



# Children of Parents with Cancer: An evaluation of a psychosocial intervention



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## **Executive Summary**

### **Introduction**

Over the past three decades there has been a marked increase in the prevalence of cancer among younger age groups, many of whom are parenting children. In Ireland it is estimated that 15% of people with cancer are aged between 20-50 years (National Cancer Registry Ireland (NCRI, 2016). Research has indicated that when a parent is diagnosed with cancer they face additional fears and anxieties as they attempt to simultaneously manage their role as parent, with their illness (Rauch & Moore, 2010, Semple & McCance, 2010a, O'Neill et al, 2016). Parents, at this time, primarily want to protect their children from worry and anxiety. However, managing this process is challenging and the illness experience affects the whole family unit. Research evidences that children, depending on age and gender, are at increased risk of psychological and social problems ranging from separation anxiety, depression, difficulties at school, leisure, family functioning and relationships (Visser et al, 2004, Osborn, 2007, Thastum et al 2009).

### **Background and Rationale**

Creating a supportive environment where children can feel comfortable expressing positive or negative emotions is essential at this time. Many parents, however, are understandably overwhelmed by the diagnosis and treatment regimes. Some require professional support and a structured intervention to assist them in communicating the illness process to their children.

One such intervention which is delivered internationally is Children's Lives Include Moments of Bravery CLIMB®, which was developed in the United States (U.S.) by The Children's Treehouse Foundation. In 2015 CLIMB4CLARE a fundraising initiative supported by the Ladies Gaelic Football Association (LGFA) initiated the introduction of the programme in the Republic of Ireland by offering training to healthcare professionals. Although it is delivered in over 30 locations countrywide, its efficacy, has not been evaluated to date.

On the foot of this rationale the pilot exploratory research study received institutional ethical approval from the Research Ethics Committee (REC) in Dublin City University (DCU). Details of the research design which used a focus group methodology with the parents and the children, and individual face to face interviews with the facilitators, can be accessed in the main report.

### **Findings**

Overall the findings from the study evidenced that attending the CLIMB® programme was a positive step for all of the children as it gave them a chance to express their worries and meet other children in a similar situation which appeared to have a somewhat calming effect as they bonded as a community. The parents were aware of this also and expressed how the programme was a great psychological support to the children and to them as parents, as they felt that the

programme removed some of the burden of responsibility of talking about the diagnosis to the children. The tools the children learned to use on the programme were life skills that could be applicable in any serious life event. Furthermore these could be, and were used by other members of the family.

The findings also evidenced that most of the children were better able to overtly express their emotions and had more open communication with their parents following the completion of the programme. They learnt adoptive strategies and ways to manage their feelings. The use of arts and crafts to facilitate the conversation and discussion with the children appeared to give them a certain level of comfort with the diagnostic language. However, the images they drew during the research process demonstrated their continued fears and worries. The important change was that the children now had words to articulate what was happening at home and they were now part of the illness conversation.

While many of the parents did not disclose the diagnosis to the children at an early stage, the children did sense a change in the home environment and intuited this change through the altered domestic routines, a finding that concurs with Scott et al, (2003), Semple & McCaughan, (2013), and Furlong (2017).

An unexpected finding that emerged from the data was the differences between spouses on when to disclose information to their children about the diagnosis. Some parents took longer to process the cancer diagnosis resulting in disagreement around disclosure of information to the children. An individual's response to illness may be influenced by their gender (O'Neill et al, 2013) and while men and woman can have similar cancer experiences, the manner in which men respond may be very different to women (Robertson, 2007).

The findings from the facilitators supported those of the children and parents in that the programme supported the overall family unit and created a safe space within which to talk about the illness. Some facilitators, however, expressed that the programme was not a fit for children of a dying parent, hence the need for a screening process. This and other structural challenges experienced by the facilitators are documented in the recommendations below.

All of the findings in this study point to the importance of taking a family centred approach to talking about cancer with the children. One of the limitations of the study is the small sample size, therefore the findings cannot be generalised.

## Recommendations

1. The initial screening process of the children prior to the commencement of the programme should include the facilitators to ensure the suitability of the child in terms of maturity and age. Also, it is recommended that a two-way conversation between the facilitators and the parents take place prior to the commencement of the programme to get the necessary background information required.
2. Have a dedicated session within the programme with both the parents and children to reinforce the skills and tools learnt on CLIMB®. This could be an activity-based session with art/games with the aim of empowering the parents to continue to use the tools learnt in the programme.
3. Develop a follow-on support mechanism for children who maybe experiencing significant emotional distress. For example, providing parents with contact details of child counselling services.
4. Consider offering a bi-monthly meeting for parents and children, facilitated by a trained parent who has expertise by experience. Parents may also want to initiate their own support structures following the programme. For example, creating a 'WhatsApp' group would facilitate the community bond established during the programme to continue.
5. Consider running the programme during the summer months.
6. Strongly recommend implementing a clinical supervision mechanism for the facilitators.
7. Having a professional overseeing the programme at a country wide level to ensure continued fitness for purpose and standardisation across all venues. A clear structure of governance of CLIMB® in Ireland would ensure this.
8. Develop a policy initiative to support the current and the future development of the programme to ensure the long-term sustainability. Suggest a family support service to be developed nationally.
9. Conduct further research taking a longitudinal approach, perhaps following the families up 6-12 months following completion of the programme.

## Section 1. Introduction

At any given time, up to one in five cancer patients are parenting children under the age of 18 years (Weaver et al, 2010). Changing demographics and increased survival rates of cancer patients present the additional probability that individuals who are faced with a cancer diagnosis will be caring for dependent children (Harris et al, 2009, Maddens et al 2009). The prevalence of cancer in younger patient groups has progressively increased over the past 30 years. This is as a result of the changing epidemiology of certain cancers, for example, head and neck cancer, skin cancer and lymphoma (Cancer Research UK, 2016). The National Cancer Registry (NCR) in Ireland estimates that 15% of cancer patients are aged 20-50 years (NCR, 2016).

