

The program format consisted of six, weekly sessions, running for approximately 2 ½ hours duration. These sessions were delivered in a peer group setting to afford participants the opportunity to meet others with similar experiences. In doing so it aimed to foster a confidential, supportive environment in which to address the primary objectives of the program- to provide support and education in the transition period following cancer treatment. Given the sensitive nature of discussion topics and the stressful time of adjustment, a non-intimidating approach was adopted to provide an environment conducive to learning new information and skills.

In brief, the program consisted of

- Six sessions addressing key topics delivered via a suitable resource or speaker; group discussion and sharing; and practical application of content via skills training and group activities.

- Coping tools and strategies practiced during and between sessions (e.g. challenging unhelpful thinking, asking for support, communicating with loved ones, etc)
- Reflection exercises, including journaling.
- Stress management strategies modelled via the practice of a relaxation exercise at the end of each session (e.g. imagery, progressive muscle relaxation, mindfulness meditation).
- Current evidence regarding prevention and early detection; and healthy lifestyle behaviours for cancer survivors.
- A participant manual to work through which included an outline and activities for each session, reflection exercises, a “wellness plan” template and plastic sleeves to store resources made available throughout the program.

Program content was informed through a review of current evidence and the findings of the focus groups run by CCQ. The theoretical framework for the program was a model of well-being therefore content covered all four components (social, physical, emotional and spiritual wellbeing) and included common survivor concerns; social roles and relationships; psychosocial responses to cancer; coping and coping strategies; stress and stress management strategies; dealing with physical changes after treatment; and making healthy lifestyle choices. Each session was led by the facilitator who introduced guest speakers, facilitated group discussion and activities, and set homework exercises.

Guest speakers, who were health professionals and experts in their field, were sought to deliver key content during sessions 2 - 6. These sessions also included practical application of material through skill training and group activities, written exercises exploring issues discussed, and a brief reflection on the session material through a structured exercise. At the beginning of each session, participants were provided with handouts including session outlines, a copy of PowerPoint presentations and homework activities.

Survivors were also given the opportunity to develop their own wellness plan to enhance physical and emotional recovery upon completion of the program. The written activities and material from each session were drawn upon for the final session, leading to the wellness plan, which provided a summary of key concepts covered and allowed consolidation of their own needs and concerns based on the a model of wellbeing. In addition, participants were

encouraged to complete a treatment summary and follow-up plan with the assistance of their treating doctor.

Carers Session

An adjunct session was held that aimed to provide carers and family members with an opportunity to share experiences and support around coping with difficulties faced when caring for a cancer survivor. The session had a psychoeducational focus and addressed topics drawn from focus group discussions, a review of the current evidence and key stakeholders.

5.3 EVALUATION METHODOLOGY

The purpose of the evaluation was to assess the feasibility and appropriateness of the *Surviving & Thriving: Moving On After Treatment* program, to ensure that a beneficial program was developed to address the gap in support services available to survivors who have completed active cancer treatment. The evaluation tools were developed by a CCQ Project Officer using both quantitative and qualitative research methods. Data and feedback were collected at baseline (pre-program), 6 weeks follow up (post-program) and at 4 months follow up to assess longer term impact.

Outcome measures included knowledge of survivorship issues, personal survivorship concerns, social support, confidence in coping, awareness of support services, and motivation to improve health and wellbeing. To determine the impact of the program, basic analysis was performed using cross-tabulations and paired t-tests to assess change between the two time points.

To gain feedback on individual sessions, including the adjunct carer session, data was collected via a self-administered questionnaire at the end of each session. Participants were asked to rate various aspects of the session including helpfulness, usefulness, relevance, content and overall satisfaction on a 5-point likert scale. Open ended questions were also included in this questionnaire to collect qualitative feedback and suggestions for improvement. Data was analysed using simple evaluation methods: frequencies, means and percentages where appropriate. Qualitative data was analysed using thematic analysis and cross-examined by two investigators.

