

Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children

C.J. SEMPLE, PHD, BSC (HONS) NURSING, RN, MACMILLAN CLINICAL NURSE SPECIALIST-HEAD AND NECK CANCER/POST-DOCTORAL COCHRANE FELLOW, *South Eastern Health and Social Care Trust, Ulster Hospital, Belfast*, @ E. McCAUGHAN, RGN, DIP ONCOLOGY NURSING, BSC, PGDHE, PHD, PROFESSOR OF CANCER CARE, *Institute of Nursing Research, University of Ulster, Coleraine, Co. Londonderry, N Ireland, UK*

SEMPLE C.J. & McCAUGHAN E. (2013) *European Journal of Cancer Care* **22**, 219–231

Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children

When a parent is diagnosed with cancer it can have a profound impact on the family, especially the children. This paper reports on the experience of parental cancer for parents' and their children and the impact of a psychosocial intervention for young children whose parent has cancer. Using a qualitative design, data were generated from separate focus groups with children ($n = 7$) and parents ($n = 6$). One-to-one interviews were conducted with professionals delivering the intervention ($n = 2$). Findings indicated that parents are often the gatekeeper to how, when and the context in which children learn about parental cancer. Many parents expressed a lack of confidence and skills as they considered communicating with their children about cancer. Parents stated the need for professional input mainly due to changes in their children's behaviour. Children had a number of fantasies and misconceptions surrounding cancer. This psychological intervention normalized their experience of parental cancer. It also improved children's understanding of cancer and equipped them with coping strategies. Professionals perceived the intervention led to improved family communication and promoted discussion of emotions. Open communication is pivotal for children whose parents have cancer but parents need supported and resourced to promote family coping when diagnosed with cancer.

Keywords: cancer, children, parents, family-centred care, psychosocial intervention.

INTRODUCTION

The National Cancer Institute estimates that 24% of adults with cancer are parenting children younger than 18 years (Rauch *et al.* 2003), equating to approximately 3 million children having a parent with cancer. In the UK, 1 in 10 cancer patients are aged 25–50 years (CRUK 2012), an age range likely to be parenting young children. The incidence rate of cancer for the younger patient group has steadily increased over the past three decades, due to a change in the epidemiology of some tumour groups; such

as head and neck cancer, skin cancer and lymphoma (CRUK 2012). Up to a third of breast cancer patients are estimated to be parents of young children. Furthermore, with increased survival rates in cancer (Department of Health 2011); the likelihood is that there will be more parents living with cancer with dependent children.

BACKGROUND

When a parent is diagnosed with cancer the family, including the children, bears the impact of the disease (Osborn 2007). As a result the family unit can all experience major changes in living patterns, roles and relationships (Scott *et al.* 2003). Parents with cancer often experience significant parental stress, which can lead to depression (Kirsch *et al.* 2003). Parenting, when depressed, is characterized by decreased psychological availability

Correspondence address: Cherith J. Semple, South Eastern Health and Social Care Trust, Ulster Hospital, Upper Newtownards Road, Belfast BT16 1RH, N Ireland, UK (e-mail: cherith.semple@setrust.hscni.net).
Source of Support: Cancer Focus Northern Ireland.

Accepted 8 September 2012

DOI: 10.1111/ecc.12018

European Journal of Cancer Care, 2013, **22**, 219–231

and less consistency with discipline. It is not surprising that parents with cancer are at a higher risk of familial dysfunction (Hoke 2001).

Research on the impact of parental cancer on children has evolved in the past two decades, highlighting that children are at an increased risk of psychological and social difficulties due to parental cancer (Visser *et al.* 2004; Osborn 2007). These difficulties can vary depending on the age and sex of the child. Difficulties reported include separation anxiety, depression and poor family cohesion (Heiney *et al.* 1997; Visser *et al.* 2004; Watson *et al.* 2006). Furthermore, parents may not be fully aware of the problems their children are experiencing, relating to parental cancer (Barnes *et al.* 2000). Anxiety levels among children would appear to be related to whether and how they are told about their parent's cancer. Whereas, the well-informed child appears to have improved coping strategies (Huizinga *et al.* 2003).

Children can be the forgotten voice within the family when a parent is diagnosed with cancer, despite being the main source of concern for the parents (Rauch *et al.* 2003). Moreover, studies have reported that children want information that is detailed and easy to understand from initial diagnosis and throughout their parents' illness trajectory (Kristjanson *et al.* 2004). With this growing recognition that open communication with children about their parent's illness minimizes distress, efforts have been made towards addressing the psychosocial impact of parental cancer on children. The main goals of these interventions include: improving children's knowledge of their parent's illness and treatment, facilitate active coping for children and enhance family communication. However, few of these programmes have a theoretical base. A number of interventions have been directed towards those with advanced-staged disease (Turner *et al.* 2008; Bugge *et al.* 2009), focusing solely on the parents (Turner *et al.* 2008; Hasson-Ohayon & Braun 2011), with others being family-focused including both parents and children (Lewis *et al.* 2006; Thastum *et al.* 2006; Bugge *et al.* 2009). The number of clinical interventions available for children whose parents have cancer are growing; however, only a few have been published, such as the Quest programme (Taylor-Brown *et al.* 1993), 'Bear Essentials' (Greening 1992) and 'The Kid's Connection' (Call 1990), and fewer still have been systematically evaluated. One such programme that is delivered internationally is Children's Lives Include Moments of Bravery (CLIMB[®]) and to the authors' knowledge there has been no independent evaluation of CLIMB[®] reported in the literature. Merely implementing an intervention is inadequate. It is essential that interventions are systematically evaluated

as this enables critical reflection of a service. This in turn provides an understanding of how a service is perceived and experienced by those receiving it. It also ascertains its efficacy in meeting the needs of recipients, and can assist with ongoing service and intervention development (Campbell *et al.* 2007).