It has been acknowledged that when a parent is diagnosed with cancer they face additional fears and anxieties while attempting to simultaneously balance their role as a parent and patient (Rauch & Moore, 2010, Semple & McCance, 2010a). Parents have reported difficulties in knowing how to communicate appropriately with their children throughout the illness trajectory (O'Neill et al, 2016, Semple & McCance, 2010a, 2010b) and they are primarily focused on protecting or shielding their children from the illness. Understandably parents can become overwhelmed and experience significant parental stress impacting on their psychological wellbeing, in some cases leading to depression (Kirsch et al 2003, O'Neill et al 2016). This has a subsequent effect on the entire family unit. When a parent is diagnosed with cancer the entire family undergo changes to routines, roles and responsibilities, all of which can cause huge disruption to both parents and children. (Scott et al, 2003).

There has been an increase in research on the impact of parental cancer on children over the last 20 years and findings have indicated that children are at an increased risk of psychological and social problems (Visser et al, 2004, Osborn, 2007). These problems can differ depending on the age and gender of the child, and can include separation anxiety, depression, difficulties related to school, leisure, family functioning and relationships (Visser et al, 2004, Thastum et al 2009). Certain attributes have been reported to facilitate adaptation to a parents' diagnosis. These include the parents own mental health status and ability to cope with the illness and family functioning, for example, parent-child communication (Su & Ryan-Wenger, 2007, Thastum et al 2008, Krattenmacher et al, 2012). It is acknowledged that children require age appropriate information about their parents' cancer and they need support communicating with parents, family members and healthcare professionals (Semple & McCaughan, 2013, Ellis et al 2016). Furthermore, children need an environment where they can feel comfortable discussing their emotions and have their experiences normalised among peers (Ellis et al, 2016).

Addressing the psychosocial impact parental cancer has on children has received attention through the development of interventions. In a recent systematic review of children's psychosocial needs and existing interventions, the evidence suggests that positive outcomes in relation to child and parental mood, child behaviour and communication can be achieved with interventions (Ellis et al, 2016).

One such intervention which is delivered internationally is Children's Lives Include Moments of Bravery CLIMB®. While this intervention has been evaluated in the U.S. (Shallcross et al, 2016) and Northern Ireland with the charity Cancer Focus (Semple & McCaughan, 2013), an evaluation has not occurred in the Republic of Ireland despite the fact it is offered in over 30 locations. Although it may be the case that the programme is working satisfactorily, cognisance must be taken of different social and cultures contexts in the south of Ireland. Furthermore, it is essential that interventions are systematically evaluated to ensure they meet the needs of those availing of the service, thereby ensuring efficacy while also contributing to continued development and review of that service (Campbell et al, 2007). One must also be mindful of the need to ensure value for money is achieved for funders, given the current economic climate. Additionally, following the launch of the 2017 National Cancer Strategy (Department of Health, DoH) it has been identified that a comprehensive psycho-oncology and psychosocial support service plan should be developed, one that encompasses both the hospital and community care. CLIMB® is one intervention that has the potential to form part of the proposed model outlined in the strategy. This evaluation research is therefore timely to examine existing services and to evaluate how they meet service users' needs, and how this service may be further integrated.

#### Aim and ethos of the psychosocial intervention CLIMB®

This is a psychosocial intervention programme developed by a non-profit organisation (The Children's Treehouse Foundation, Colorado, USA) in 2001 that is dedicated to the emotional support of children who have parents with cancer. CLIMB® is a six week group intervention offered to children whose parents have cancer. The programme which is facilitated over a period of six weeks is based on the principles of mental health promotion, not psychotherapy. Intended for children ages 6-11, the aim is to build upon the child's strengths and increase his/her ability to cope with stress associated with the parent's illness. The objectives of the programme are to demystify cancer for the children, help them feel less isolated, learn to communicate their feelings with others, and learn how to cope with feelings such as sadness, anger and confusion. Through group activities, small groups of children engage in art therapy and play therapy as tools to enable them to express their feelings. Children learn basic

information about cancer, and under the guidance of caring professional therapists, the children develop coping skills. The CLIMB® program helps to normalise feelings of sadness, anxiety, fear and anger of the child. It helps to support communication of these complex feelings, increases the child's knowledge about cancer, and facilitates communication between the parent and child.

### **1.1 Rationale for current evaluation**

CLIMB4CLARE is a fundraising initiative supported by the Ladies Gaelic Football Association (LGFA). Clare Clarke worked with the LGFA when she was diagnosed with breast cancer. As a mother of two young children she was searching for support for them when she discovered that CLIMB® was being delivered in Northern Ireland through Cancer Focus. Climb4clare worked with the family therapist in Cancer Focus and they started organising training in 2015 in the Republic of Ireland. Her aim was to make the programme available throughout all cancer care centres in Ireland through the support of LGFA and assistance from the Irish Cancer Society. Funding for CLIMB® training comes directly from CLIMB4CLARE, who cover all the training costs. On completion of the delivery of every programme each individual centre receives a grant direct from Climb4Clare to run CLIMB®. CLIMB® is now offered in over 35 locations in the Republic of Ireland with over a 100 trained facilitators (see appendix 1). To date an evaluation has not being undertaken.

### **1.2 Aim & Objectives**

The aim of this proposed study which replicates Semple & McCaughan evaluation (2013) is to explore the experience of families when a parent has cancer and the impact of CLIMB® on children whose parent has cancer.