At 4 months follow-up, a self-administered questionnaire was posted to participants to collect data on post-program use of program resources, and satisfaction with speakers, content and structure. In addition, a focus group with the pilot program participants was conducted to assess longer term effects. The topic guide included the following points for discussion:

- In what ways has the program helped you address your concerns/issues?
- In what ways has the program NOT helped you address your concerns/issues?
- What parts of the program did you like?
- What parts of the program did you dislike?
- Is there any information what was not presented that should have been?

The focus group was held at the Cancer Council Queensland and run by a facilitator and note-taker, and data was analysed using thematic analysis and cross-examined by two separate investigators.

5.4 RESULTS

Pre -program

The pre- and post-program questionnaires were completed by 17 participants. The majority were female (82%), aged between 40 and 59 (82%) and married (71%). Three quarters (71%) lived with their family or partner with the majority (94%) living in the Brisbane metropolitan area. Just over half (59%) were in the paid workforce, and one quarter (24%) had retired. Some 71% had been diagnosed with breast cancer with remaining cancer types including squamous cell carcinomas, prostate and colorectal.

As the program was developed with a psychoeducational focus, current knowledge about issues was assessed. Participants were asked to rate how informed they were about common survivorship issues (social, psychological/emotional, physical, spiritual) as well as their knowledge of nutrition and physical activity recommendations on a scale of 1 'Not at all informed' to 10 'Well informed'. The mean rating for knowledge of social issues was 6.2; for psychological/emotional issues was 6.1; for physical issues was 5.8; and for spiritual issues was 5.5. The mean score for knowledge of nutrition and physical activity recommendations was 6.5. Based on this scale, these scores indicate that participants were "somewhat" informed about these issues.

Prior to commencement of the program, participants were asked to report what they hope to gain through participation. The most commonly identified theme was peer support/validation of feelings.

“Through my participation I’m hoping to gain more knowledge and feel that I’m having the same fears and emotions of other fellow survivors”

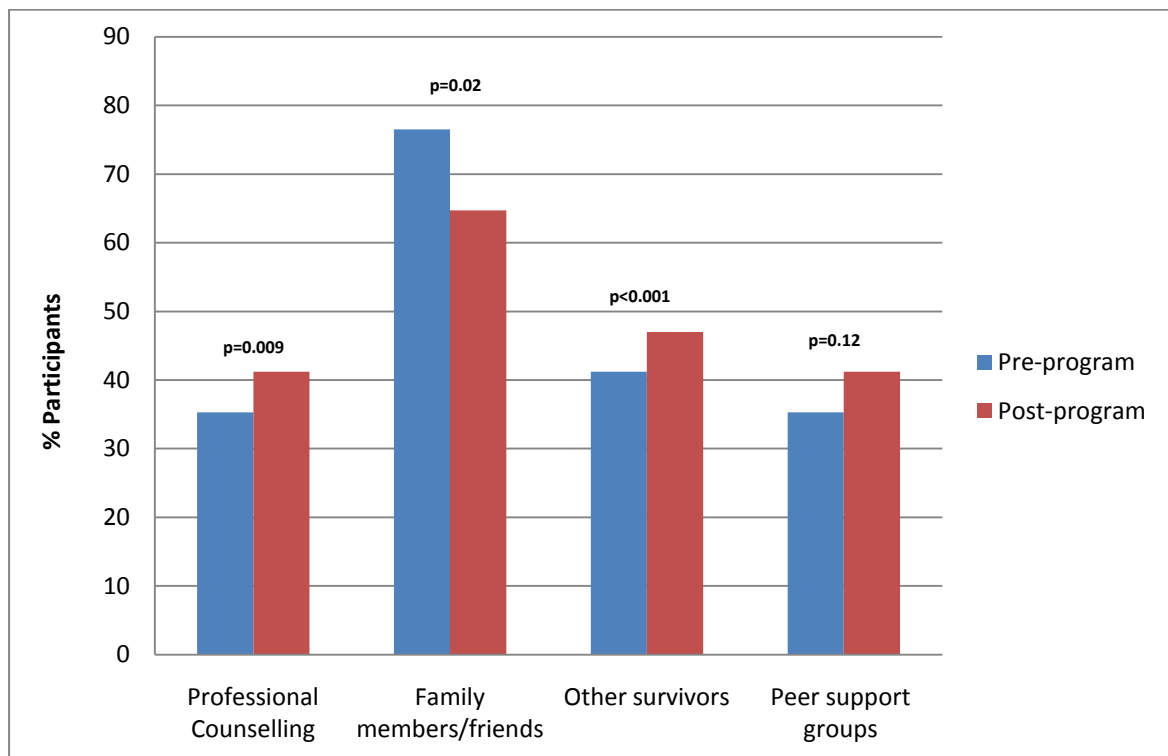
Other themes identified were knowledge; confidence; awareness of supports, and a longer life. This qualitative data can be used as a benchmark to determine the impact of the program on meeting the expectations of this sample.