This paper reports on how parental cancer is experienced by the family and the impact of a psychosocial intervention (CLIMB[®]) for young children held at Cancer Focus Northern Ireland (Cancer Focus), the new name for Ulster Cancer Foundation, which is a cancer charity organization in Northern Ireland (NI), UK. The evaluation of this psychosocial intervention (CLIMB[®]) is from three perspectives to include the children attending, their parents and professionals [family support workers (FSWs)] who deliver the programme.

Purpose and philosophy of the psychosocial intervention – CLIMB[®]

This is a psychosocial intervention programme developed in 2001 by The Children's Treehouse Foundation, a non-profit organization in Colorado (USA) dedicated to the emotional support of children who have parents with cancer. CLIMB[®] is based on the premise that children are powerfully shaped by their external environment and behaviour is a function of social context, which has been referred to as the 'power of context'. CLIMB[®] is run as a 6-week group intervention for children whose parents have cancer. Through getting together and using art and play activities they learn basic information about cancer. As part of this group intervention, children are encouraged to express their feelings such as sadness, anxiety, fear and anger. The goals of CLIMB[®] are to: (1) provide age-appropriate education about cancer, cancer treatment and the cancer experience; (2) normalize emotions that a child experiences when their parent has cancer; (3) support communication of complex emotions associated with parental cancer; and (4) improve coping by connecting children whose parents have cancer.

The originators of CLIMB[®] in Colorado (USA) provide training workshops for oncology professionals (social workers, nurses, FSWs, psychologists) to facilitate the translation of this intervention programme to local cancer organizations. Cancer Focus identified a gap in service provision for children whose parents have cancer and having explored how best to address this, the FSW at Cancer Focus attended the training workshop during 2008. Within NI, the psychosocial intervention (CLIMB[®]) is provided and held on the premises of the cancer charity organization (Cancer Focus) and one of the Cancer Units.

Since implementation in 2008, 11 programmes have been held, with three to six children enrolled on each programme. This psychosocial intervention at Cancer Focus offers 1.5 h group meetings for 6 consecutive weeks for children aged 5–12 years, who have a parent or a significant adult with cancer. Each week follows a similar format to help create a sense of structure and security through routine (welcome, team building activity, educational component about cancer, different emotions discussed with a specific activity to help child acknowledge, express and cope with their feelings, summary/close). A prerequisite to attending this programme is children have an awareness of their parent's cancer diagnosis.

THE STUDY

Aim

The aim of the study was to explore the experience of families when a parent has cancer and the impact of a psychosocial intervention to support young children whose parent has cancer (CLIMB®). More specifically, the objectives were to explore:

- children's experience of having a parent with cancer;
- parents or their spouses experience of having cancer when caring for their children;
- communication with young children when Mum or Dad has cancer;
- the impact of a psychosocial intervention from the child's perspective;
- the impact of a psychosocial intervention from the parent's perspective;
- the impact of a psychosocial intervention as viewed by professionals who deliver the service; and
- how the psychosocial intervention could be enhanced.

Design

The exploratory nature of the research indicated the use of a qualitative approach (Creswell 2003). Therefore, a descriptive qualitative study was conducted, exploring the

experience of family life when a parent has cancer and to describe the impact of a psychosocial intervention to support young children.

Participants

The target population were children who had completed the psychosocial intervention from two consecutive programmes (November 2011, March 2012) and their parents. Separate information sheets were given to the children and parents during session 5 and invited to attend for an evaluation session 2 weeks later (1 week after completion of the programme).

The inclusion criteria for the children and parents are present in Table 1.

Two professionals (FSWs) at Cancer Focus who facilitate the psychosocial intervention were also invited to participate in one-to-one interviews.

Data collection

Focus groups are frequently used in explorative and evaluative research, giving participants the opportunity to share and discuss their ideas, which can provide valuable insight into phenomena of interest (Parahoo 2006). The focus groups were conducted in the familiar surrounds of the Cancer Focus premises, where the children attended the psychosocial intervention. A topic guide to frame the focus group for the *children* was developed, based on current literature and in collaboration with the FSW. An expert child researcher was also consulted to ensure the questions were phrased correctly. The topic guide focused on a child's experience of having a parent with cancer, what they learned during the psychosocial intervention and suggestions to enhance the programme. An experienced researcher (first author) conducted the focus groups with the children, in conjunction with a trained FSW at Cancer Focus. The children were encouraged to draw and write as part of the focus group as an adjunct source of data collection. Drawing and writing is developmentally appropriate for young children to reveal how they understand illness and communicate their experiences (Horstman *et al.* 2008).

Table 1. Inclusion criteria

Inclusion criteria for children	Inclusion criteria for parents
<ul style="list-style-type: none"> ● Have a parent diagnosed with cancer for at least 3 months ● Emotionally able to participate ● Completed a CLIMB programme ● Informed assent of child ● Informed consent by parent 	<ul style="list-style-type: none"> ● Parent of a child/children who has completed CLIMB® ● Emotionally able to participate ● Informed consent

CLIMB, Children's Lives Include Moments of Bravery

Simultaneously, focus groups were conducted with the *parents* in a separate room at Cancer Focus and facilitated by a researcher experienced in qualitative interviews with cancer patients. A topic guide was also developed and covered the impact of parental cancer on the family, communicating within the family when a parent has cancer, perceived benefits of the psychosocial intervention and how the programme could be enhanced.

In-depth, one-to-one interviews were also held with two *professionals (FSWs)* at Cancer Focus to explore their experience of delivering the psychosocial intervention for young children and the impact of the intervention for both children and parents. The focus groups and one-to-one interviews were taped using an unconstructive battery-operated device, and complemented by field notes.

Ethical considerations

Ethical approval was sought and granted for the University of Ulster Research Ethics Committee. To ensure that child assent and parental consent was obtained, detailed information sheets were developed suitable to the age of eligible participants in line with the NHS (2007): National Patient Safety Agency guidelines. Furthermore, to minimize distress, focus groups were conducted at the familiar premise and in a similar format to previous intervention sessions. Follow-up psychological support was available for all participants, but not required.

Data analysis

Interviews were transcribed verbatim to facilitate analysis. Thematic analysis, by two researchers, was carried out using methods formulated by Miles and Huberman (1994).

