Child cancer FOUNDATION

Young Voices, Wise Choices

Incorporating a children's voice into organisational decision-making processes. The Child Cancer Foundation experience.

Kerry Price and Rachel Pienaar

Acknowledgments

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We would also like to thank Dr Heather McDowell for her advice on research design and the Family Support team here at Child Cancer Foundation, especially Amy Cammell. Without their contributions, this research would not have been possible.

Finally, and most importantly, we would like to thank the children and families who participated in this piece of research for the spirit, generosity, participation and knowledge they shared so kindly. The photos illustrating this report were taken by the participants of the Young Voices, Wise Choices Project and have been reproduced with consent of participants parents.

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Executive Summary

The New Zealand Child Cancer Foundation (the Foundation) provides a range of support to children and families who experience a childhood cancer diagnosis. As a 'consumer centric' organisation, the Foundation investigated mechanisms to incorporate children's voices into the organisation's decision-making processes. Young people's participation—or lack thereof—has been an area of broad debate in youth policy in recent decades. Young people's participation is seen as vital for the future of democracy, and youth policies need to establish youth representation structures where young people learn democratic citizenship and leadership via youth councils or youth parliaments[i].

In 1989, the United Nations Convention on the Rights of the Child (UNCRC) – which New Zealand ratified in 1993 – established a child's right to participate in society. Specifically, one of the rights guarantees every child an opinion and for that opinion to be heard. The challenge for many children's charities is how to capture this voice. While youth organisations can engage in direct representation through youth councils or advisors, this is a challenge for organisations such as Child Cancer Foundation. The question arises, 'How do you engage children in meaningful decision-making processes and incorporate their voice into the work of organisations?' This report discusses a process utilised by the Foundation to engage children and explores the results, which were both insightful and some of which were expected.

Dan Te Whenua Walker
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SADERS 25' SEASON
PANGO MĀ WHERO, KA OTI TE MAHI.
Finlay Brewis
Geb Calder
Tom Christie
DREAM big
little one
Big Sister...
SECOND PLACE
I have a monkey in my chair.
MONKEY IN MY CHAIR
THECUTESTARTSNOW
SLT DON'T RINSE
SUPER SMILE

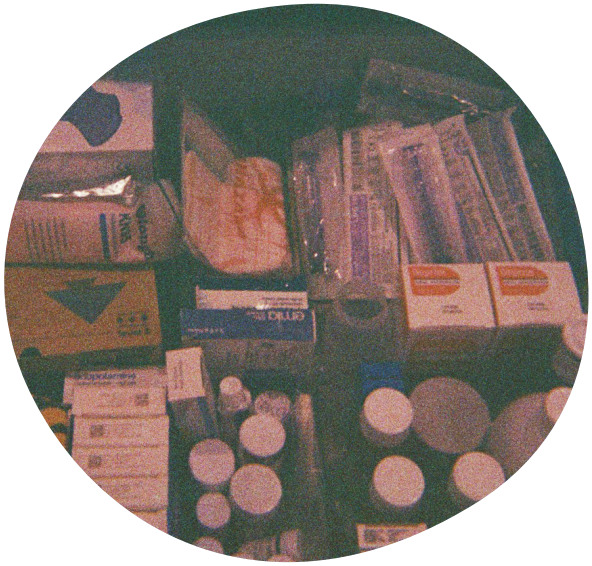
Introduction

As a child and family-focused entity, the Foundation is committed to capturing the needs, perspectives and voices of children in the work of the charity. The organisation wanted to find out more about the way the children we work with see and communicate about their situation and environment. This type of research is supported by our vision and values which place the child and family at the center of the organisation. It also increases our impact in a way which is dynamic, transformative and representative of the children we support. Much of what we learned was expected in terms of our initial assessment of the literature, our own social impact work conducted in partnership with Huber Social, and existing engagements with children via initiatives such as our Star Ambassadors and Online Antics programmes. There were, however, some novel findings particularly in relation to siblings, the value of the process itself, and the important role of technologies and soft toys, all of which are discussed below.