Post-program

Program effectiveness was based on responses from 17 participants who completed both the pre and post-program questionnaires. As detailed above, participants were asked to rate their level of knowledge about common survivorship issues (social, psychological and emotional, physical, spiritual, nutrition and physical activity recommendations). Post-program, results showed that there was a significant ($p < 0.001$) improvement in knowledge for all issues listed.

Participants were also asked to report their use of support services. Post-program there was a significant increase in obtaining support from professional counselling supports (psychologist, psychiatrists, etc) and other survivors, as indicated in Graph 1: Sources of Support (below). There was also a non-significant increase in use of peer support groups and a significant decrease in use of family members or friends and which was surprising as the program was developed using a group format and delivered in a peer support setting.

Graph 1: Sources of Support



Upon completion of the program, participants reported a statistically significant ($p=0.008$) increase in the level of support they receive for dealing with survivorship issues. They also had significantly increased their awareness of support services and resources available to them in the community ($p<0.001$); and were significantly more confident that they could access these services and resources ($p<0.001$). In addition to this, there was a trend towards greater confidence in ability to cope with challenges throughout life ($p=0.06$), as well as a trend towards motivation to make changes to improve overall health and wellbeing ($p=0.08$).

Not all participants commented in the open-ended questions of the post-program questionnaire, however, qualitative responses were analysed. Participants were asked to report what they had gained through participation in the Surviving & Thriving program. The main themes included:

- Peer support/validation of feelings

Participants appreciated the opportunity to share and empathise with other cancer survivors, and hear that what they were experiencing was common.

- *“Networking with fellow survivors was wonderful – no boundaries”*

- *“It has given me an insight that those feelings that I am experiencing are normal, okay and to not fight with them”.*
- Knowledge and confidence
 - *“I have been given tools to gain some control back of my own wellbeing”.*
- Motivation
 - *“A commitment to continue in recovery and enjoy this life”*

When referring back to the pre-program question in which participants stated what they hoped to achieve, synonymous themes were identified post-program which included peer support/validation of feelings, knowledge and confidence. This suggests that the program was beneficial in addressing some unmet needs faced by this particular sample of cancer survivors.