Initially, the transcripts were read and re-read by the first author (CJS) and initial impressions noted before the data were coded and categorized. To enhance the validity a second researcher (EMcC) read the transcripts, followed by further refinement of themes through critical dialogue.

Findings

Two focus groups were conducted with children who had completed the psychosocial intervention, with a total of seven children recruited. From the separate focus groups with the parents, a total of six parents were recruited into the study. Demographics of the children and parents are presented in Table 2. The age of the children ranged from 6 to 11 years. Of the children attending the psychosocial intervention, it was mainly their mothers who were diagnosed with cancer, having either breast, ovarian or skin cancer. Referrals were predominately self-referral from parents, while others originated from social workers or nurses. Self-referrals reflected parents independently seeking professional support through the Cancer Focus Family Support Service. This was often as a direct consequence of behavioural or emotional changes in their children.

Children commencing the psychosocial intervention did not undergo any formal psychometric screening. Nonetheless, prior to commencing the psychosocial intervention all the families had input of varying degrees from the FSW. This support varied from a telephone call to parents or previous one-to-one support sessions for the parent, and/or children with the FSW. Subsequently, the FSW highlighted the potential benefits for these young children in attending this psychosocial intervention.

Table 2. Demographics of children and parents

Children				
ID	Age (years)	Gender	Parent with cancer	Site of parental cancer
C1	7	Girl	Mum	Breast
C2	7	Girl	Dad	Testicular
C3	6	Girl	Mum	Ovarian
C4	9	Boy	Mum	Ovarian
C5	11	Girl	Mum	Melanoma
C6	11	Boy	Mum	Breast
C7	8	Boy	Mum	Breast
Parent				
ID	Role	Cancer diagnosis	Site of parental cancer	
P1	Mum	Yes	Breast	
P2	Mum	No	Testicular	
P3	Dad	No	Ovarian	
P4	Mum	Yes	Melanoma	
P5	Mum	Yes	Breast	
P6	Mum	Yes	Breast	

The findings from the children, parents and professionals are reported collectively under three main themes '*communicating with the children about cancer*', '*effects of cancer within the family*' and '*impact of the CLIMB[®] intervention*'.

COMMUNICATING WITH THE CHILDREN ABOUT CANCER

Communication with children about cancer: parents' perspective

Parents clearly articulated the devastation and the whirlwind of emotions after finding out they or their spouse had cancer. When faced with a diagnosis of parental cancer, parents inevitably considered death as a very real outcome. Concern for their children was foremost in their minds, with fears surrounding them or their spouse not being part of important milestones, such as educational achievements, birthdays and wedding days. Parents were also overwhelmed and frightened by the prospect of having to share the cancer diagnosis with their children, especially when they were trying to deal with their own emotional reactions and those of their spouse.

Parents appeared to have a natural desire to protect their children from the anxiety and uncertainty created by a cancer diagnosis and the painful realities of treatment. As a consequence, the timing and the manner in how children received information about their parent's cancer varied considerably. For some parents, communicating this difficult news was very soon after their diagnosis, responding to what they perceived as the immediacy of the situation. This cohort of parents highlighted how their children were perceptive of change in the parents' emotions and routine within the home. They were also concerned that their children may overhear through 'neighbourhood talking'. Parents who engaged in prompt disclosure of their cancer diagnosis articulated how they attempted to provide information about their illness as demonstrated in the following quotation.

My kids they knew something was going on like, when I came back from the hospital . . . and the neighbours were coming in, I had to tell . . . I wanted to be very open, I said to Molly (8-year-old daughter) and Jack (3-year-old son) that I had a bad bug and it was there and I had to get rid of it or it would make me very, very, very sick, I did say that I would be losing my hair and that, and that I would have to go in for an operation and that . . . I just didn't want not to tell her and then maybe hear from the playground in school or hear the wrong things. (Mum with breast cancer)

Other parents delayed in sharing the news with their children. The rationale for this initial non-disclosure was multifaceted, to include: their children were too young to understand, parents wanted to know more about the prognosis, parents felt ill equipped for the task of sharing the news having a desire for instructive support and resources on how best to share their diagnosis and deal with their children's reactions to the situation. Parents highlighted that such support and resources were often lacking and seldom provided by professionals directly involved in their care. Others considered themselves as emotionally unable to undertake this role due to the distress they were experiencing such as fear and panic, therefore sensing it was too onerous to deal with the potential aftermath of sharing this news with their children. For those parents who reported the need for emotional readiness and time for preparation to undertake this role, significant energy was channelled into maintaining non-disclosure as denoted below.

there was a lot of closed doors and a lot of trying to distract him more and a lot of whispering . . . I suppose I then wasn't emotionally . . . I wasn't emotionally able to talk to him. (Mum with breast cancer)

The context varied on how the children learned that their Mum or Dad had cancer. Some parents shared the diagnosis collectively with their children but for those who had children at different development stages parents often decided it was best to tell them separately. It was mainly mothers in this study who had cancer and in most situations it was the mother who shared the cancer diagnosis with the children. For all parents a degree of planning went into this event of telling the children, from talking it through with spouse/partner, rehearsing what to say, to accessing books specifically designed as communication aids for adults when talking to children about cancer such as the 'Secret C: Straight Talking about Cancer' (Stokes, 2009).