Our aim is to use the data collected to support our strategic planning and service delivery. Having reviewed the literature (Dryden-Palmer et al., Blamires et al., Hovland et al., Armstrong K,), many of our results, particularly those to do with siblings, are consistent with findings in more formal studies. Dryden-Palmer et al. note that it is common for siblings to feel confusion, jealousy, resentment and guilt, or to blame themselves for the distress they witness[ii]. In a New Zealand context, Armstrong, K., showed siblings of children with chronic health conditions were affected negatively and potentially long-term from a range of factors. The impacts of these issues can lead to depression, anxiety and post-traumatic stress symptoms, and affect beliefs around self-worth[iii].

Another piece of work conducted by the Foundation found that around 32% of siblings experience PTSD symptoms similar to the child with a cancer diagnosis[iv]. Armstong, K. also makes recommendations that speak to the inclusion of siblings in an age-appropriate manner in the sharing of health information and family decision-making as part of the wider family unit. Certainly, the data collected from this study suggests the benefits of sibling inclusion is beneficial to the child with a childhood cancer diagnosis. Although additional research would be helpful to support this finding, there is evidence that positive sibling relationships provide a protective factor[v] (Gass, Jenkins, Dunn).

Through research undertaken by Hanlon, A., we were cognisant of the need to use a methodology that did not re-traumatise the children we engaged with. This led us to the Photovoice Methodology (Johns Hopkins Center for Health Equity[vi]) which allowed for a facilitated child-led process. The consequence of this approach was a set of positive discussions as the participants reframed their experiences, while at the same time valuing the process in and of itself. Our hypothesis is that this methodology allows for participants to be heard and feel valued. While this is discussed more below, it is one of several novel findings that provide further areas for additional research.



Ethics and Consent

As a not-for-profit provider of psychosocial and other support services, and as the sessions were intended to be service-designed and evaluative in nature, the Foundation did not explicitly seek academic ethics approval via national or regional ethics committees. We did however design a process which followed a strict protocol around participation, individual child and parental consent, participant non-identification and a process that considered trauma-informed programme design. The methodology allowed each session to be participant-directed and each child could exit the programme at any time, with two doing so. Parents were invited via letter to engage with their children and ask them to participate. Children, via discussion with their parents, were then asked to volunteer and give their own signed consent. For parents unfamiliar with focus group formats, we explained the process and noted that the Foundation was interested in the themes that arose from the groups collectively rather than individual comments. The participant consent form is attached as Appendix One. Written consent from parents and the child were required for the child to participate in the Photovoice sessions.

Methodology

Following extensive consultation with members of the Foundation's Family Support Team, a Health Psychologist specialising in working with children, and a Health New Zealand[1] Play Specialist, the Foundation determined to hold a series of online focus group sessions using a Photovoice methodology developed by Johns Hopkins Center for Health Equity[2] which we called Creative Investigation sessions (CI). All participants were from families currently on caseload and receiving direct support from the Foundation. Children were then numbered, alongside their status as either a child with lived experience of cancer or a sibling and their age and gender. This data was then entered into ChatGPT alongside an instruction to generate six randomly selected groups of seven per group based on age characteristics (under six years old or between six years and thirteen years old) and cancer status (children with a childhood cancer diagnosis in the last two years between the ages of four and thirteen). Using artificial intelligence (AI), we were able to generate random groups of individuals of mixed ethnicity, gender and socio-economic status from around New Zealand. Eligibility for participation included all 331 children on caseload with twenty-four being selected.

Sibling inclusion was deemed important as work conducted by the Foundation into Trauma Informed Care indicated that around thirty percent (32%) of siblings with a brother or sister with a long-term condition or palliative diagnosis experience post-traumatic stress symptoms (PTSS) at the same or similar levels to their unwell siblings[vii]. Palmer et al. has also noted that *"promoting and facilitating family interactions and engaging younger family members in the hospital experience [has] been shown to reduce patient and family anxiety, enhance family adaption, and improve child and family outcomes."*[viii]

The first sessions with each group were introductory and included name sharing, an interactive game and a 'how to use the camera' segment which had been sent in a pack along with the thematic questions[3] to be used for the whole programme prior to session one. Session one was held after school with the second and longer session held during the June/July school holidays.

Each participant received a disposable camera and was asked to take photos to visualise their point of view in response to a set of thematic questions. At the end of the six sessions, cameras were returned to the Foundation in prepaid envelopes to be developed and sent to both the Play Specialist and the children participating via their parents. By using a Photovoice methodology we hoped to prompt and encourage the child to think about responses that were driven by the child's perspective and creativity.