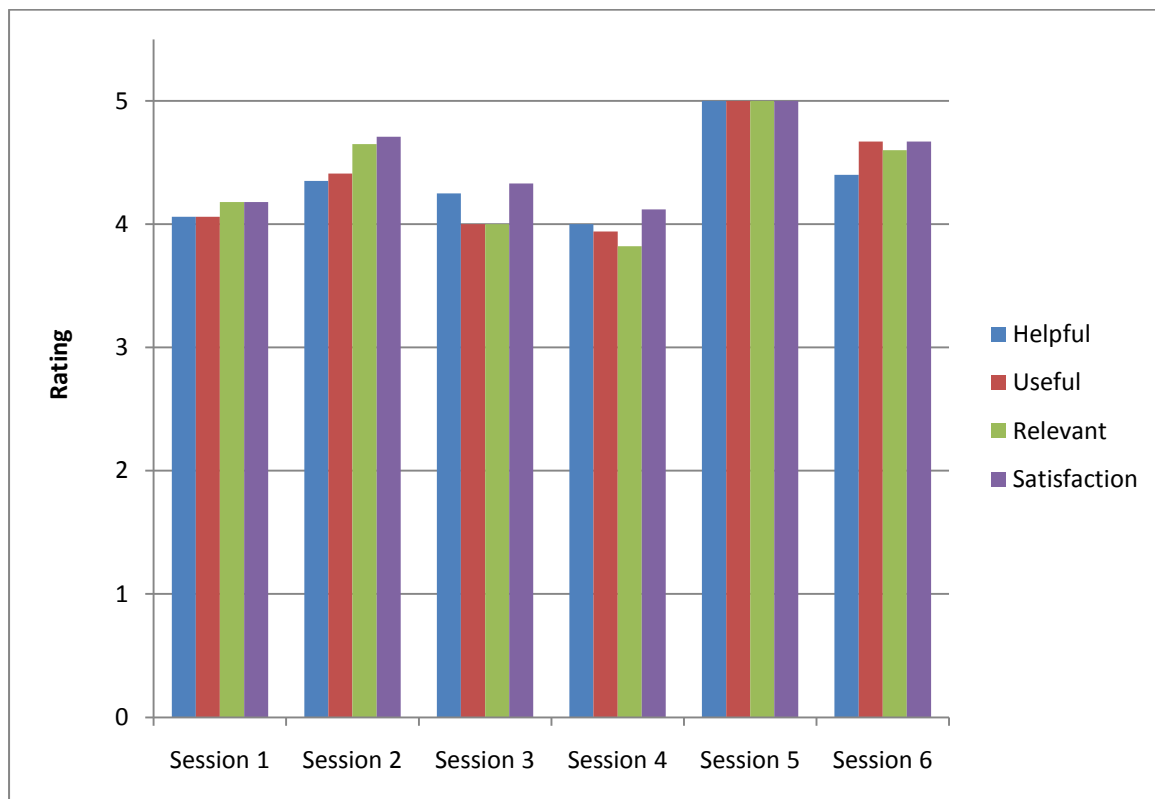
When asked to provide suggestions for improvement, two common themes were identified which included longer/split sessions and group diversity.

- *“Time is a crucial factor... maybe next time 2 sessions dedicated to emotional implications. This may be the only forum we get to ask questions in a safe environment – oncologists only know their area and pass on a lot of stuff ‘not my area’ next!”*
- *“I found the breast cancer coalition skewed some of the sessions – perhaps a smaller component next time”.*

Session Evaluations:

Participants were asked to rate the helpfulness, usefulness, relevance and satisfaction of each session on a 5 point likert scale with 5 being “very” helpful/relevant/useful/satisfied and 1 being “not at all”. Overall session evaluations showed that participants rated all sessions highly and reported that they were all helpful, useful, relevant and satisfactory (mean scores > 3.8), as seen in the graph below.

Graph 2: Session Ratings



The most highly accepted and helpful session focused on staying healthy after treatment, nutrition and physical activity (Session 5). All participants gave this session a top rating of 5 for each of the abovementioned areas. Suggestions for improvements included allowing more time for each presentation or dividing the session into two separate sessions; *“I think that the nutrition program as well as the exercise program should have been separate sessions, it was so informative”*.

The session ranked lowest was delivered by a paediatric oncologist who focused on the late and long term effects of cancer and its treatment (Session 4). While participants rated the session as ‘4=helpful’, qualitative responses suggested that this session be revised to include more relevant information and presentations, or removed from the program. Choice of guest presenter may have limited acceptance to this session:

“An oncologist who works with adults would have been most helpful. More info on specific treatments for adult cancer would have been best”.

This feedback was vital in reinforcing the need to ensure facilitators recruit appropriate guest presenters to deliver key content.

Focus Group Findings:

Six participants took part in the final evaluation focus group. Participants were asked to discuss how the program has helped them address their post-treatment concerns/issues.

Themes that emerged from this discussion included:

- Provided information and education
- Practical strategies and tips to cope with feelings
- The opportunity to review and reflect on cancer experience
- Impacts on future decision making
- Opportunity to meet like minded people and to share experiences
- Guest speakers/facilitator
- Learning about mindfulness and managing thoughts
- Very helpful resources
- Face to face contact was important
- Acceptance of feelings and opportunity to mourn their experience
- Facilitated the transition from patient to survivor, dealing more effectively to move forward

When asked to discuss how the program was not helpful in addressing participants concerns, the three main themes identified were that it did not reduce feelings of uncertainty or increase confidence in communicating with their health care team and that more time and information was needed on nutrition and physical activity.

