



Review of Paediatric Group Programs for Children with Cancer and their Families

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Introduction

The project *'Review of Paediatric Group Programs for Children with Cancer and their Families'* will explore and review paediatric group programs with the aim to guide the future development of programs delivered by the Children's Cancer Centres (CCC) across the state-wide Paediatric Integrated Cancer Service (PICS). The project will explore the available published literature on group programs conducted for children with cancer and their families, and identify key themes and theories that inform the way in which group programs are executed within Australia and internationally. Furthermore, this report will benchmark the paediatric cancer programs that are offered in paediatric centres across Australia and at a selection of international sites.

The following questions have been used as a guide for the review and analysis of the literature and current group program practice:

1. What are some of the psychosocial impacts associated with a diagnosis of childhood cancer for the child and their family?
2. How can group programs be used to address the psychosocial impacts of a childhood cancer diagnosis?
3. What are the key principles and objectives of group programs, in particular those for children with cancer and their families?
4. What therapeutic outcomes can be expected for the patient/family attending group programs? Is there evidence in the literature that shows that these objectives are being met?
5. Are there any factors that influence the therapeutic impact and/or success of group programs? How can group success/effectiveness be evaluated?
6. What evidence base and/or theoretical frameworks have supported the development and implementation of paediatric cancer programs?
7. What groups are currently being offered to children diagnosed with cancer and their families at the CCC?

Methods

- The literature review component of this report generated a comprehensive list of 38 peer-reviewed journal articles available through the databases Medline, PsycINFO and CINAHL. While there is a dearth of literature focusing on paediatric cancer patient and family groups, the literature found was able to inform the aims of this report.
- Paediatric cancer centres and support services throughout Australia and the world were contacted for information and feedback on the group programs that they facilitate. This information was reviewed, collated and outlined in the report to allow for a benchmarking of the group programs being offered worldwide.

Participating Programs

Australian paediatric centres:

RCH	Royal Children's Hospital, Victoria, Australia
MMC	Monash Medical Centre, Victoria, Australia
RHH	Royal Hobart Hospital, Tasmania, Australia
PMH	Princess Margaret Hospital, Perth, Australia
SCH	Sydney Children's Hospital, New South Wales, Australia
CHW	Children's Hospital Westmead, New South Wales, Australia
WH	Wollongong Hospital, New South Wales, Australia
JHH	John Hunter Hospital, Newcastle, Australia
CYWHS	Women's & Children's Hospital, Adelaide, Australia
RCHB	Royal Children's Hospital, Brisbane, Australia
MCH	Marta Children's Hospital, Brisbane, Australia

International centres:

HSC	Hospital for Sick Children, Toronto, Canada
CHRM USA	Children's Hospital at Richmond Memorial, Columbia,
CHOP	Children's Hospital of Philadelphia, USA
UKK	Universitabkinderklinik, Bern, Switzerland

Support Services:

CTV	CanTeen, Victoria, Australia
CHV	Challenge, Victoria, Australia
RKA	Red Kite, Australia
CQA	Camp Quality, Australia
VSK	Very Special Kids, Victoria, Australia
ChIPS	Chronic Illness Peer Support, Victoria, Australia

- A questionnaire was sent out to approximately 20 cancer centres internationally, however only one response was returned. Therefore, information on internationally offered group programs has been sourced from hospital websites and published literature.
- The CCC Parent Advisory Group (PAG) was asked to obtain feedback from parents of children receiving treatment at the hospital at the time of this report. The PAG were given a number of questions which they could present to parents, enquiring about the groups they have/have not attended and what they would like to happen in the future.
- The limited availability of published literature indicates that group programs for children with cancer and their families are largely under-researched. In order to expand the scope of this review, a more general exploration of literature on group programs has been conducted and reviewed in relation to issues identified as cancer-specific.

Literature Review & Results from Benchmarking

Question 1 – What are some of the psychosocial impacts associated with a diagnosis of childhood cancer for the child and their family?

The diagnosis of a life-threatening illness such as childhood cancer is proven to have major psychosocial impacts on the child, family and their wider social environment. Not only are children with cancer subjected to long periods of hospitalisation, painful procedures and uncertainty of prognosis, they also face emotional, financial, physical and social disruption as they learn to adjust and cope to their illness (Cohen & Walco, 1999; Farkas Patenaude et al. 2005). Some common psychosocial effects of a childhood cancer diagnosis on the family are anxiety, depression, grief, guilt, social isolation, altered body image, sibling concerns and adolescent specific issues; these are outlined below.

Anxiety and Depression

- A number of journal articles suggest that two major psychosocial outcomes of a childhood cancer diagnosis are anxiety and depression (Barrera et al, 2004; Conway et al, 1996; Heiney et al, 1988; Houtzager et al, 2001). It has been suggested that anxiety and depression may arise from the stress and lack of control that families with a new diagnosis face, where outcomes are out of their control. “Uncontrollability is one of the core characteristics of the situation family members have to face when a child is diagnosed with cancer, and anxiety is the most salient emotional reaction that is evoked by this uncontrollability” (Houtzager et al, 2001:316). Anxiety and depression are not limited to the patient and can be experienced by other family members including parents and siblings.
- It is reported that many siblings of children with cancer will hide their feelings and emotions in order to protect themselves and their family. However, a lack of open communication can often lead to aggravated feelings of anxiety (Houtzager, Grootenhuis & Last, 2001:315).
- In contrast, a literature review by Eiser, Hill & Vance (2000, cited in Farkas Patenaude et al, 2005:12) found that cancer survivors “did not

show deficits on measures of anxiety, depression, or self-esteem when compared with population norms or matched controls". Furthermore, depression scores in cancer survivors did not differ to those in the general population.