Communication with children about parental cancer: children's views

The children reported that prior to learning about their Mum or Dad having cancer they sensed that something was wrong at home. This was evidenced by a sense of change within the home, such as more people visiting, gifts arriving like flowers and increased telephone calls. The children emphasized that they wanted to know about their parents' illness, and wished they had been told as soon as possible after their parent learned about the cancer

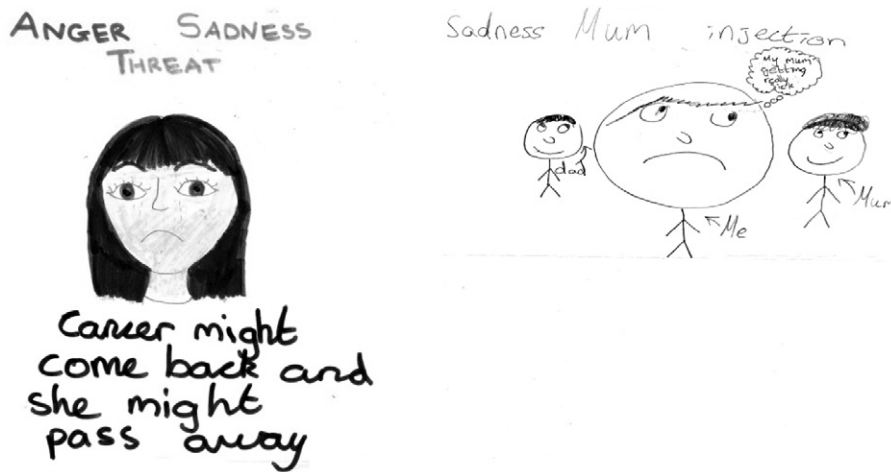


Figure 1. Drawings by the children on their perceptions of cancer.

diagnosis. They also had a strong desire for ongoing updates on their parent’s progress or condition. Furthermore, children found it helpful knowing when their Mum and Dad were attending clinic appointments and the outcome of these appointments.

The children who experienced open communication and sharing of information about their parent’s cancer highlighted how they felt involved in this new family situation. This style of open communication within the family appeared to engender trust between them and their parents. In contrast, one child reported on overhearing her Mum sharing the news with her older sibling and reported feeling excluded, unimportant and frightened.

For some of the children this was not their first exposure to cancer within the family setting. These children had some pre-existing knowledge about cancer that shaped their thinking and attitudes regarding this illness. The pictures inserted above were drawn by the children and it is apparent that they viewed cancer as a serious condition requiring treatment. The children connected cancer with death and some of them feared that their actual parent would die from cancer (Fig. 1).

Children’s knowledge and understanding of cancer before the psychosocial intervention was basic and incomplete. They had a number of fantasies and misconceptions, including concerns that cancer was contagious and they might catch it like the cold from hugging their parent. This misconception was reinforced for many children when their parent was having chemotherapy, especially as the parent had to avoid contact with other people who were sick due to the risk of infection.

It’s a bit stupid but I used to think that you could catch cancer but XX (FSW) told me that I can’t.
(11-year-old girl)

Another misconception held by some of the children was, believing they were responsible for their parent’s cancer. These children had blamed themselves for their parent’s cancer due to their bad behaviour or by saying upsetting things either to, or about their Mum or Dad.

I thought it was my fault . . . by being annoying sometimes. (8-year-old boy)

Children’s emotional response to their parent’s cancer diagnosis (as reported by the children)

Children shared their feelings surrounding having a Mum or Dad with cancer, which appeared to very much mirror and reflect the emotional reactions of adults to a cancer diagnosis. These reactions included crying during the initial disclosure of the diagnosis by their parent. Other children shared their feelings of sadness and anger, especially at the injustice of their parent having cancer. As noted earlier, children also feared the death of their parent, which is clearly articulated by this 11-year-old girl:

I felt really upset and a wee bit angry . . . felt angry that cancer was going to ruin all of our lives. I never knew there were different types of cancer. I had only heard of one cancer and most of the people who had that one cancer that I had knew had died, so I thought that my Mum had that and I got even more upset.

EFFECTS OF CANCER WITHIN THE FAMILY

Impact of parental cancer on the family as perceived by the children

Children often correlated the physical impact of cancer with the ill-parent being ‘sick in bed’ and their ‘need for medicine’, which is expressed in the children’s drawing (Fig. 2).



Figure 2. Drawings by the children expressing their perception of how cancer was impacting their parent.

Furthermore, children were able to clearly articulate the physical side-effects of cancer treatment they observed in their parents such as fatigue, pain and vomiting. One of the child's drawings included a small bowl that was constantly at her Mum's bedside due to the nausea and vomiting experienced from the chemotherapy.

Children not only reported on the physical effect of cancer on the ill-parent's body but were also very much attuned to the emotional impact of cancer for their Mum or Dad. They described how they saw tears or sad facial expressions from the parent with cancer. Other mood changes were also observed by the children, such as anger.

Cancer makes parents feel sad and treatment makes them feel sleepy and angry. (11-year-old boy)

Moreover, the children perceived that the emotional impact of cancer was not limited to the ill-parent but observed how the healthy parent was feeling the stresses and strains of the situation as illustrated by the quote below.

My Dad (healthy parent) got a bit stressed and he started to shout a bit. It made me feel angry too. (11-year-old girl)

Children were aware that the effects of parental cancer were not solely limited to their Mum and Dad but everyone in the family, especially them as young children at home. The changes noted for the children mainly centred on the disruptions to day-to-day family routines. The children clearly expressed how many facets of home life changed, especially when their Mum or Dad was having treatment or during periods of hospitalization. These

changes focused on fewer opportunities for extracurricular activities, such as dance classes and changes at meal times, especially dinner menus. Other routines changed, to include friend's parents or family friends transporting them to school.

Most of the time dinners were really like not like homemade or anything they were like something out of the shop or takeaway or something as my Mum was too tired to make a big meal . . . I had to stop some hobbies. I did traditional group but I had to stop as my Mum was too tired to pick me up and my Dad worked away from home which made it even harder for her. Most of the time she didn't have anyone to help her. (11-year-old girl)

Nevertheless, the children had a level of understanding that change to family life was necessary, particularly during treatment and when the physical effects of treatment were very evident. Although they were somewhat 'put out' by these changes, especially when it infringed on their social activities and curtailed special events such as their birthday parties, they appeared to develop a sense of acceptability.

Impact of parental cancer on the family as perceived by parents

The parents in this study outlined the adverse impact of this unique and challenging family situation on their children, which ranged from irritability to poor performance at school to dysfunctional behavioural. The behavioural changes noted in their children included negative emotions being displayed such as worry, anger and separation

anxiety. In addition, some parents reported how their child was acting up, more tearful and in some cases expressions of self-harm, which are clearly described below.