#### **Objectives**

- To explore children's experiences of living with a parent with cancer
- To explore parents or their spouses experience of having cancer when caring for their children
- To explore how children and parents communicate when a parent has cancer
- To explore the impact of CLIMB® from the child's viewpoint
- To explore the impact of CLIMB® from the parent's viewpoint
- To explore the impact of CLIMB® from the professionals delivering the intervention
- To examine how the delivery of the psychosocial intervention could be enhanced

### 1.3 Research Design

Due to the exploratory nature of this research a qualitative approach was considered to be the most appropriate (Creswell, 2013). A qualitative approach provides a meaningful way of understanding and describing human experiences. It has been acknowledged there is no perfect research design rather the most appropriate design is chosen to answer the research question and purpose of the study (Bryman, 2012). In order to explore the experiences of families when a parent has cancer and understand the impact of the psychosocial intervention on children a descriptive qualitative study was used.

Initially the children were asked to draw a visual representation of cancer as a means of demonstrating their understanding of the illness. These visual illustrations were used as an adjunct to the narrative data from the focus groups with the children. The process of drawing allowed the children to demonstrate their knowledge of cancer and their experience of the parents' illness. Drawing, as a research methodology has been used as a method of data collection in health and illness primarily with children (Guillemin 2004). In addition, the children were already used to this activity as it was one of the activities employed in the psychosocial intervention sessions.

### 1.4 Participants

The target population were children who had completed the CLIMB<sup>®</sup> intervention and their parents. Potential participants were invited to attend for an evaluation session 1 week following the completion of the intervention. Separate plain language statements were provided to the children and parents in the penultimate session of the intervention. The inclusion criteria for the children and parents are presented in the table 1.

*Table 1.*

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

Participants were recruited from two centres in the Republic of Ireland. In addition to the children and parents, four social workers and one facilitator were also included in the study, all

of whom had completed 2 days training in delivering the CLIMB® programme. For the purposes of this report and in the interests of maintaining participant confidentiality all will be referred to as facilitators. See table 2 for demographic details.

*Table 2; Participants demographics*

<b>Children</b>				
<i>ID</i>	<i>Age (yrs)</i>	<i>Gender</i>	<i>Parent with Cancer</i>	<i>Type of Cancer</i>
C1	11	Female	Mother	Breast
C2	8	Female	Mother	Breast
C3	11	Male	Father	Colon
C4	10	Male	Mother	Breast
C5	6	Male	Mother	Breast
C6	8	Female	Mother	Breast
C7	10	Male	Mother	Breast

<b>Parents</b>			
<i>ID</i>	<i>Gender</i>	<i>Cancer Yes/No</i>	<i>Type of Cancer</i>
P1	Female	Yes	Breast
P2	Female	Yes	Breast
P3	Male	No	n/a
P4	Female	No	n/a
P5	Male	No	n/a
P6	Male	No	n/a
P7	Male	No	n/a

## **1.5 Ethical Considerations**

Ethical approval was sought from the Research Ethics Committee (REC) in Dublin City University prior to the research being conducted. To ensure that child assent and parental consent was obtained, detailed plain language statements and consent forms were developed that were age appropriate and in line with guidelines from the Department of Children and Youth Affairs (2012) and REC guidance. Additionally, to minimise distress, focus groups were conducted in the same location that the intervention was delivered and in a similar format to the previous intervention sessions. Arrangements were made for follow-up psychological support for participants if required, however, this was not required for either site.

## **1.6 Data Collection**

Focus groups are suited to the collection of qualitative data, particularly when the topic of enquiry is considered sensitive. They are flexible, stimulating, assistive in information recall and capable of producing rich data (Parahoo, 2014). Focus groups were conducted with the children by the first author in conjunction with the facilitator delivering the intervention. A topic guide based on current literature was used to focus the group discussion. At the beginning of the focus group the children were asked to write three words describing what cancer meant to them. This was followed by requesting the children to draw a visual representation of cancer as a means of demonstrating their understanding of the illness (Guillemin2004).

In this study the drawings were used as an adjunct to the narrative data generated from the focus groups. The process of drawing allowed the children to visually demonstrate their knowledge of cancer and to visually display their experience of their parent's illness. Drawing also facilitated the children with a means of portraying their emotions, either simply or in a more complex way (Guillemin 2004). This methodology was particularly suitable in this study as the children were already using this activity. It was one of the activities, in addition to play therapy that was employed in the psychosocial intervention sessions. The first author was familiar to the children as she had been attending all of the programme sessions prior to data collection, as a rapport building exercise with the children.

Concurrent focus groups were conducted with the parents by the second author in a separate room from the children. Similarly a topic guide was used to lead the discussion on the impact of parental cancer on the family, communication within the family when a parent has cancer and to seek their perspectives on the impact of the psychosocial intervention and how it might be enhanced.

Interviews were also conducted by the first author with the facilitators delivering the psychosocial intervention to explore their experiences of delivering the programme and to seek their perspectives on the impact the programme had for both parents and children.

## **1.7 Data Analysis**

Focus groups and individual interview data were transcribed verbatim. Data was analysed using Krueger's (2000) framework. Transcripts were read and reread line by line by the first and second authors. This data was initially coded and categorised thematically and following a critical discussion by both authors, final themes were generated. In addition, both authors, utilising Roses framework (2007), engaged in a critical dialogue prior to interpretation of the

drawings produced by the children. The authors' interpretations were also guided by the children's focus group narrative data around the pictures.

As part of the focus group the children were asked to write three words describing what cancer meant to them and to follow this up with a visual image. Some of the children integrated the images and the words, (see figure 1). All of the children were particular about their use of colour when constructing the images, they needed the 'right' colour. Most of the children used dark colours such as black and dark blue in the pictures. Following the drawing exercise the children were asked to describe the drawings and what they meant to them.