The themes that were identified in relation to what participants liked about the program included the resources, the safe environment for sharing experiences, the nutritionist's presentation, the exercise physiologist's presentation and the psychologist's presentation on addressing intrusive thoughts and managing thinking. Disliked components of the program included the homework activities, and the presentation from the paediatric oncologist on late and long term side effects. Suggestions for improvements included only having one presentation per session, allowing more time for the session on stress management and coping or dividing this session into two, and more practice to understand the concept of mindfulness.

Final postal questionnaire:

The final postal questionnaire was returned by 11 of the 17 participants (65%). All respondents reported that they used the participant manual throughout the program, with 73% having used it since completion of the program.

When evaluating the facilitator, participants were asked to indicate the extent to which they agreed with statements from 1 'No, definitely', to 4 'Yes, definitely'. All but one, (91%) of the participants definitely agreed that the information and support provided by the facilitator met their needs. Also, 82% reported that the facilitator was definitely easy to talk to and that they definitely felt comfortable sharing personal information with the group.

When asked about homework activities, 91% of participants reported that they completed these on a weekly basis, however, just under half (45%) did not keep a journal and interestingly half (55%) did not establish a wellness plan. In relation to the duration of the sessions, 82% reported that the length was appropriate with 73% reporting that there was sufficient time to ask questions; however 45% reported that the program was not on at an appropriate time (evening).

Carer Session

A total of 8 participants attended the adjunct carer session. Participants were asked to rate several elements of the session on a 5 point likert scale with 5 being "very" helpful/relevant/useful/satisfied and 1 being "not at all". Overall, all participants reported that they were satisfied or very satisfied with the session (mean= 4.5). They found the session helpful and useful (4.3) and the content was reported as very relevant (4.6). However, when asked whether given the opportunity to attend a support group specific to carers, less than half (43%) reported that they would. When asked to make suggestions for improvement, 38% commented that there was a lot of content to cover in one session and that perhaps more sessions would be helpful.

5.5 DISCUSSION

The findings suggest that overall the program was beneficial in facilitating peer support and allowing participants to share their experiences in a supportive environment; increasing knowledge and confidence in dealing with cancer challenges; providing practical tips and

strategies for coping and stress management; and providing education on nutrition and physical activity after cancer treatment.

As this pilot program was exploratory, the primary aim was to gain consumer feedback to assess the impact and appropriateness of the program for cancer survivors who have completed cancer treatment, to ensure the development of an appropriate and feasible support service. For evaluation purposes, the data collected will be used to reflect on achievement of program objectives.

Objectives 1 and 2 centred on providing the opportunity to gain understanding of issues, normalising their feelings and gaining support through a group environment. The most prominent theme that participants identified as helpful to their recovery in the qualitative feedback was the opportunity to talk, share and learn from fellow survivors, which was facilitated through the group format of the program. Participants also reported a significant increase in knowledge of the common social, psychological, physical, behavioural and spiritual issues post-program. Furthermore, they were very appreciative of the opportunity to normalise these issues and feelings through discussion with their peers.

Objective 3 referred to providing participants with the opportunity to gain coping skills. Results showed a non-significant trend towards greater confidence in ability to cope with cancer challenges. In addition, the appreciation of discussing coping was a common theme delivered through qualitative feedback.

Objective 4 involved providing participants with the opportunity to gain knowledge about lifestyle behaviours. Participants were significantly more informed about nutrition and physical activity recommendations; however, other lifestyle behaviours (alcohol, healthy body weight, smoking and sun protection) were not addressed through this questionnaire making the strength of this evaluation somewhat limited.

Objective 5 involved providing participants with the opportunity to establish a wellness plan. While the facilitator did provide the opportunity, results from the final postal questionnaire showed that participants did not widely adopt this or complete it.