Post-traumatic Stress Symptoms

- A number of studies (Krickson & Steiner, 2001; Kazak et al, 1998 & 2001; Meeske et al, 2001) have found that many survivors of childhood cancer and their parents experience "moderate-to-severe" symptoms of post-traumatic stress (Farkas Patenaude, 2005:12).

Grief

- Grief and/or feelings of sadness are commonly experienced by childhood cancer patients and their parents. Grief is not only experienced around the death of a child, but also around diagnosis, where families are grieving the loss of their hopes and dreams for a happy and healthy child. Likewise, children who have cancer will often grieve the losses and changes associated with their diagnosis (Lauria, 2001)

Guilt

- Feelings of guilt are often associated with a childhood cancer diagnosis, particularly on behalf of the parents and siblings. Parents may feel that they have failed at protecting their child from harm, or may try to attribute a particular cause for the cancer diagnosis (eg. Choosing not to breastfeed) (Lauria, 2001). Siblings may feel guilt for being the 'healthy' child, or may feel that something they have said or done has contributed to their sibling's illness (Houtzager et al, 2001). Murray (1999:26) found that sibling's "reactions to guilt included depression, withdrawal, and accident prone and constant acting out behaviours. Ultimately, these behaviours led to poor school performance and feelings of low self-worth".

Social Isolation

- The diagnosis of childhood cancer is an extremely distressing and challenging time for children and their families. Families are suddenly

thrown into a life of long-term treatment, painful procedures, frequent hospitalisation, changes to the family system and many other psychosocial complexities. These issues impact significantly on families and result in an increased risk of anxiety, depression, financial burden and family breakdown which in turn may contribute to social isolation (Bensink et al, 2007:6; Farkus Patenaude et al, 2005; Woodgate, 1999).

- Social isolation not only affects children with cancer, but can have a major impact on their 'healthy' siblings. Murray (1999:26) reported that "siblings... feel very isolated from parents, extended family members, and friends" following a cancer diagnosis in their brother or sister.
- The social perception of 'cancer' continues to be taboo within the community, and children with cancer, in particular adolescents may find that friends and family are less available to them for support due to a discomfort with the notion of cancer (Lambeth, 2001).

Body Image

- One of the major stressors experienced by children with cancer, in particular adolescents, is the physical changes they experience as a side effect of treatment, such as hair loss, weight fluctuations, menopausal symptoms, fatigue and body dysmorphia (Lambeth, 2001; Lauria, 2001). Conway, Thompson & Caldwell (1996: 16) state that "body image is particularly important during adolescence as it is a period of the individual's life when rapid and dramatic changes in physical appearance occur which have tremendous social and psychological repercussions". Treatment for cancer can cause further or different changes in the physical appearance of adolescents which can cause significant distress and concern for the person being treated.
- A study conducted by Yale Comprehensive Cancer Centre (Look Good... Feel Better, 2005) found that cancer patients reported that their self-image was affected by changes such as hair loss, weight changes, scarring, and skin changes and they were ridiculed and teased by peers who did not understand the illness. Parents of these adolescents related that their children became depressed and less engaged in sports and other social activities because of physical changes.
- Reiter-Purtill & Noll (2003, in Kazak, 2005:32) found that "children and adolescents at highest risk for peer difficulties are those whose

treatment affects the central nervous system or who have obvious changes in physical appearance”.

Impact on Siblings

- Psychosocial impacts affecting the siblings of a child diagnosed with cancer can often go unnoticed amidst the chaos and distress of the family unit. Siblings will have to adjust to the diagnosis of cancer in the family, the changing of roles in the family, the sudden imbalance of attention as the sick child becomes a priority in the family along with an array of emotions such as fear, guilt, concern, isolation, frustration and jealousy (Houtzager, Grootenhuis & Last, 2001:315).
- Murray (1999:25) states that “there is evidence that siblings of children who die are at increased risk for developing severe psychosocial problems”.
- A collaborative study by Sahler (1994, cited in Barrera et al, 2004) found that “63% of siblings of children with cancer experience some psychological adjustment difficulties at any one point after the diagnosis. Siblings aged 6 to 12 years have been reported to exhibit more maladaptive levels of anxiety and depression and more behaviour problems than the ill children or older siblings do”.
- In contrast, studies by Barrera et al (2004) found that siblings were resilient to many psychosocial impacts resulting from their sibling’s cancer diagnosis, usually strengthened in families with high protective factors and resources. Most siblings will not suffer major psychological and/or behavioural difficulties.

Impact on Adolescents

- Adolescence is a difficult time both socially and developmentally and in relation to this, adolescents experiencing cancer have a number of stressors related to the diagnosis, treatment and social consequences of their cancer (Ritchie, 2001; Woodgate, 1999; Heiney et al, 1990). Adolescence is a time of developmental change, bringing with it a complexity that heightens feelings of stress, anxiety and social isolation. “Normal development becomes even more difficult when the stress of adapting to a chronic, life-threatening illness such as cancer is superimposed on developmental tasks” (Heiney et al, 1988:20; Ritchie, 2001).

- Heiney et al (1990:75; 1988:20) suggests that a cancer diagnosis in adolescence affects psychosocial issues such as “social isolation, decreased self-esteem, and decreased opportunities for mastering developmental skills” as well as affecting feelings of control, anxiety and depression.
- Adolescents undergoing cancer treatment will usually find that they lose independence from their parents and spend increased time in their parent’s care. A study by Smith, Ostroff, Tan & Lesko (1991, cited in Woodgate 1999) suggested that the increased contact and involvement that adolescents have with their family will significantly affect their self-perceptions, as they become more dependent on family and less autonomous beings.