The images were analysed using components of Rose's visual methodology framework (2007). The images signified terror, cancer as a monster, a nightmare, a tsunami, and spiders. All of the images, with the exception of one, were congruent with the focus group data. The image that differed both in content, form and colour was figure 2. This particular child (aged 11) first drew three very small images of what cancer meant to her; scared, a spider, and a monster. It is interesting that these smaller images were incongruent with the larger more colourful, delicate image of 'the ghost of good will'. This particular child's parent had a secondary diagnosis of cancer. One could interpret this drawing as demonstrating the child's attempt to contain the fear she is experiencing. It seems that she appears to understand the gravity of her mother's illness. On the other hand, the image of the ghost could be interpreted as the child creating a preferred image; one that conveys a feeling of lightness and hope, and one that is more acceptable to her. In figure 3 the drawing represents cancer being killed by radiotherapy, with the smaller image on the left representing his mother being happy.

The findings from the parents, children and healthcare professionals, while being presented separately under the specific participant groups, are woven together in the discussion to present an overall coherent narrative designed to meet the objectives of the study.

## **Section 2: Findings; Parents' experiences**

### **Shock of the diagnosis and not knowing what to do and the uncertainty of the future**

All of the parents were understandably devastated on receiving a diagnosis of cancer. As one parent recounted:

*'Your world falls apart because you can just visualise them [the children] not having a mother growing through all those awkward, horrible teenage years ...' (P1)*

Many of the parents in addition to dealing with their own emotions at the time of diagnosis faced dilemmas of whether or not to tell their children the 'bad news'; what to tell them and how to tell them.

*'We wanted to hide from the kids. We were just in kind of ... not in denial I would say but unsure of what to do, and where to go, and how to say anything, because of course we were just dealing with the shock of it' (P2)*

Another parent compared the situation to:

*'Going into a spin .... you know the spinning tops that you have, where it has a coil string around it and then you pull the string and it sends the spinning top on a spin. It was like we were both coiled up right beside the [Doctors] desk. Got the diagnosis, and then it was just pulled and the two spinning tops just went into a spin. And if you can imagine these two spinning tops, what happens is, every time they touch anything it just goes flying, if they touch each other they go even worse, and so it took about probably, about 6 weeks or even longer for us to kind of reconnect. We were in two different worlds. And what happened then was there was an amount of distance and I couldn't understand, I couldn't assimilate the information, and I wasn't prepared to take any action with the children until I had assimilated it myself' (P3).*

### **When to tell**

Another parent decided to tell the children about the diagnosis after they had been receiving chemotherapy for a month. Losing one's hair was the impetus for disclosure at this stage because of the visibility of the treatment. Some of the children, according to the parents experienced other children making fun of a mothers changed appearance. Also, some of the parents had disclosed the diagnosis to friends and they were afraid that the children would overhear things in the playground.

As the parents struggled to come to terms with the diagnosis some of them became aware that the children, especially the older ones, sensed a change in the atmosphere at home. For many of the parents surgery and or treatments commenced immediately following diagnosis. Thus, these parents had no choice but to give the children some explanation for hospital visits and in some cases hospitalisations. Agreement between partners on when to, what to and how to tell the children varied. Partners did not always agree on the timing of disclosure.

One parent described how their seven-year-old daughter became aware of increased phone calls, whispered conversations and friends visiting the house. This particular child asked her father directly did her mother have cancer and he felt he had to respond honestly. In this particular case the mother was upset at the disclosure. However, the father felt that this was an opportunity to be open with the child who already suspected that all was not well.

### **What to tell**

Other parents in an effort to protect their children gave them information 'in small bite sizes' explaining why a mother or father needed to visit the hospital frequently or be absent for longer periods for surgery. While many gave this information, they did not explicitly use the

term cancer. Rather they used 'protective language' like 'strong medicine' (P7) to talk about the illness.

Another parent described how he liked to research topics that he lacked sufficient information on. He sourced a methodology that was developed in another country on how to disclose a cancer diagnoses to children. Both he and his wife agreed this was a useful methodology and used it as a guide to talk to their children about the illness and in deciding what to tell them.

*'Okay we're telling them, well let's follow a format, let's follow an agreed methodology' and so we did that, didn't we, and we used kind of a nice story to talk about the cancer, how we would talk about it to the kids. (P3)*

Some of the parents were very surprised that the facilitators in CLIMB® explicitly used the term 'cancer' to talk to the children and to encourage the children to talk about their feelings. The children's willingness to openly use this term and to talk about treatments and also their emotions and worries paved the way for better communication between the children and their parents and led to deepened relationships.

## **2.1 Children's experiences**

### ***Children's understanding of cancer***

The children [see table 2 for demographics] described how they hated the mention of the word cancer with some expressing how it scared, shocked, saddened and annoyed them. Others described it as silly, mean, scary, ridiculous, hard and disturbing.

*'It makes me feel sickly, because when I hear it, my tummy gets butterflies in my tummy' (C6, 8-year-old girl)*

All the children used visual images to help them describe what cancer represented to them. The images ranged from monsters, nightmares, clowns, and spiders. All of the things it seemed, that frightened them. The children represented these various images artistically (see figures 1-4).

As discussed above the use of picture drawing and colouring was a non-threatening way in which to introduce the term 'cancer' to encourage the children to talk about it, and to express the emotions that arose for them as a result of a parent being so diagnosed.