Bad in terms of she has been comfort eating. I mean you can see Leigh (daughter), she is pretty over weight. She still would comfort eat. Hasn't been able to sleep by herself which is one of the reasons why I came to XX (FSW) in the first place. She was actually joining me in bed most of the time. Just upset. She was pulling out her eyelashes. She had next to no eyelashes left. And just crying . . . not herself whatsoever. Leigh (daughter) is a real fun loving wee girl; she is a great wee girl but . . . devastated her. (Mum with melanoma)

The demonstration of behavioural changes placed immense guilt on a number of ill-parents, internalizing this as mainly due to their lack of availability of 'good' parenting, both physically and psychologically. Being unable to manage the physical demands of parenting was especially evidenced in the narratives of parents who required adjuvant therapies after surgery such as radiotherapy and chemotherapy and/or those with a relapse of their illness. These parents articulated that the side-effects of treatment, and most especially fatigue associated with chemotherapy, impacted most on their parenting ability. This led to their lack of concentration, ability to think clearly, retain information and make decisions. A direct consequence was the blurring and changes in family roles such as their inability to assist or supervise with their child's homework. For some parents who were in a seemingly never-ending cycle of treatment, they noted that fatigue also had a negative impact on their mood and emotions, resulting in irritability and less ability to deal with the psychological demands of parenting.

IMPACT OF THE PSYCHOSOCIAL INTERVENTION FOR YOUNG CHILDREN – (CLIMB®)

Parents desire for their children to attend the psychosocial intervention

Parents in this study recognized their need for professional help, which they had not received so far within their hospital care, and consequently contacted a local cancer charity (Cancer Focus) for support with parenting issues surrounding cancer. This initial contact led to engagement with the FSW at Cancer Focus. Some parents shared with the FSW how they were finding communication the diagnosis of cancer to their children challenging. For

others parents, their desire for professional input was to gain reassurance that the '*right thing had been done*' in telling their children about cancer and that '*nothing was missing*'. Some of these parents perceived their children to have a fragmented and superficial knowledge of cancer describing it as '*having pieces of the jigsaw*', '*words without meaning*' and '*a better grasp was required*'. Parents also felt it was important that their children would have a neutral forum outside of the home to honestly express their worries or emotions without a sense of needing to protect their parents. Moreover, other parents seen notable negative behavioural and emotional changes in their children and acknowledged the need for professional support.

The FSW provided parents with information on the range of family support services at Cancer Focus, to include this psychosocial intervention for young children (CLIMB®). After a period of contemplation, parents felt the intervention would help normalize their child's experience of parental cancer as they would have the opportunity to meet other children in a similar situation. In addition, this intervention would provide their child with the outside support desired by the parents. Parents overriding ethos for gaining professional help was that they wanted what was best for their children, in an endeavour to minimize any potential for future behavioural or emotional problems.

Parents' perceptions of the psychosocial intervention

At the conclusion of the psychosocial intervention programme parents highlighted that their children had not only an increased understanding of cancer but were demonstrating more adaptive coping strategies with improvements in their mood and behaviour as illustrated by a parent below.

It's normalizing the situation because he is able to talk about it, I'm able to talk about it. He didn't used to be able to say the word 'cancer' and now he can. We talk openly. We used to say (mouths the word 'cancer' silently) or we used to not say the word. (Mum with breast cancer)

Parents generally considered that enabling open communication about cancer for children was positive. However, there was an acknowledgement that as children learnt more about cancer and treatment options it had the potential to create new fears that previously had not been considered. For example, children may learn from listening to the other children's stories, about different treatments with arduous side-effects that their parent's has not and

most likely will not require or the likely progressive nature of some cancers. Nonetheless, parents expressed relief that their children were receiving professional support and now perceived the emotional well-being of their children as shared between themselves and the FSWs.

The unanticipated benefit reported by some parents as their children attended this psychosocial intervention was the *ad hoc* support gained from meeting other parents. For some parents, this exchange of how they were experiencing parental cancer was helpful, even though their situations differed with regards to gender, role (patient or spouse) and type and stage of parental cancer. However, several parents proactively disengaged from discussing their situation with other parents, clearly articulating that they did not want to be part of an informal support group.

Children's perceptions of the psychosocial intervention

One of the main outcomes of this psychosocial intervention for children was the provision of peer support. This enabled participants to meet other children whose parents had cancer within a relaxed and fun environment, normalizing their experience somewhat and reduced the feeling of isolation.

Someone in all our families has cancer. (pause) You know it's not just you. (8-year-old boy)

Some of the children felt the intervention created a 'safe space' where they could forget about their worries. Other children reported on how they gained some additional knowledge about cancer to include a definition and information on different treatments. The children also highlighted that a key benefit of the programme was the clarification of misconceptions they had about cancer, which seemed to result in less worry and anxiety for the child.

Though it was my fault for Mum catching cancer . . . My Mum had went away for a weekend and the next day I found out that she had cancer and I thought it was something to do with her going away . . . so I thought it was my fault for not stopping her going away. (11-year-old boy)

The children also described how the psychosocial intervention provided them with a forum to explore their own emotions surrounding their Mum or Dad having cancer. They recalled how during each evening of the programme a different emotion was discussed with the aid of art and crafts, to include happy, worry, anger and sadness. It also provided them with possible tools to facilitate coping. For

example, each child made a 'worry box' to include writing their specific worries on paper. After discussing their specific worries with the FSW or a volunteer they were encouraged to place them in the box.

These creative therapeutic activities appeared to assist the children with the communication of complex emotions associated with their parent having cancer like anger and fear, as summed up by one child below.