Question 2 – How can group programs be used to address the psychosocial impacts of a childhood cancer diagnosis?

Research on the topic of social supports for cancer patients, though limited, demonstrates that increased psychosocial support is a protective and therapeutic factor for these families, and can have numerous positive impacts on the child, parents, siblings and extended family. Woodgate (1999:202) views social support as “a metaconstruct, with multiple dimensions that include the type of relationships, the type and frequency of supportive behaviours, and the quality of support”. Studies show that patients undergoing cancer treatment will often experience isolation and rejection, and aren’t able to rely on family and friends for the level of social support required during this difficult time. In order to increase levels of social support, patients and their families may turn to support groups to deal with the psychosocial issues that arise following a cancer diagnosis (Taylor et al, 1986).

Group programs are widely used as a therapeutic tool in a range of settings. For children and families, group treatment is considered beneficial for social adjustment, information sharing, problem-solving, helping others, normalisation of experiences and peer interaction. “Support groups exist because of the widely accepted belief that meeting and talking with other people who understand and share one’s unique experiences and challenges with illness can be psychologically comforting and instrumentally useful” (Plante et al, 2001:437). Plante et al (2001) classified support groups into 5 sub-groups: emotional support groups, psychoeducational groups, adaptation/skill development groups, symptom reduction groups, and summer camps.

- *Emotional support groups* are formed with the objective of improving psychological adjustment to illness and facilitating socially supportive discussion with peers. In paediatric oncology, this type of group philosophy could be adapted in discussion focused groups for adolescents, siblings or parents, where the emphasis is on emotional adjustment.
- *Psychoeducational groups* also focus on adjustment to illness, but tackle this from an education and information standpoint, providing useful information and strategies for dealing with psychosocial impacts of the illness. Groups such as ‘parent education’, ‘new diagnosis’, and ‘coming-off treatment’ may choose to use a psychoeducational framework. Plante et al (2001:438) found that psychoeducational groups may improve medical compliance,

however are ineffective in improving physical symptoms associated with the illness.

- *Adaptation/skill development groups* focus on improving psychosocial adaptation as well as enhancing particular skills. This format is particularly relevant to Kazak's (1999) cancer group model which aims at improving adjustment to the illness whilst enhancing cognitive coping skills, with the view of reducing symptoms of anxiety and post-traumatic stress disorder. This model has shown positive outcomes for children with cancer and their families.
- *Symptom Reduction Groups* have been reported as beneficial in reducing physical symptoms through behaviour modification. These groups focus on ways in which changes in behaviour can directly influence symptoms of the illness, and although relevant to many paediatric illnesses, have not been applied to paediatric cancer.
- *Summer camps* are offered by many cancer support organisations and focus on providing a social-recreational experience for children and adolescents with cancer and their siblings. Plante et al. (2001) have found that these therapeutic camps help to improve anxiety, self-esteem, adjustment to illness and skills in management of the illness.

Question 3 – What are the key principles and objectives of group programs, in particular those for children with cancer and their families?

Increasing Social Supports

- “Empirical studies of paediatric cancer show that parental social support is associated with adaptive functioning outcomes and that lack of social support for parents is related to greater risk for ongoing difficulties” (Kazak, 2005:32). Hoekstra-Weebers et al (2001) suggests that social support acts as a protective factor in parental adjustment and is beneficial for psychological well-being.
- Hoekstra-Weebers (2001:226) state that “higher levels of perceived support were reportedly related to lower levels of psychological distress for parents of children in treatment and to fewer post-traumatic stress disorders for parents of childhood cancer survivors”. However, a study by Pelcovitz et al. in 1996 reported that increased family and extra-familial support did not correlate with reduced post-traumatic stress symptoms in mothers of children with cancer.
- Many of the group programs that are outlined in the literature emphasised the role of social support in the development of group objectives. Heiney et al (1990) suggests that this support is most prominent during the crisis phase of the disease, when families are in most need of support and containment to assist with adjustment to illness. Research over time has demonstrated the need for and importance of psychosocial supports throughout and following cancer treatment in children (Mitchell, W. Clarke, S. & Sloper, P. 2005).

Improving Psychosocial Adjustment & Coping

- Farkas Patenaude et al (2005:12) suggests that there is a “significant group of children and family members (estimated to be 25-30%) who do not cope well or who have significant personal, family, and social difficulties” following a childhood cancer diagnosis. Furthermore, Hoekstra et al (2001:225) looked at adaptation in parents and found that 25-30% will have an increased risk of having problems with adjustment to their child’s illness.

- Many studies addressing psychosocial adjustment are framed within a model of stress and coping, and increased social supports has been linked with improved coping and adjustment and lowered stress and anxiety (Farkas Patenaude, 2005; Kupst & Schulman, 1988; Woodgate, 1999:206).
- The effectiveness of particular coping strategies in aiding adjustment to illness depends very much on the individual, existing coping resources and the individual situation (Farkas Patenaude, 2005:13).