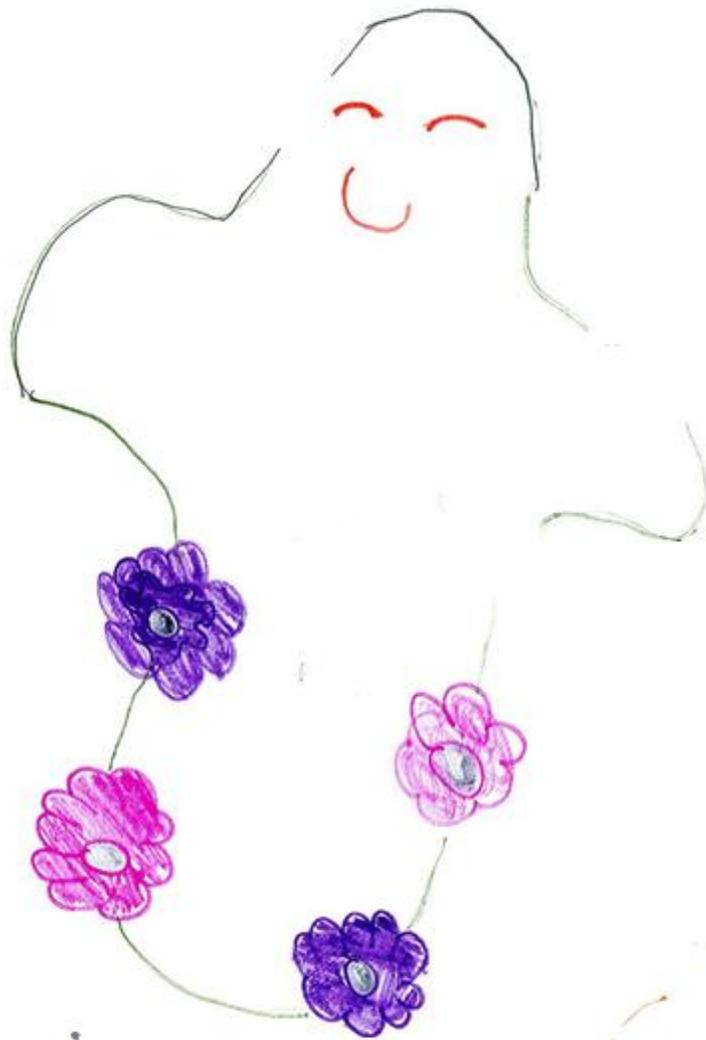
For many of the children, the term 'cancer' was not new. They had heard it being used in relation to grandparent's illnesses and deaths; as well as extended family members such as aunts and family friends. One of the children, an 11year old girl, emotionally recounted how many female members in her extended family had already died from cancer.

While the data evidenced that cancer was not a new term to the children, not all of the parents had explicitly told their children that they had cancer. In some instances this occurred only when the children attended the programme. One of the children articulated how she did not like using the term and how it affected her 'because it sort of disturbs me, because it makes me feel funny, so I can't really focus' (C6: 8-year-old girl)

Another child articulated the meanness of cancer and expressed how he did not like 'the way it acts to my mum, and I don't like her having it' (C5: 6 year old boy) Many of the children were emotional when recounting how they learned about a parent's illness and they also displayed emotion and empathy when hearing the other children in the group talk about their own experiences.



Figure 1.



*The ghost  
of good  
will.*

Figure 2.



Figure 3.



Figure 4.

### ***Finding out about cancer and learning to talk about emotions***

The manner in which the children discovered that a parent had cancer varied. One of the children found out accidentally when she observed her Mother packing her bags and asked; *'why are you packing bags? Her mother replied, "I am going to the hospital because I have cancer" (C6: 8-year-old girl).*

On the other hand, some parents created a space and a time to tell the children about the diagnoses. One of the children recounted how he knew something was wrong when both parents arrived to pick him up from school:

*'I knew something was going to happen because that day my dad and my mum collected me from school and that's like really uncommon... it's always something bad when they both pick me up from school. I always think that'. (C 4: 10-year-old boy)*

Another child recounted how she knew that something was wrong when her Mother returned home from work early:

*'Well she came home from work early and she just had her like MRI and she came back early and that's never a good thing because she never comes back early after when she's having her chemo and then she came in and told us...' (C1: 11-year-old girl)*

Another boy (C 7: 10-year-old) wondered why his father had sent a friend to pick him up from school that day and later in the evening. When he asked why this had occurred, his father told him that they were in the hospital for tests and they found out that his mum had cancer.

Another child asked why his father had to travel to another country and was told he had gone for treatment for his cancer. (C3: 11-year-old boy) Another child whom both sets of grandparents had died from cancer expressed that while he was shocked *'I knew it was going to happen but then I didn't think it was actually going to happen, but it did'* (C4, 10-year-old)

### **Benefits of CLIMB<sup>®</sup> for the children**

Attending the program gave all the children emotional support and knowledge about cancer. Meeting others in the same predicament reassured them and appeared to have a calming effect. While some were excited, particularly when a parent informed them that they would learn more about cancer, others expressed feelings of being 'scared and worried' about attending. These feelings however, dissipated as the weeks progressed and they looked forward to the weekly meetings. One of the boys expressed that he liked attending because he knew:

*'That we could talk about the sickness our mum's are having or our dad's and we could learn about it more and more to get less scared... I learned that cancer has two different treatments to try and get rid of it: chemo and radiotherapy. Chemo can pop good cells and bad cells, and radio [therapy] can pop just bad cells, and it focuses on one spot' (C7: 10-year-old boy).*

*'if like one of your parents has cancer you should go to it [Climb®] because you can like describe what you're feeling and tell them everything, like you don't really have to keep anything a secret because nobody is different to you there. 'Everybody [there] has parents who have cancer'... (C1: 11-year-old girl)*

In addition, children as young as six years expressed an overall conceptual knowledge of the workings of cancer treatments as evidenced by the data segment below:

*'It's only taking one big cell. All the little cells are still there. That's why my mum has to have weekly days of another type of it. [Treatments] That's why she has to have lots of little ones, which is going to take all the little bad cells' (C5: 6-year-old boy).*

All of the children enjoyed how the programme used arts and crafts to help them to express their emotions of anger and sadness and to learn how to articulate these emotions in dealing more effectively with their feelings. The worry box was a central device for the children in learning how to manage these feelings. The children used this tool to write a note about their worries and to keep this secretly in the worry box.