We made a body map. Well you put your friend or whoever you are with on a giant piece of paper and you draw round them and then you both add in like emotions and were you would like feel the emotions . . . like nervous in your stomach and you would be sad in your heart . . . like feelings you can see on the outside but some that people can't see on the inside . . . like if your upset and you start crying people can see it but if you don't cry nobody can see it and nobody can help you so it's better to let it out. (11-year-old girl)

Professionals (FSW) perspective of psychosocial intervention

The professionals (FSWs) summarized the main assertions of psychosocial intervention as: (1) learning about cancer in an age-appropriate fashion; (2) exploring feelings and emotions associated with parental cancer; (3) interaction between children within a group context to normalize emotions; and (4) to reduce the feeling of isolation, which is highlighted by the quote below from a FSW.

Emotion and cancer are the core elements of CLIMB so to be able to come to the CLIMB programme is to be able to talk about your feelings. Because I think a lot of young children don't understand what the emotion is that they are feeling . . . So it is about untangling the emotions and giving them a tool kit so that they understand the emotions they are dealing with because everything is happening so quickly. People are crying and everybody is bringing casseroles and everything has gone confusing . . . One element of this is that it is a bit like a party but everybody keeps crying, so it is a very confusing thing. Granny keeps coming, brilliant, we get cake every day but then Dad is really sick and can't get up. So it is about untangling it all and helping them understand what is going on.

Akin to the parents' views of this psychosocial intervention, the FSWs considered the programme as a mechanism of providing parents with reassurance that their children had input from professionals who are skilled in

communicating with children about parental cancer. Furthermore, parenting responsibilities around minimizing the impact of parental cancer for their child is now, in part, shared with professionals, describing it as a 'pressure off parents' or 'weight of their shoulders'.

Suggestions on how to refine the psychosocial intervention (CLIMB®)

Some parents shared their logistical concerns around the timing of the sessions being from 5.30 PM to 7.00 PM, as this coincided with evening mealtime and scheduled time for homework. One idea offered by parents to counteract the timing issue was the provision of a meal for the children at the commencement of each session. Currently, the psychosocial intervention is located in two urban areas in NI and families from more rural settings reported on how they were geographically disadvantaged. This investment in travelling time was especially pertinent when life was already busy with the demands from family life and receiving cancer treatment.

Furthermore, parents suggested that an information session on how to best facilitate a child's coping amidst parental cancer would be of immense benefit. They highlighted key topics such as recognizing stress warning signs and how best to manage their child's moods and behaviours. Finally, some parents and children felt the group size was too small. The average group size for this psychosocial intervention at Cancer Focus is three to six children. Therefore, when one or two children need to dropout out, for example, due to the decline in a parent's condition, this results in a very small number of children within the group. The potential for group interaction and learning from others is subsequently diluted. Such a scenario did occur during this evaluation. A father of two children attending the intervention entered into a terminal phase of his illness, thus reducing the group size from five to three children. The absence of these children proved very evident, highlighting the potential progressive nature of cancer to the other children in the group.

DISCUSSION

This study demonstrated that parental cancer pervades numerous aspect of family life. Parental cancer is a stressful event in a family; therefore, healthcare professionals must be cognizant of the potential distress and psychosocial dysfunction that parents and their children may experience. Parents and their children often both need support to help understand the challenges experienced or those they may confront, especially at diagnosis, during active

treatment and recurrence. However, the literature would suggest that family-centred cancer support is lacking for those affected by parental cancer (Turner *et al.* 2008). Other studies have indicated that parents feel unsupported by professionals when diagnosed with cancer (Elmberger *et al.* 2000; Helseth & Ulfsaet 2005; Semple & McCance 2010a). This includes the paucity of instructive support on how to talk to their children, despite parents expressing a lack of confidence and skills to communicate with their children about cancer (Barnes *et al.* 2000, 2002; Kennedy & Lloyd-Williams 2009). The impact of this lack of support cannot be underestimated, as parental distress can lead to depression, which can have a direct impact on the psychological functioning of the child (Visser *et al.* 2004).

Information giving and communication styles varied between families and often appeared to depend on such issues as parent's attitude towards cancer, their emotional readiness to communicate with children, progressive nature of the parent's illness and the age of the children. This is supported, in part, by Kennedy and Lloyd-Williams (2009), who reported that parents approach to communication depends on parent's own psychological status. Nonetheless, as parents are often the gatekeepers of pivotal information about their illness they must be encouraged to embrace an open style of family communication to facilitate coping and family cohesion (Huizinga *et al.* 2003).

This study demonstrated that children often have fears, fantasies and misconceptions about cancer. Such thinking may not be apparent to parents, as Visser *et al.* (2004) report that children often find it very hard to talk about their concerns related to the illness of their parent. This further emphasizes the importance of parents actively engaging in communication with their children, providing them with relevant accurate and factual information about their illness. Communication should include using the word cancer, and avoiding euphemisms such as 'bad bug'. This information should be provided in an age-appropriate manner, which can alleviate anxiety and promote coping (Visser *et al.* 2004). In addition, Nelson *et al.* (1994) and Rosenheim and Reicher (1985) concluded that anxiety levels for children who had been informed of their parent's cancer were lower than in families that did not communicate about parental cancer.

Parents in this study had sought and gained relief and reassurance that a professional was now involved in providing support to their child. Bugge *et al.* (2009) and Thastum *et al.* (2006) have reported that parents often independently seek support with parenting during their cancer illness. Parents sometimes consider themselves inexperienced to deal with the turmoil created by parental cancer, while feeling overwhelmed with emotion. Parents

may also seek professional help if they observe notable behavioural or emotional changes with their children.

Parents struggle not only with providing emotional support but attending to the physical needs of their children, with the duality of roles of being a patient and primary caregiver (Billhult & Segesten 2003; Semple & McCance 2010b). Parents should receive advice on finding a balance between the demands caused by the cancer and the treatment and the care and attention for the children. This is especially pertinent at crucial juncture of the cancer journey, such as active treatment, or when experiencing complications, or during moments when parents experience significant distress. At these junctures 'cancer' has a very prominent presence in the home and the ill and the healthy parent are less accessible for the child. Parents should be encouraged to mobilize practical help from core people within their support network to help with the parenting roles, such as transporting children to school etc., ironing and other household chores.