Encouraging communication

- Group work has been seen as a mechanism to provide a space for children experiencing cancer treatment to voice their anxieties in a safe and supportive forum. Conway, Thompson & Caldwell (1996) suggest that adolescents especially may feel frightened or guilty about speaking with friends or relatives for fear of causing upset. Peer support groups provide a space for the safe expression of emotions and anxieties.
- Rudin (1986) states that cancer patients, in particular adolescents will frequently use denial as a way of coping with the possibilities of disability and death. Peer support groups are a way to encourage the discussion and exploration of fears, and to deal with these fears in a positive way rather than through the use of denial.
- Ishibashi (2000:2) states the importance of information sharing with children who have had a cancer diagnosis. She suggests that a lack of knowledge about their cancer and treatment could lead a child to uncertainty and negative feelings, which in turn lower a child's desire to cooperate with the treatment centre and medical professionals. Hymovich (1990, cited in Ishibashi, 2000:3) suggests that "children with cancer need adequate, accurate, and developmentally appropriate information about their illness to understand the meaning of cancer". Ishibashi's research does not explore whether this information is better given in an individual or group setting.
- Carpenter, Sahler & Davis (1990) stated that information sharing is a contributor to a reduction in anxiety. In particular, being able to share feelings with peers who are experiencing similar emotional changes can provide both patients and siblings with feelings of recognition and community.

- A number of studies (Fritz et al, 1988; Koocher & O'Malley, 1981; Kupst & Scholman, 1988) found that open communication can be correlated with better adjustment in paediatric cancer survivors (Farkas Patenaude, 2005:14).

Reducing anxiety

- Conway, Thompson & Caldwell (1996:13) found that adolescents attending support groups expressed similar anxieties and concerns such as anxiety around the threat of relapse. Open discussion around anxieties during support groups helps to promote normalisation of feelings of anxiety and encourage participants to share and collaborate on strategies to reduce anxiety.
- Ishibashi (2000) encourages the sharing of information as a way of reducing uncertainty associated with the cancer diagnosis. This reduction in uncertainty aims to increase feelings of control, and thus result in lowered anxiety for patients and families. Information sharing can occur on an individual level however may be more cost-effective and collaborative in a group setting.
- A sibling group run at the Academic Medical Centre in the Netherlands use the psychosocial support model by Last & Grootenhuis (1998) to inform their group programs. This model looks at control strategies used by siblings in order to assist with adjustment to their sibling's illness. They describe predictive control (optimism), vicarious control (attributing power to medical staff), illusory control (hopes and wishes), and interpretative control (search for information to construct meaning). The sibling group run at this hospital aims to reduce sibling anxiety by increasing control, in particular interpretative and vicarious control (Houtzager et al, 2001).
- Attending groups that are held away from the hospital ward can be therapeutic for reducing the anxiety of children and adolescents receiving cancer treatment. The ward can be associated with feelings of illness, pain and anxiety due to diagnostic related events and procedures, and attending groups that are in a non-clinical environment and are not primarily focused on the medical aspect of their cancer can take the child's focus away from the anxiety and distress they experience as a patient of the hospital (Lambeth, 2001).

Increasing Peer Interaction

- Woodgate (1999:204) and McDonald (2001:139) both agree that children and adolescents with cancer value the support they receive from friends, both with and without cancer. Although relationships with friends who do not have cancer are considered equally valuable, children reported that they “received information, understanding, empathy, and acceptance from peers with cancer that could not always be provided by healthy peers”.
- In contrast, a study by Noll et al in 1991 showed that although children receiving cancer treatment experienced social isolation, this did not affect their popularity, number of friends, loneliness or self-worth (Woodgate, 1999:205).

Normalisation of Experiences

- Peer interaction plays an important role in the normalisation of both emotional and physical changes experienced by children with cancer. In adolescents, hospitalisation threatens a need for conformity and acceptance as their life becomes quite separate from their peers. Interaction with others with similar experiences allows for group cohesion and acceptance and is particularly important in forming a supportive peer network within the group (Farrelly, R. 1994; Heiney, 1990; Ritchie, 2001).
- Peer interaction can have a socially normalising effect on children with cancer as it allows them to interact with other children as opposed to the numerous medical staff they see whilst in hospital (Heiney et al, 1990). Ritchie (2001:172) states that “the gains adolescents receive from healthy peer relationships... are not afforded by relationships with adults”.

Prevention of Long-Term Psychosocial Problems

- Addressing psychosocial issues in the early stages of a cancer diagnosis, or whilst the patient is still undergoing treatment helps to prevent long-term psychosocial problems arising for the child and their family (Heiney et al, 1990). Barrera et al (2004:103) states that a “high level of social support appears to play a protective role in psychological adjustment of siblings of paediatric cancer patients, with age and gender as modifying factors”.

Question 4 – What therapeutic outcomes can be expected for the patient/family attending group programs? Is there evidence in the literature that shows that these objectives are being met?

Increased Social Support

- A study by Barrera et al (2004) found that siblings of childhood cancer patients experienced less depression, anxiety and behavioural problems when they had increased social support, as social support played a protective role in psychosocial adjustment.
- Ishibashi (2000:5) found that “adolescents with cancer who receive more support from valuable people develop coping strategies and have normal lives of interaction with their parents and friends”.

Improved Psychosocial Adjustment & Coping

- A feeling of support and community is important for families experiencing the cancer diagnosis of a child. Group programs are designed to provide information and psychosocial support for families during this time, which helps them to cope with and adjust to the cancer treatment (Houtzager et al, 2001; Ishibashi, 2000). Furthermore, Murphy (2004) reports that group work in music therapy can be used in the development of coping skills in children both on an inpatient and outpatient basis.

Increased Communication

- Conway, Thompson and Caldwell (1996:13) state that groups in which patients can express and assimilate emotions associated with both their developmental stage and adjustment to illness can be a powerful tool for increasing communication and encouraging psychosocial adjustment.
- Murphy (2004:353) reports that improvisational music therapy groups have been found to increase social-emotional communication.