Objective 6 referred to participants understanding of resources and services available in the community. Results showed that participants were significantly more informed of both the resources and services available in the community to assist them with support and information. Furthermore, they were significantly more confident in their ability to access these. Qualitative feedback reinforced these findings.

Objective 7 related to providing relatives, partners or carers with support to assist them in gaining understanding of survivorship issues and to strengthen their support. All participants found the content relevant to them personally and reported that they were satisfied with the session. However, this session was not well attended and interestingly, less than half reported that they would attend a support group specific to carers.

Overall, content covered was appropriate and beneficial in helping survivors adjust in the transition from treatment to emotional and physical recovery; however more practical information on leading a healthy lifestyle and physical rehabilitation was suggested to increase the impact of the program. The homework, which included reflection activities, journaling and developing a wellness plan, treatment summary and follow-up care plan were not widely adopted which should be considered in any revisions to the program.

Although participants reported a significant increase in the utilisation of medical and other support services, the program was not overly successful in reducing the feelings of uncertainty following treatment, therefore clear and comprehensive information on communicating with health professionals and establishing appropriate follow up care is needed. Providing tips on effectively communicating with health professionals should be presented to assist survivors in getting the most out of their consultation. Additionally, to address feelings of uncertainty, the importance of establishing follow-up care and surveillance mechanisms should be presented along with questions that may be helpful in doing this.

In relation to format of the program, session duration was appropriate, however the time of the sessions (evening) was not favoured. Furthermore, participants felt that content regarding physical activity, nutrition, stress management and coping strategies would have been more beneficial given more time or offered through a separate session dedicated to each topic, rather than combined. Choice of guest presenter is vital for session effectiveness, as shown

in the feedback received for session 4 in which a paediatric oncologist delivered information on late and long term effects of cancer treatment. This session received the lowest satisfaction with a prominent theme from qualitative feedback indicating that the information needed to be relevant to adults.

There were some limitations of this exploratory study, including the small sample used in the piloting and evaluation of the program, in particular the low attendance to the adjunct carer's session. Furthermore, the sample was a convenience sample of participants sourced through existing Cancer Council Networks; local support groups; allied health contacts; radiation departments and medical oncologists; and Cancer Helpline and Counselling Service referrals, therefore may not be representative of the general cancer survivor cohort.

5.6 RECOMMENDATIONS

From the evaluation, several recommendations can be made for the revision of the program:

1. Dedicate whole sessions to key content, including nutrition, physical rehabilitation, coping and stress management.

The delivery of more than one topic per session can cause information overload, or leave little time for questions. To ensure participants get the most out of the session, the topic should be allocated the time needed to deliver it effectively.

2. Remove the homework activities, including journaling and the wellness plan.

While homework activities address vital components of the program, practical application of the necessary skills through group activities throughout the sessions may result in greater levels of participation.

3. Open the program to both cancer survivors and carers, partners or family.

Develop the programs content to be applicable to both cancer survivors and carers, partners or family. The content delivered through a program can be made relevant to both parties, including the practical skills-building activities. Extend an invitation to carers, partners or family to attend sessions of interest to them, or the whole program.

4. Recruit relevant and knowledgeable guest presenters to deliver key content.

Information delivered through a guest speaker needs to be relevant to the target population. When choosing presenters, ensure they have the relevant expertise, and liaise with them as to what to present.

5. Offer flexible delivery of the program.

Depending on participant interest in the program and organisational capabilities, flexible delivery of the program should be offered. Sessions should be offered at differing times, both day and evening to cater for those who have recommenced work. Flexible delivery of the sessions (weekly vs. fortnightly vs. monthly) is also recommended to allow for greater commitment and attendance.

7. PROJECT OUTCOMES

In light of the evaluation findings, the program has been revised to ensure it is feasible and appropriate for cancer survivors who have completed active treatment and their carers. The revised program is entitled “*Moving Forward*” and has been amended to include more comprehensive information on nutrition, physical rehabilitation, coping and stress management. Content included in the pilot program remains in *Moving Forward*, however it is covered more succinctly, and also presented through complementary resources. Below is an overview of the *Moving Forward* program.