The majority of children who have a parent with cancer will display resilience in coping with the impact of their parent's illness. Nonetheless, some children will experience serious problems from this stressful event, resulting in separation anxiety, anger, sleep disturbance and lower self-esteem. This study highlighted that these psychosocial problems can be addressed through a peer group intervention programme for children. At the completion of this 6-week programme children displayed less mood disturbance and lower anxiety. Similar findings have been reported with other structured group intervention programmes for children who provided age-appropriate factual knowledge on cancer, normalized children's emotions surrounding parental cancer and encouraged family communication (Bugge *et al.* 2008, 2009). In this current study, professionals (FSWs) at Cancer Focus perceived that a major contributing factor to improved adjustment is the peer support gained from meeting other children who are in a similar situation. This provides the children with a sense of belonging, which contributes to confidence building (Libo & Griffith 1996).

One of the key recommendations from parents was to empower them with tools and techniques to help promote family coping or deal with ongoing behavioural or emotional issues displayed by their children. Parents felt this would also enhance their capacity to deal with other family challenges that might arise in the future. Given the increasing body of work and practice in mental health, which actively promotes fostering family resilience as a key ingredient to promoting mental well-being and successful coping of family members under adversity (Allison *et al.* 2003), parents with cancer should be empowered to

build on their family's ability to collaboratively solve problems. Parents interpersonal skills that promotes direct and honest communication and open emotional expression should also be enhanced. Consequently, this could be a protective function in withstanding the ongoing challenges of life for families with parental cancer.

This key recommendation of promoting family resilience should be integrated into oncology practice as attending a family-based intervention programme may not be appropriate for all families. Furthermore, such programmes are only accessible to a small subsection of the population. It must be acknowledge that the well-informed and supported child often demonstrates a high degree of resilience and competency in spite of stressful situations and regularly does not need a psychosocial intervention programme (Gazendam-Donofrio *et al.* 2011). Whereas, parents often need reinforcement that the approaches they have adopted are working and to identify strengths, assets and resources within the family. Thus, in routine clinic practice parents should be equipped and resourced with the skills to deal with their children when diagnosed with parental cancer.

Limitations

This sample may not be representative of the views of all families with parental cancer because the parents in this study actively sought out help to mainly deal with behavioural issues with their children. One must also be cautious not to over generalize the findings of this small-scale qualitative study. This is due to the sample size but also the context of focus groups, which does not permit random selection that contributes to the representation of larger groups.

Recommendations

- Increased awareness among oncology professionals of the potential difficulties for families when a parent is diagnosed with cancer who have young children and the importance of providing appropriate support.
- Empower and support parents who are newly diagnosed with cancer on the importance of open communication to facilitate family coping.
- Routine assessment of family coping (parents and children), with referral to appropriate support service for those with psychosocial needs.
- Adequate number of children at commencement of a peer-group intervention, to account for potential

drop-outs throughout programme, that is, minimum number of six children per group.

- Concurrent educational session for parents to explore communication within the family, diversity of children's responses, maintaining routine, reinforce parenting responsibilities (boundary setting maintained).

Future research

- Identify characteristics of families that are at greatest risk of poor adjustment.
- Future development and testing of tailored interventions that meets the needs of families impacted by parental cancer to determine what works, for whom and when should it be implemented during the cancer journey.

CONCLUSION

Parental cancer is a challenging life event for the family. It can cause physical, psychological or social difficulties, and may in turn present as developmental, behaviour and family relationship challenges. It is important that health-care professionals are mindful that parents have a desire

for support on aspects of parenting with cancer, such as telling the children, managing home life during treatment. Therefore, where and when required, parents should be offered supported in helping them and their children to cope with this life event.

The psychosocial intervention (CLIMB) was evaluated favourably by the children and parents. In summary, it allowed children to learn more factual information about cancer, benefit from peer support and gain tools and techniques to deal with negative emotions surrounding parental cancer. For parents, it provided them with reassurance that their child's emotional needs were being met.

ACKNOWLEDGEMENTS

We would like to thank the children, parents and Family Support Workers at Cancer Focus Northern Ireland who helped us by giving of their valuable time and sharing of their experiences during the interviews. The research team would like to offer a special thanks to Rachel Smith for all her help in coordinating the focus groups with the children and parents, and to BBC Children in Need for supporting this work.

REFERENCES

Allison S., Stacey K., Dadds V., Roeger L., Wood A. & Martin G. (2003) What the family brings: gathering evidence for strengths-based work. *Journal of Family Therapy* **25**, 263–284.

Barnes J., Kroll L., Burke O., Lee J., Jones A. & Stein A. (2000) Qualitative interview study of communication between parents and children about maternal breast cancer. *BMJ (Clinical Research Ed.)* **321**, 479–482.

Barnes J., Kroll L., Lee J., Burke O., Jones A. & Stein A. (2002) Factors predicting communication about the diagnosis of maternal breast cancer to children. *Journal of Psychosomatic Research* **52**, 209–214.

Billhult A. & Segesten K. (2003) Strength of motherhood: nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Sciences* **17**, 122–128.

Bugge K.E., Helseth S. & Darbyshire P. (2008) Children's experiences of participation in a family support program when their parent has incurable cancer. *Cancer Nursing* **31**, 426–434.

Bugge K.E., Helseth S. & Darbyshire P. (2009) Parents' experiences of a Family Support Program when a parent has incurable cancer. *Journal of Clinical Nursing* **18**, 3480–3488.

Call D.A. (1990) School-based groups: a valuable support for children of cancer patients. *Journal of Psychosocial Oncology* **8**, 97–118.

Campbell N., Murray E., Darbyshire J., Emery J., Farmer A., Griffiths F., Guthrie B., Lester H., Wilson P. & Kinmonth A.L. (2007) Designing and evaluating complex interventions to improve health care. *BMJ (Clinical Research Ed.)* **334**, 455–459.

Creswell J. (2003) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*, 2nd edn. Sage Publications, Thousand Oaks, CA, USA.