Reduced Anxiety

- A study conducted by Houtzager (2001) in the Netherlands on the effectiveness of sibling groups in reducing anxiety using the State Trait Anxiety Inventory for Children, found that the mean anxiety scores for siblings who attended a sibling group of 5 weekly sessions were significantly reduced following group attendance.
- Heiney et al (1988) reported that anxiety in adolescents was decreased following participation in an adolescent support group run in South Carolina, USA.

Increased Peer Interaction

- Ishibashi (2000) reported on two studies that found that attendance at peer group therapy programs resulted in children with cancer receiving “information, understanding, empathy, and acceptance from peers with cancer”. Furthermore, childhood cancer survivors reported that these peer interaction focused groups gave them optimism and hope and encouraged positive thinking. These survivors found peer support groups beneficial.

Normalisation of Experiences

- Feelings of normality, or being normal, are important for children and adolescents who are experiencing cancer (Ritchie, 2001). In socialising and working with other people with similar experiences, the group process may normalise experiences of children with cancer and increase social cohesion.

Question 5 – Are there any factors that influence the therapeutic impact and/or success of group programs? How can group success/effectiveness be evaluated?

The review found limited available literature addressing the practical factors that influence the effective facilitation of group programs, for example attendance rates and availability of resources and facilities. However, these factors were prominent in the discussions with national services about barriers to successful group programs. Question five will discuss the findings related to factors that influence group programs both within the literature and from national benchmarking.

Group planning and structure

- Heiney & Wells (1989:803) suggest that the planning of a group program involves “defining the group’s focus, obtaining leader consensus, and organizing the group”. How well the group is planned in the beginning stages is likely to influence the success of the group once facilitated. It is also important to distinguish whether the group is going to be open or closed, single-session or ongoing, and which method will have the most therapeutic benefits for participants. In making these decisions it is useful to look at age, gender, demographics and family and sibling characteristics.
- *Single-session Vs Ongoing* – Ebenstein’s (1998) research into single-session groups suggests that they are a popular option in hospital settings as opposed to ongoing groups. These groups are time-limited, however are effective at targeting specific therapeutic goals in a short amount of time. The purpose of single-session groups does not differ from those which are ongoing; however there may be difficulties in setting realistic goals in single-session groups, as there is less scope for making major psychosocial impacts. The recruitment process involved in single-session groups can be time-consuming and ineffective; open ongoing groups can be more time-effective in the recruitment process. Ongoing groups can be useful in forming group cohesion and social bonds within the group, as participants become familiar with the facilitators and other members over the group’s life-span.
- *Open Vs Closed* – Open groups are those which have no attendance expectations and participants can join at any stage of the group process (Pavlicevic, 2003). This type of group can be useful for cancer patients who have an unpredictable schedule and who may not

always be well enough to attend groups. However group members may change regularly in open groups, which can influence group cohesion and social bonding. Closed groups on the other hand, have a stable membership, and participants ideally attend all group sessions (Pavlicevic, 2003). This can be beneficial in establishing a trusting and cohesive group environment which stimulates open discussion, but can be difficult for participants undergoing treatment who may not be able to attend all sessions.

- *Selection/Screening of Participants* – How participants are selected or referred to group programs can influence the group dynamic and therapeutic impact. Groups may be open to all families attending the cancer centre or may be referred by hospital staff who select the families they consider to require group intervention (Douglas, 1991). Also contributing to the group dynamic is the range of families that choose to participate in group programs. For example, feedback from the CCC Parent Advisory Group suggests that some families do not feel that they require additional supports and that the hospital already provides an adequate level of support for them.

Physical location of Group

- The success of a group program may be influenced by the setting in which it is facilitated. It is important to have appropriate facilities in which to run the program, and ensure that medical needs are being attended to if patients are participating. Furthermore, the choice to hold group programs in either metropolitan or rural centres may impact on the number of families able to access these services.

Group Attendance

- It is commonly reported by group facilitators around Australia (RCH, MMC, PMH, RHH, SCH) that group success is influenced by attendance, or lack of, by participants. Through the benchmarking of programs it became evident that attendance at groups was low in comparison to the entire target population, meaning less benefits for those who attended in terms of social support and group activities, however more support on a one-on-one basis. Attendance at groups was believed to be influenced by the family's availability on the day, clinic time (may clash with scheduled group time), level of advertising/marketing that has gone into the group, level of enthusiasm from staff, hesitancy to visit the hospital on non-clinic days and/or the support offered was already being met by an external

community support organisation. Offering [group programs] as short sessions, on site and on appointment days may facilitate attendance.

- The overarching theme reported by group facilitators is that groups had begun successfully, however lost momentum over time, with numbers of participants dwindling. Although there was enthusiasm from families to have group programs available, and adequate numbers would RSVP for programs, actual turn-out numbers were too low. Most centres considered that the resources and time spent planning and facilitating the groups was too great for the low attendance numbers, and groups were cancelled.
- A study by Goldsborough (1990) on a sibling group run at the Children's Hospital in Oakland found that it was difficult to convince parents of the benefits and importance of a sibling group. As a result, attendance numbers were generally lower than anticipated. Although small attendance numbers could be frustrating for workers, Goldsborough states the importance of continuing the group, as even groups with small numbers had similar benefits to those with larger attendance.