A second device was the anger cube, which was made in week 5, where the emotion being discussed was anger. The children drew pictures or wrote words of things that made them feel good or happy and placed these on each side of the cube. Then when the children were experiencing anger they threw the cube and used their own suggestions to modify these feelings. For example, if they were angry and the cube directed them to count to ten, or listen to music, they had a choice of strategies to adopt or alternately roll the cube again for another type of activity. The success of the above strategies is evidenced in the data segment below:

*'before [coming on the CLIMB® programme] I'm always in such a bad mood in the morning... on one of the pink ones [writing slips] I wrote down I were quite worried if my mam would die and stuff... and I wrote down like when my mam was in hospital because it was really hard like' (C1: 11-year-old girl).*

Another child expressed how the programme had helped him not to blame himself [for his father's cancer] and that he now discussed things with his older teenage sister and had told her about the activities and strategies he had learned.

### ***Parental cancer altering everyday domestic life***

All of the children expressed feelings of sadness when they discovered their parent's illness and talked about how the illness had altered their daily routines. The overarching change in everyday life for the children was observing parental fatigue. This affected so many aspects of daily life and activities. For example, cooking meals changed from having full dinners to more simple dishes. One of the children expressed this:

*'she's really tired and we don't cook as big meals so [we] just cook like pasta sometimes...she's always in bed and she always allows me on the computer when she's in bed but she never does that normally' (C4: boy 10year old)*

Another child recounted how his father was always tired and spent all his time on the couch and when he 'puts a movie on he just falls asleep like [for] the whole movie' (C3: 11-year-old). However, it seemed his father's energy levels had improved after they had got a dog. While on the other hand, another child expressed how their mothers' illness had resulted in increased hygienic vigilance around the dog. For some of the children play dates were also curtailed because of parental fear of infections. Other children talked about how the fact of their parent's inability to drive affected their social activities. They were now using public transport or getting taxis and dependant on extended family and friends to take them to the various activities that children engaged in.

The data also evidenced that despite the activities on the programme many experienced heightened tensions in the home. They talked about quarreling with other siblings and missed having one to one time with the ill parent.

*'The girls (sisters) have been having time with mummy but I haven't. I don't really get to see mummy most of the time, because the cancer's stopping me' (C5: 6-year-old boy)*

## **2.2 Facilitators' perspectives and experiences**

### ***Learning about cancer and talking about emotions***

The facilitators described varying experiences of delivering the programme. Some were very experienced having delivered the programme up to seven times while others were relatively new and had delivered the programme on two occasions.

One facilitator describes how helping children to deal with their feelings around cancer on the CLIMB® programme enables them to name their feelings, explain what a feeling is and gives them tools to manage these emotions. The format of the programme also enables peer

support to be established within the group of children. The children also learn that they are not alone, that they are not the only ones with a parent with cancer, and the isolation they may have experienced prior to coming to the programme is dissipated.

Meeting other children in the same situation as themselves somewhat normalised the experience for them. Having other children to talk to appeared to alleviate some of the anxiety for them. They are able to see that they are no longer the only ones who feel this way. There are other children going through the same thing. One facilitator also described how peer support can be more important than what the facilitator has to offer, and in this way the group support can be very powerful among the children.

*'so they're all kind of going through a similar experience and they hopefully then listen to each other a little bit because it's way more important to what ... I always feel the things that they say out loud in the group are way more important than anything I'll ever say in the group' (F2)*

The children are also learning about cancer and the different treatments that their parents are going through in an age appropriate manner and in a language that they can understand through art or games. The programme also provides the children with tools to deal with their emotions, which are akin to life skills, and these can be shared with other siblings and their parents. Facilitators also acknowledged that these tools can help the children to better communicate with their parents and the facilitators while engaging in a fun art activity.

*'It's very hard for kids to talk to adults, particularly when in 90% of the homes the adults won't talk to each other. So, I think the little tools help them communicate with adults. (F5)*

Participating in the programme also gives the children an opportunity to talk about their emotions. Frequently, children feel that there are some issues they can or prefer not to discuss with their parents.

The CLIMB® programme repositions the children at the centre of the family once more, a position they held prior to the cancer diagnosis

*'I think actually the number one thing for me is they become an important person again. And I don't mean they're forgotten about in homes at all. I mean, the child will still be in it. But at the end of the day, all of a sudden, the visitors who came to see them aren't coming to see them anymore. So, they come into a room and it's all about them. It's not about anybody else. It's about them' (F5).*

Children are also better informed about their parent's cancer and better equipped to deal with their feelings. The programme can also provide the children with the confidence to ask difficult questions they may not have felt they could have previously asked. Children are now involved

in the illness journey. The programme teaches the children skills that they may be able to use to help support their parent, so giving them a purposeful role to play.

*'I just think it's about them, is a strength of the programme and that it's not about adults which it normally is. It's very much focused on them and how they can help the adult rather than the other way around. You hear little stories of them making breakfast in bed or whatever, I mean, they must feel like... and it's not about making the kid the adult in the house but it does help them think well we can do something to help here, too' (F5).*

### ***Creating spaces to talk about cancer***

Facilitators described how frequently parents are afraid to talk to their children about cancer and that when the children start the programme how the parents feel that it is time to begin this conversation with their children. The parents value the professional support that the programme offers in commencing this dialogue. The facilitators also described how frequently parents are desperate to do something to help their children develop an understanding of the illness. Enrolling them on the CLIMB® programme makes them feel that they are doing something positive and useful for their children. Often cancer treatment regimens and schedules result in some parents feeling they do not have the space or time to give to their child but the programme creates and offers that space so that the children can talk about their worries and concerns. This is a relief and somewhat creates a respite for parents as it also provides space for the parents to process their own worries and uncertainties.