CRUK (2012) *Cancer Statistics for the UK: Cancer Research UK*. Available at: <http://info.cancerresearchuk.org/cancerstats/incidence/age/>

Detpartmen of Health (2011) *Improving outcomes: a strategy for cancer*. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf

Elmberger E., Bolund C. & Lutzen K. (2000) Experience of dealing with moral responsibility as a mother with cancer. *Nursing Ethics* **12**, 253–262.

Gazendam-Donofrio S.M., Hoekstra H.J., van der Graaf W.T.A., van de Weil H.B.M., Visser A., Huizinga G.A. & Hoekstra-Weebers J.E.H.M. (2011) Adolescents' emotional reactions to parental cancer: effect on emotional and behavioral problems. *Journal of Pediatric Psychology* **36**, 346–359.

Greening K. (1992) The 'bear essentials' program: helping young children and their families cope when a parent has cancer. *Journal of Psychosocial Oncology* **10**, 47–61.

Hasson-Ohayon I. & Braun M. (2011) Being a parent and coping with cancer: intervention development. *Palliative and Supportive Care* **9**, 149–152.

Heiney S.P., Bryant L.H., Walker S., Parrish R.S., Provenzano F.J. & Kelly K.E. (1997) Impact of parental anxiety on child emotional adjustment when a parent has cancer. *Oncology Nursing Forum* **24**, 655–661.

Helseth S. & Ulfsaet N. (2005) Parenting experiences during cancer. *Journal of Advanced Nursing* **52**, 38–46.

Hoke L.A. (2001) Psychosocial adjustment in children of mothers with breast cancer. *Psycho-Oncology* **10**, 361–369.

Horstman M., Aldiss S., Richardson A. & Gibson F. (2008) Methodological issues

- when using the draw and write technique with children aged 6 to 12 years. *Qualitative Health Research* **18**, 1001.
- Huizinga G.A., van der Graaf W.T., Visser A., Dijkstra J.S. & Hoekstra-Weebers J.E. (2003) Psychosocial consequences for children of a parent with cancer: a pilot study. *Cancer Nursing* **26**, 195–202.
- Kennedy V.L. & Lloyd-Williams M. (2009) How children cope when a parent has advanced cancer. *Psycho-oncology* **18**, 886–892.
- Kirsch S.E.D., Brandt P.A. & Lewis F.M. (2003) Making the most of the moment: when a child's mother has breast cancer. *Cancer Nursing* **26**, 47–54.
- Kristjansson L.J., Chalmers K.I. & Woodgate R. (2004) Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum* **31**, 111–119.
- Lewis F.M., Casey S.M., Brandt P.A., Shands M.E. & Zahlis E.H. (2006) The enhancing connections program: pilot study of a cognitive-behavioral intervention for mothers and children affected by breast cancer. *Psycho-oncology* **15**, 486–497.
- Libo L.M. & Griffith C.R. (1996) Developing mental health programs in areas lacking professional facilities: the community consultant approach in New Mexico. *Community Mental Health Journal* **2**, 163–169.
- Miles M.B. & Huberman M. (1994) *Qualitative Data Analysis: An Expanded Sources Book*. Sage Publications, Thousand Oaks, CA, USA.
- Nelson E., Sloper P., Charlton A. & While D. (1994) Children who have apparent with cancer: a pilot study. *Journal of Cancer Education* **9**, 30–36.
- NHS (2007) National Patient Safety Agency. National Research Ethics Service. Information Sheets and Consent Forms; Guidance for researchers and reviews Version 3.2. NHS.
- Osborn T. (2007) The psychosocial impact of parental cancer on children and adolescents: a systematic review. *Psycho-Oncology* **16**, 101–126.
- Parahoo K. (2006) *Nursing Research: Principles, Process and Issues*, 2nd edn. Macmillan Palgrave, Basingstoke, UK.
- Rauch P.K., Muriel A.C. & Cassem H. (2003) Parents with cancer: who's looking after the children? *Journal of Clinical Oncology* **21**, 117–121.
- Rosenheim E. & Reicher R. (1985) Informing children about a parent's terminal illness. *Journal of Child Psychology and Psychiatry, and Allied Disciplines* **26**, 995–998.
- Scott J.T., Prictor M.J., Harmsen M., Broom A., Entwistle V., Sowden A. & Watt I. (2003) Interventions for improving communication with children and adolescents about a family member's cancer. *Cochrane Database of Systematic Reviews (Online)* (4), CD004511.
- Semple C.J. & McCance T. (2010a) Parents' experience of cancer who have young children: a literature review. *Cancer Nursing* **33**, 110–118.
- Semple C.J. & McCance T. (2010b) Experience of parents with head and neck cancer who are caring for young children. *Journal of Advanced Nursing* **66**, 1280–1290.
- Stokes J.A. (2009) *The Secret C: Straight Talking about Cancer*. (2nd ed) Winston's Wish.
- Taylor-Brown J., Acheson A. & Faber J.M. (1993) Kids can cope: a group intervention for children whose parents have cancer. *Journal of Psychosocial Oncology* **11**, 41–53.
- Thastum M., Munch-Hansen A., Wiell A. & Romer G. (2006) Evaluation of a focused short-term preventive counselling project for families with a parent with cancer. *Clinical Child Psychology and Psychiatry* **11**, 529–542.
- Turner J., Clavarino A., Yates P., Hargraves M., Connors V. & Hausmann S. (2008) Enhancing the supportive care of parents with advanced cancer: development of a self-directed educational manual. *European Journal of Cancer* **44**, 1625–1631.
- Visser A., Huizinga G.A., van der Graaf W., Hoekstra H.J. & Hoekstra-Weebers J.E.H.M. (2004) The impact of parental cancer on children and the family: a review of the literature. *Cancer Treatment Reviews* **30**, 683–694.
- Watson M., St James-Roberts I., Ashley S., Tilney C., Brougham B., Edwards L., Baldus C. & Romer G. (2006) Factors associated with emotional and behavioural problems among school age children of breast cancer patients. *British Journal of Cancer* **94**, 43–50.