Resources

- Lasting Impressions, an adolescent group run in South Carolina feels that community resources are vital for the group to run successfully (Heiney et al, 1990:14). Without resources for marketing, activities, food, transport and practicalities, groups would be unable to provide a high standard, comprehensive and free service to participants. Princess Margaret Hospital in Western Australia found that because of a lack in attendance at the groups that they have run in the past, the use of time and resources needed to facilitate a group did not work out to be cost-effective, and as such the group programs were cancelled.

Evaluation of Groups

- In evaluating the effectiveness of group programs it is important to source a range of perspectives. Heiney, Hasan & Price (1993:389) suggest seeking evaluations from the participants, parents, facilitators, nurses and physicians as you then receive evaluations from both an emotional and logistical/administrative standpoint.

- There is little empirical evaluation of group programs found in the available literature. Many of the reported programs conduct an evaluation based on the feedback of participants and families. Evaluation feedback from centres participating in the benchmarking indicated that group programs are having a positive impact on children and their families.
- Houtzager, Grootenhuis & Last (2001:315) write about a sibling group being run in the Netherlands. This group is evaluated by participants and parents as having a positive impact on the siblings attending the group. Although this evaluation cannot make a representative claim to the entire sibling population, the positive evaluations support the need and continuation of sibling groups.
- Some of the studies of group programs were evaluated based on standardised scores measuring anxiety, depression and post-traumatic stress symptoms and reported positive test outcomes (Kazak et al, 1999; Houtzager, Grootenhuis & Last, 2001).

Question 6 – What evidence base and/or theoretical frameworks have supported the development and implementation of paediatric cancer programs?

Developmental Stage Theory

- Developmental theory is concerned with children and adolescents advancing developmentally at an age appropriate time. Children suffering from illness may not always reach these developmental stages due to factors such as social isolation, over-protectiveness from parents and physical impairment. Therefore, it is suggested that “psychosocial care for [children] with cancer requires an understanding of how the cancer experience can threaten the continuing achievement of psychosocial and cognitive developmental tasks” (Ritchie, 2001:166). Groups that encourage peer interaction, normalisation, the sharing of feelings and concerns and information sharing encourage children and adolescents to complete developmental tasks and stages (Heiney et al, 1990; Ritchie, 2001).

Crisis Intervention Theory

- Therapeutic group programs will usually incorporate crisis intervention theory, which places high importance on the sharing and deconstruction of common feelings and concerns, problem solving, and peer support (Heiney et al, 1990:15)

Existential Theory

- Existentialism theorises that people engage in a search for meaning in the experiences they have. Heiney (1990:16) suggests that paediatric cancer patients and their parents need to “find personal meaning in the experience and must adapt, mature, and set realistic life goals” which can be facilitated through group programs. Many groups will allow children and parents the space to talk through their meaning making processes and draw on other people’s experiences to make sense of their own.

Cognitive Behavioural Theory

- The “Siblings Coping Together” program (Barrera et al, 2004) is run at The Hospital for Sick Children in Toronto, Canada. This program uses cognitive behavioural theory to address psychosocial issues experienced by siblings of paediatric cancer patients in a group environment. Research behind this group program has found that siblings may experience distorted cognitions due to the changes in family system, feelings of abandonment from parents, resentment for their sick sibling, and guilt because of their health. This study found that both siblings and their parents reported improved psychological adjustment following their participation in the group. Furthermore, these benefits were also measured using empirical data from anxiety and behaviour scores recorded before and after the group.

Psychosomatic Theory

- Dance/movement therapy is theorised through the notion of psychosomatic expressions arising during diagnosis and treatment of childhood cancer. “A fundamental premise is that psychological processes, such as affect and cognition, are expressed consistently on a nonverbal level. Increasingly, results from studies on psychoneuroimmunology... emphasize the need to view the interplay between somatic manifestations of disease and psychological constructs” (Cohen & Walco, 1999:35). They also describe the Laban movement analysis which looks at a “comprehensive notation system of body movements that may be integrated to define aspects of intra and interpersonal functioning”.

A component of this review is the benchmarking of paediatric cancer group programs offered within Australia and at selected centres worldwide. Cancer centres Australia wide were contacted for feedback on the programs that they currently facilitate and how these programs are organised. Further information has been obtained from cancer centres worldwide through questionnaires, published literature, and website information.

Question 7 – What groups are being offered to children diagnosed with cancer and their families at the CCC?

Look Good Feel Better

Look Good Feel Better (LGFB) is a group program run throughout Australia, New Zealand, USA, UK and Canada, with the objective of improving the self-esteem and image of cancer patients by giving them skills in managing the physical side-effects of cancer treatment. The program was founded by the Cosmetic, Toiletry and Fragrance Association of Australia in 1990 and is now offered through out the country to both adults and adolescents.

LGFB is primarily offered to females (although males may also attend) and is free of charge. It is designed to teach skills in make-up application, skincare, the use of wigs and other accessories, and to create a social environment where cancer patients can socialise and share experiences.

A specialised LGFB program has been designed for teenagers and recognises the developmental changes that adolescents experience. Adolescents will often struggle with the physical side effects of cancer treatment such as hair loss, weight gain/loss and skin reactions, and LGFB helps to prevent anxiety and depression by providing practical ways to deal with concerns about appearance. The objectives of the LGFB program are:

1. To provide peer support for adolescents;
2. To provide a program which supports patients to discuss and share their experience of cancer in a safe non-threatening environment;
3. To provide patients with the opportunity to learn about a range of coping strategies; and
4. To provide patients with the opportunity to have fun with peers.