Session 1- Understanding your reactions: Stress & stress management

The content covered in this session includes common survivor concerns, understanding stress, relaxation for stress management, and available support services.

Session 2- The CancerSmart Lifestyle: Behaviours for health

This session delivers the CancerSmart lifestyle recommendations for physical activity, a healthy diet, healthy body weight, alcohol, smoking and sun protection, with a particular focus on healthy diet and nutrition for recovery. Participants are also introduced to SMART goal setting in this session.

Session 3- Managing concerns: Feeling good and finding calm

Session 3 should be delivered by a psychologist or similar professional and covers warning signs of distress, coping and coping strategies including managing thoughts and problem-solving.

Session 4- Physical Rehabilitation: Building strength and flexibility

This session will be delivered by an exercise physiologist and covers late and long term effects of cancer treatment, benefits of physical activity and practical exercises for cancer rehabilitation.

Session 5- Shared understandings: Effective communication

Session 5 focuses on communication; communicating with loved ones and importantly communicating with health professionals. Participants are provided with strategies for communicating with health professionals and the importance of establishing appropriate follow-up care.

The final session dedicated to developing a wellness plan has been removed as participants did not widely adopt this plan. Similarly, the homework activities, including journaling have been removed. These components of the pilot program have been replaced by regular activities throughout the program to promote personal skill development, such as goal setting, problem solving, coping and stress management, as these skills are vital for ongoing recovery. Tipsheets have also been developed to complement these activities.

The adjunct carers' session was not well-attended and of those who attended, less than half reported that they would attend a carer-specific support group. Program content was revised to be applicable to both cancer survivors and carers, partners or family. The education and skill-building activities are appropriate for both cohorts as essentially they are used in everyday life. The *Moving Forward* program will be open to both survivors and carers, removing the need for an adjunct session.

In terms of materials, existing resources are used to complement each session. In the pilot program participants received a manual; however this has been replaced in the *Moving Forward* program. Participants will continue to receive PowerPoint presentations and along with existing resources, several tipsheets have been developed for the purposes of this program, which include:

- SMART Goal-Setting
- Problem-Solving
- How to read food labels
- Communicating with Health Professionals
- Physical rehabilitation: Preparing to Exercise
- Physical rehabilitation: Intermediate Exercises
- Physical rehabilitation: Progressed Exercise

All resources will be made available to participants to store in a folder supplied to them by the Cancer Council Queensland.

In addition, a comprehensive facilitator manual has been developed to assist health professionals from a variety of organisations (hospitals, community health centres, cancer care centres, etc) deliver the program in accordance to Cancer Council Queensland

Guidelines. This allows for adoption of the program in regional centres that have the facilities to do so, expanding the reach of support services for post-treatment survivors in Queensland.

Whilst the actual content from program to program may differ dependent on the relevant guest speaker, the facilitator is responsible for providing the framework and offering consistency through introducing the topics and making the necessary links between sessions. It has also been designed to provide guest speakers with guidance for content to be delivered through their presentation. The manual was reviewed in consultation with both CCQ's Cancer Counselling Service and Viertel Centre for Research in Cancer Control to ensure sustainability of the program.

8. CONCLUSION

The Surviving & Thriving: Moving On After Cancer project aimed to determine the acceptability of an education and peer support program for cancer survivors who have completed cancer treatment, by examining the needs of this group and developing, implementing and evaluating a program to help address the gap in support services available to this cohort in Queensland.

The project demonstrated that cancer survivors who have completed treatment experience ongoing concerns and unmet needs. It also demonstrated that providing them with the opportunity to access an education and support program provided a helpful step for this group to move forward to physical and emotional recovery.

The findings of this project informed the development of an education and support program designed specifically for cancer survivors who have completed treatment and their carers, partners or family. The *Moving Forward* program is currently being incorporated into Cancer Council Queensland's Community Services department in Brisbane, and will be slowly rolled out to the other CCQ offices across Queensland. Furthermore, CCQ will promote the program to other organisations including hospitals, cancer care centres, community and government health centres to increase the reach of the program and to establish ongoing networks of support for this population.

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