Parents are often anxious about talking to their children, and CLIMB® provides them with the tools to start that process. The programme provides mechanisms for the children to start the conversation around cancer. It gives them a vocabulary and helps them to understand the disease process in a language that is simple and easily understood. The facilitators described how the children now feel included in the experience of the illness and are provided with an understanding of the treatments their parent is undergoing. In addition, the children now have their own peer group to discuss the cancer with. Through the children asking questions of their parents, it forces the parents to start talking about issues they may have been avoiding as the children are now empowered to ask questions. The facilitators also felt that CLIMB® offered reassurance to the parents by removing some of the burden of responsibility for a short period of time. Parents know there is someone else there for the children at the moment to help them with their emotions and to communicate in a language that the children understand. This

is important for parents and they appreciate being informed by the facilitators of what they will be doing in each session.

Parents are often shocked by the children's responses to the programme, particularly the children's 'buy-in' to it. They look forward to the sessions and they are upset if they have to miss a session. Parents want to support and protect their children and being part of CLIMB® offers them a sense of community if only for a short time with other children. The parents know the children have the support of others in the group. There is a commonality among them. It also provides parents with tangible tools to use with the children after the programme is over. However, parents remained worried about their abilities to successfully navigate future events.

The 'Get Well' card the children make at the last session is often overwhelming for the parents as it demonstrates to them that their children understand what is going on and illustrates how they are managing it.

### **What next?**

The challenges that the facilitators experienced revolved around the type of referrals and uptake of numbers for the programme as well as follow up for children and parents. Due to the varied locations and centres at which CLIMB® is offered, there is no standardised approach to recruiting children to the programme. Facilitators in both sites included in this study relied upon the cancer support centre to enrol children on the programme. However, they would have also received referrals from their hospitals to the cancer centres. Some facilitators expressed the need to be involved in the screening process prior to the commencement of the programme to ensure that it was appropriate for the children. This however did not always occur despite the fact it was part of the referral criteria on to CLIMB®. This led to some challenges such as parents bringing their children to the first session when they had not used the word 'cancer' before.

Some of the facilitators suggested that altering the time schedules of the programme would make it more accessible for parents as some participants encountered traffic difficulties. One facilitator suggested that centres might broaden the calendar year for CLIMB®. Currently it is run in line with the school year and not offered over the summer months.

Some of the facilitators described how the variation in ages and development of the children on the programme frequently affected the group dynamics. All facilitators acknowledged how important it was to have a co-facilitator delivering the programme as this acted as a support

mechanism and enabled them to debrief after each session. Some facilitators who had just started to deliver the programme felt they would have benefited from more structured/formalised feedback by speaking with other facilitators who had more experience of delivering the programme. They felt this would be a vital element in not only helping them build and develop their skills for future programmes but also act as peer supervision.

Some facilitators also mentioned the need to provide some form of follow up support and aftercare for the children should it be necessary. This highlights the apparent present lack of family support services for families affected by cancer in Ireland, CLIMB® endeavours to fill this gap in services. CLIMB® is a self-contained programme and it is advertised as this to parents, the facilitators are not in a position to offer follow-up support to families once the programme is completed. There are some cancer centres that do offer counselling services to children but these resources are scarce and both facilitators and parents have described their concern on this. Given the limited services for families affected by parental cancer CLIMB® is the only programme aimed at young children, resulting in a gap in services for older children and children with learning disabilities. One of the facilitators acknowledged '*CLIMB® is not the answer to everything*'. There needs to a more structured family support service in place. This is a wider policy issue that needs to be specifically addressed by the new Cancer Strategy which was published in 2017 by the Department of Health (DoH).

Some facilitators felt the programme is not designed for parents who have a secondary diagnosis or whose treatment is non-curative. The structure of the programme is not a fit with a parent dying, as the needs of children in this situation would require different skills.

### **Section 3. Discussion**

The findings from the study showed that a cancer diagnosis in a family is a devastating event for the entire unit. Parents understandably were shocked with some needing time to process the information before they could think about discussing it with their children. The timing of the disclosure to the children varied amongst the parents in this study. Some depending on their level of self-awareness and emotional intelligence began this conversation at an early stage while on the other hand, many of the parents felt ill-equipped to deal with the emotionality around the word cancer. Findings that concur with what is already known about parents responses to a diagnosis (Raunch and Moor, 2010; Semple and McCance 2010a). This finding supports the benefits of having timely conversations with children to promote open communication and reduce mistrust, thus reducing the psychological and social problems that may arise, for both the children and parents (Visser et al, 2004, Osborn 2007).

The findings in this study evidence that parents were surprised at the ease at which the children adopted the language of the illness. They were not reticent about openly using the term 'cancer' and the programme helped them understand the various treatments and side-effects that the parent with cancer was experiencing. However, despite the children's apparent ease with the language of cancer the images they drew demonstrated their fear, worries and of how their imaginations understood the illness. Interestingly, a dichotomy appeared to exist between the parent's version of the children using the word cancer and the children's reports. The children described how they hated the mention of the word 'cancer' with some expressing how it scared, shocked and annoyed them, while others described it as silly, mean and ridiculous.

Although the use of arts and crafts to facilitate the conversation and discussion with the children appeared to give them a certain level of comfort with the diagnostic language, their images demonstrated the reverse. Participating in the programme gave the children the words to articulate what was happening at home and they were now part of the illness conversation. While many of the parents did not disclose the diagnosis to the children at an early stage, the children did sense a change in the home environment. They knew that something was wrong. They intuited this change through the altered domestic routines, a finding that concurs with that of Scott et al, 2003, Semple & McCaughan, 2013, and Furlong, 2017. Attending the CLIMB® programme was a positive step for all of the children. It gave them a chance to express their worries and meet other children in a similar situation, which appeared to have a somewhat calming effect as they bonded together as a community. This finding highlights the value of promoting a comfortable, normalised environment in which the children can talk to their peers (Ellis et al 2016). The parents were aware of this also and felt that the programme was a great psychological support to the children and to them as well. They felt that the programme removed some of the burden of responsibility on them. The tools the children learned to use on the programme were life skills that could be applicable in any serious life event, which furthermore could be and were used by other members of the family.