The program has been run at The Royal Children's Hospital since 2004 and has received extremely positive feedback from participants. It has also been run at Monash Medical Centre twice yearly, aimed at a younger (under 12's) age group. The program is open to girls and boys aged 12-20 who are receiving cancer treatment or have recently come off treatment at the CCC. This is a single-session program that runs for two hours with up to 12 participants, three times per year.

Oncology Sibling Group

Oncology Sibling Groups are aimed at giving information and support to the siblings of children with cancer. The objectives are to provide age-appropriate information about cancer and cancer treatment, to promote discussions about the unique psychosocial experiences of siblings, promote peer interaction and support and normalise the hospital experience that their sibling is experiencing. This is done through group activities such as collages and strength cards and talks by hospital staff such as nurses, doctors, scientists and social workers. This group also involves a tour of the hospital ward and simple procedures (ie. Blood pressure test, height, weight).

Oncology Sibling Group is run at the Royal Children's Hospital as a single-session, full-day therapeutic program that was established from a needs-assessment questionnaire distributed to parents at the Children's Cancer Centre. It is run tri-annually for school-age children who have a brother or sister who is undergoing, or has undergone cancer treatment. It can have anywhere between 5-30 participants, with the larger groups being subdivided into age appropriate groups (6-11, 12-18). It has been operating for six years and has always received extremely positive feedback from participants and parents.

Parent Education

From the many stressors and uncertainty of a new cancer diagnosis as outlined in the literature, it became evident that parents of children with cancer may benefit from a parent education group. Many parents speak of the anxiety and distress that comes from a lack of knowledge about their child's cancer, so increasing the practical and medical knowledge of parents was an important objective in the forming of this group. The outcomes are hoped to be a reduction in anxiety, peer interaction, increased knowledge of the available social supports and increased medical knowledge and understanding.

The Family Education Program (FEP) has been run at the Royal Children's Hospital for the past year. This group is run three times a week and is an open ongoing structure. It is primarily targeted at families who are newly diagnosed, however parents are welcome to attend at any stage of their treatment and can return for follow-up sessions. The group is run by nurse-educators, with the assistance of the social work team. The FEP is available at MMC however, due to the number and frequency of new diagnoses, the information is provided individually to families.

Child Brain Tumour Education Sessions

Brain Tumour Education Groups were formed in response to the need for families of children with brain tumours to have specialised information relating to their child's cancer. These open group sessions are run at the Royal Children's Hospital 2-3 times per year and are designed to provide information and social support to families with a child diagnosed with a brain tumour. They have a guest-speaker who presents on a brain tumour specific topic and follow with an informal discussion with staff and other parents.

Girls World

Girls World is a group previously run at the Royal Children's Hospital for female cancer patients aged 7-14. The group aims to provide patients with the chance to meet other girls their own age, provide peer support to each other and further develop personal social skills. This group was primarily participant lead, with a social worker providing additional support. Girls World was run on a monthly basis, with 1½ hour sessions to discuss a new topic each month. It was well received by participants, however was unable to continue due to physical restrictions when the ward was renovated and reconfigured. This program is to be reinstated once administrative issues have been resolved.

Innovative Models of Support

Tele-Counselling

Videotelephone based support services have come about in the past ten years in response to the difficulties experienced by rural families in accessing a high standard of care following discharge. A study by Bensink et al (2007:2) found that specialist support services were less available and accessible to families living in rural and remote areas. Innovative models of support such as videotelephony have made support services available to these families regardless of demographic or availability and help to bridge some of the barrier that these families have in accessing support. Studies investigating the effectiveness of videotelephony as a support model have found that clients exhibited higher levels of initiative, trust and spontaneity when using vidotelephone technology, as opposed to face-to-face interventions.

One Australian community based philanthropic and support group has recently piloted a group tele-counselling service for mothers throughout Australia which runs weekly sessions for 8 week periods. This is a closed group of up to 6 participants and is facilitated by 2 social work counsellors. The organisation has reported that not only are remote families accessing this service, but mothers living in the metro areas are also accessing the tele-counselling service. Preliminary evaluations have found that mothers are finding tele-counselling very positive as it allows them to seek support in a safe, understanding and easily accessible forum. The majority of families using this service have been on treatment for around one year, and find that as their contact with the hospital is reduced, tele-counselling is providing extra support.

Surviving Cancer Competently Intervention Program (and New Diagnosis)

An innovative program for adolescent cancer survivors and their families has been developed at the Children's Hospital in Philadelphia to address the long-term psychological impacts of childhood cancer. Kazak et al. (1999) found that many families who had completed treatment for childhood cancer had ongoing symptoms of post-traumatic stress. To address these symptoms a one-day family group intervention program was designed with the aim of reducing symptoms of distress and

improving family functioning and development. This intervention model uses cognitive behavioural therapy with family therapy approaches and has been evaluated by families as being helpful. Standardised tests found that attendance at this program reduced symptoms of post-traumatic stress and anxiety.

'The Surviving Cancer Competently Intervention Program - New Diagnosis' was later designed as a preventative measure to address anxiety and post-traumatic stress symptoms in parents of children newly diagnosed with cancer (Kazak et al, 2005). This three-session intervention also incorporates cognitive behavioural therapy and family therapy and has shown results of reduced anxiety and post-traumatic stress symptoms in parents subsequent to attending the program.

Limitations of Research

- *Limited published literature* – In 1988, Heiney et al. conducted a thorough literature search around paediatric cancer programs and found that there was little research outlining the process and effects of these groups. There is still a limited amount of research on this subject, however a small number of independent studies provide ungeneralisable figures around the effects of group programs. This literature review would have benefited with an increased amount of published empirical research on paediatric cancer group programs and is limited by the small scope which it had to work within.
- Many of the studies assessing outcomes of paediatric cancer group programs are evaluated by participants and their parents. These evaluations are not empirical and may be influenced by 1) developmental age of participants, 2) accuracy of evaluation such as underreporting of psychosocial symptoms or unwillingness to express feelings openly, 3) parents may not have an accurate understanding of their children's psychosocial status,

Discussion

The literature review component found that the psychosocial impacts of a paediatric cancer diagnosis were highly researched and were consistent throughout the world, with the primary impacts being anxiety, depression, grief, guilt and social isolation and specific issues for siblings and adolescents.

The literature suggests that group programs are a beneficial and valuable form of psychosocial support for children with cancer and their families. There are a number of different group formats which come with varying objectives and philosophies, subsequently affecting the outcomes available to group participants.

Group objectives reflected the psychosocial impacts and were directly related to the improvement or dissolution of psychosocial problems for children with cancer and their families. Although minimally reported within the literature, the evidence of outcomes for group participants showed that group objectives were, on the most part, being met. It was clear from the research that there is evidence to show that group programs can be very beneficial to families experiencing childhood cancer

Evidence based evaluations show that group programs are achieving their objectives of reducing anxiety, depression and post-traumatic stress symptoms, and feedback from participants has been consistently positive. The examination of the research and theoretical underpinnings of group programs indicates that these programs should be successful in meeting objectives and providing psychosocial support. However, it was commonly reported nationwide that hospitals were unsuccessful in meeting participant quotas for group programs and programs were not considered to be a sound investment for cancer centres in regards to use of resources and staff commitment. There are many factors that influence the success of group programs, some of them being group planning, availability of resources, group attendance, availability of appropriate physical space for program facilitation and response to evaluation. There is a need for group programs to have enough resources for effective staffing, facilitation, research and marketing in order to increase group success.

The benchmarking component shows that there are nationwide similarities in the groups that are being offered in paediatric cancer services, as most centres have, or have had in the past, groups for

siblings, adolescents, and parent education, and have considered or are running groups for new diagnosis, coming-off treatment and body image issues. However, there is no common practice being adopted by cancer centres, and as such no standards for how groups are run. Facilitation of group programs vary from social work dominated programs to those which incorporate a multi-disciplinary approach. Similar groups offered at different cancer centres vary in age specifications, timeframes, and structure but on the most part maintain unity in objectives and outcomes.

The inconsistency in design of group programs nationally suggests that programs are being run with little empirical input from research and evidence based practice. This suggests a need for cancer services offering group programs to imbed evaluation, evidence and research into the way that group programs are designed and facilitated.

Recommendations

1. This review indicates that paediatric cancer group programs are beneficial and valuable in the psychosocial care of families experiencing childhood cancer. However, there is no clear best-practice model for how group programs should be designed and facilitated which suggests that there is a need for research and evaluation into group program design. It is therefore recommended that a review of current group programs at the Royal Children's Hospital and Monash Medical Centre is conducted and ongoing research and evaluation continue to inform the redesign of current programs.
2. Dominant themes within the literature and benchmarking indicated that sibling groups and adolescent focused groups have evidence-based benefits in reaching outcomes for psychosocial care. It is recommended that these populations are targeted in the group programs being offered at the Royal Children's Hospital and Monash Medical Centre and that the need for improved facilities for these programs to be facilitated be addressed.
3. The review indicates that a multi-disciplinary approach is often adopted in the facilitation of group programs in Australia and worldwide. It is recommended that in the redesign of group programs, collaboration with other services and with a multi-disciplinary team is considered.
4. The benchmarking of group programs in Australia indicates that group programs commonly have difficulties with meeting attendance quotas and obtaining adequate resources. It is important to have flexibility in the way that group programs respond to the needs of the population and adapt group programs to meet the changing needs of families. It is assumed that with adequate resources, paediatric cancer centres would be able to employ a dedicated group worker to be responsive to needs as they arise. It is therefore recommended that increased resources be made available for a dedicated group worker to conduct regular needs analysis and pilot group programs as the needs for them arise.
5. Finally, it is recommended that innovative models of group programs are explored (such as tele-counselling) and resources be made available for the facilitation of these models of psychosocial care should a need for these arise.

Conclusion

The 'Review of Paediatric Group Programs for Children with Cancer and their Families' has explored paediatric group programs by looking at published literature as well as consulting practical knowledge throughout Australia and selected centres worldwide. Although much of the literature is outdated and/or non-cancer specific, it has provided a basis for the analysis of group programs in regard to psychosocial issues, group objectives and outcomes, influences in group efficacy and theoretical underpinnings for group programs.

The review has shown that the psychosocial impacts of a childhood cancer diagnosis warrant the need for extended social supports. From the literature we can conclude that the objectives of group programs correlate with the psychosocial needs of families experiencing childhood cancer. The reduced impact and improved coping in relation to these issues are reflected in the expected outcomes found within the literature. The benchmarking of group programs offered in Australia and throughout the world has shown that although there is a consistency in the type of programs offered in paediatric cancer centres, there is little consistency in the standard or format of these programs.

The literature review and benchmarking of group programs presents a strong argument for the continuation and standardisation of group programs in paediatric oncology settings, however does not give any clear indication of the most beneficial design and facilitation of group programs. Further research into the beneficial outcomes of group programs and optimum group program design would benefit this review. Furthermore, a comparative study of effectiveness of group program design across paediatric cancer centres would provide further insight.

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