The findings from this study evidenced that most of the children were better able to openly express their emotions and had more open communication with their parents following the completion of the programme. They learnt adoptive strategies to manage their feelings. One parent however, expressed a concern that his six year old child was displaying increased somatic symptoms since starting the programme. This father described how the child would internalise his emotions prior to starting the programme. However, he did acknowledge that the programme had given his son the words to express and process his emotions and this may

have been a reason for his increased somatic symptoms. This one instance concurs with the findings of Shallcross et al (2016) who suggest that when children gain a greater understanding of their emotions, a short-term increase of negative emotions may result from this insight. While the findings from this study align with those of Shallcross et al (2016) and Semple & McCaughan (2013) cognisance needs be paid to the challenges involved in delivering a programme that covers a broad age span. It may be that one to one sessions are necessary for children with significant distress as recommended in another psychosocial intervention (Phillips & Prezio, 2016). This recommendation also concurs with an expression of the parent that additional one to one session may be beneficial to the above mentioned child. This also demonstrates the importance of facilitators being able to manage the different needs of the various children. Despite the differences between the children's level of emotional maturity and the disparity of ages, the parents and children unanimously agreed on the benefits of the programme. The parents felt that the strategies learnt on the programme empowered the children to manage their emotions, again a finding that concurs with other scholars (Shallcross et al, 2016, Semple & McCaughan, 2013). The parents in turn felt empowered and better equipped to discuss and share the illness with their children and to include them in the illness conversation.

Another unexpected finding that emerged from the study was the differences between spouses on when to disclose information to their children about the cancer diagnosis. Some parents took longer to process the diagnosis resulting in disagreement around disclosure of information to the children. It has been noted in the literature that individuals' responses to illness may be influenced by their gender (O'Neill et al, 2013). Although it has been acknowledged in the literature that men and woman can have similar cancer experiences, the manner in which men respond may be very different to women (Robertson, 2007).

The findings in this study point to the importance of taking a family centred approach to talking about cancer with the children. As previously mentioned there is no structured family support service available in the Republic of Ireland. This is a wider policy issue that needs to be specifically addressed by the new Cancer Strategy which was published in 2017 by the Department of Health (DoH). There remains a significant gap in psycho-oncology and psycho-social support services with only two of the designated cancer centres having dedicated psycho-oncology services, one of which is part time (DoH, 2017). Although a new proposed model which adopts a multi-disciplinary approach in the hospital and the community through cancer support centres is recommended, this proposal will require a co-ordinated and resource rich supports. As identified in the strategy, cognisance must be taken of the predicted growth in

incidence of cancer and demand for services in the coming years, all of which will necessitate additional requirements to be added to current inadequate services (DoH, 2017).

### Developmental Ideas

The facilitators acknowledged that it would be beneficial to have a facilitated group for the parents/carers while the children are taking part in the programme. This does not have to be facilitated by a trained health professional but could be guided by staff in the cancer centres. Indeed, the parents themselves acknowledged that this frequently occurred informally and they found it to be a very powerful source of support. Facilitators also suggested offering a seventh session with the parents and the children together. This seventh proposed session could present an opportunity to explain to the parents what the children had learnt over the six weeks, thereby reinforcing the skills and tools used. This seventh session could also be an opportunity for the children and the parents to do something together creatively through arts/activity. The facilitators could show the parents the tools that were used and from then pass these on to the parents so empowering them to continue as a family. Parents need to feel empowered that they are best placed to work with their children. Currently parents are not part of the programme so this session may make it more cohesive for the parents, providing them with the confidence to continue with the skills learnt through CLIMB®. This is particularly relevant for parents in the Republic of Ireland due to lack of family support services for those affected by parental cancer.

The facilitators acknowledged that parents struggle with the transition at the end of the 6 week programme, feeling doubt and insecurity in their ability to manage the situation. The facilitators described that the involvement of the parents at the end of the programme could facilitate the continued conversations with the children that had initiated during the programme.

### **3.1 Limitations**

One of the limitations of this study was the small sample size, and therefore the findings cannot be generalised. In the second site due to unforeseen circumstances there was a change of facilitator mid-way through the programme. This unavoidable personnel change may have altered the dynamic of the delivery of the programme on that site.

## Section 4. Recommendations

1. Facilitators should be involved in the screening process of the children prior to the commencement of the programme in order to ascertain the suitability of the child in terms of maturity and age. This screening process should be protocol directed. Also it is recommended that there is a two way conversation between the facilitators and the parents prior to the commencement of the programme in order to obtain the necessary background information required.
2. To have a dedicated session within the programme with both the parents and children to reinforce the skills and tools learnt on CLIMB®. This would be an activity based session using art/games with the aim of educating and empowering the parents to continue to use the tools learnt in the programme.
3. To develop a follow-on support mechanism for children who maybe experiencing significant emotional distress. For example, providing parents with contact details of child counselling services.
4. To consider offering a bi-monthly meeting for parents and children facilitated by trained expert parent. Parents may also want to initiate their own support structures following the programme, for example creating a WhatsApp group. This would facilitate the community bond established during the programme to continue to grow and develop.
5. To consider offering the programme during the summer months.
6. It is strongly recommended to implement a clinical supervision mechanism for the facilitators.
7. To have a professional oversee the programme at a country wide level to ensure continued fitness for purpose and standardisation across all venues. A clear structure of governance of CLIMB® in Ireland would ensure this.
8. To develop a policy initiative to support the current and future development of the programme to ensure the long-term sustainability. A family support service to be developed nationally is also suggested. This should be a priority for the new National Clinical Lead for Psycho-oncology, yet to be appointed by the National Cancer Control programme (DoH, 2017).
9. Another recommendation would be to conduct further research taking a longitudinal approach, perhaps by following the families up 6-12 months post completion of the programme.

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# Appendix 1. Map of Centres Offering CLIMB®