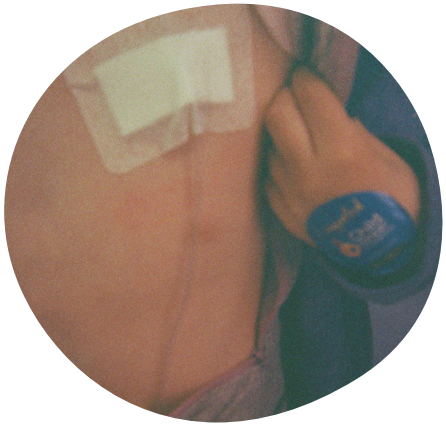
Johns Hopkins Center for Health Equity describes how Photovoice works as:

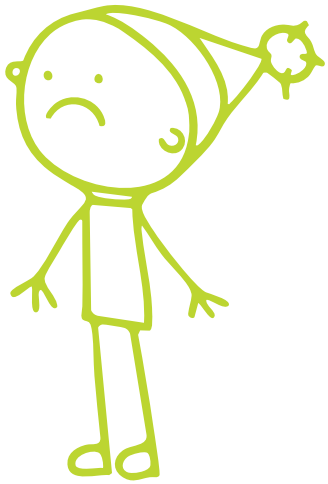
- Participants take photographs: People directly impacted by a certain issue are given cameras or smartphones to document their day-to-day lives or specific experiences.
- Discussion and reflection: After capturing their images, participants discuss what their photos represent. These reflections can highlight critical insights about their challenges, aspirations, or the realities they face.
- Creating a narrative: Through storytelling, participants attach personal meanings to the images. This narrative adds context to the photographs and can be used to communicate powerful stories to a wider audience.

[1] *The Play Specialist works in a hospital setting in a Health New Zealand/Te Whatu Ora service which is the country's provider of health and hospital services.*

[2] *Photovoice is a participatory visual qualitative research method (research that involves direct collaboration with those affected by an issue being studied for the purpose of action or change) that combines photography and narrative storytelling to capture individuals lived experiences, particularly those from marginalized or underserved communities. The approach allows participants to visually document their environments and experiences, enabling them to share insights into social, political, and health-related issues. Photovoice is frequently used in public health, sociology, and community development to empower participants and engage them in advocacy and policymaking. Photovoice | Johns Hopkins Center for Health Equity.*

[3] *We have used the phrase 'thematic questions' as questions which were asked in an indictive and loosely structured fashion. They were asked in a manner that allowed the children to define their response without retraumatising or placing to much structure around how they chose to interpret what was asked, creativity was encouraged.*





The Foundation agreed photos were to be owned by the child with rights of use provided to Child Cancer Foundation following consultation with the parent or guardian of the child. The Foundation had considered using a validated tool such as the Stirling Children's Wellbeing Scale; however, given the tool itself is designed for children eight and above, this would exclude a significant portion of those we wanted to engage and would not address some of the areas we wished to explore. Instead, we developed a set of four thematic questions. These questions were:

1. Who am I?/What makes me… me?
2. Who/what is important to me?
3. What's it like living with my illness?/What's it like living with my sibling's illness?
4. What helps me and my family?

Each participant was asked to take a photo or photos that represented the above four questions. These photos would then be shared with the rest of their CI group in the second session which was held approximately six weeks after the first session. The children and facilitator explored the photos and what they meant to the presenting child and any resonance the pictures had with other group members.

As noted, above groups were organised into two age cohorts of four to six years old and seven to thirteen years old. They were further divided into those with lived experience of a childhood cancer diagnosis and sibling groups. Each group had between five to seven children, with slightly more male participants than female participants. There was a gender disparity (57% male, 43% female) which was largely a result of two female participants withdrawing. The use of the Photovoice methodology was selected as it enabled a child-led discussion to take place and therefore avoid the re-traumatisation of participants to the greatest extent possible. Despite this, two participants felt unable to continue beyond the first CI session. Siblings participated via their own CI groups. Each group participated in two sessions conducted online to ensure participation from across New Zealand.

The online sessions were facilitated by an expert Play Specialist from the Children's Haematology and Oncology Centre (CHOC) at Christchurch Hospital. A Manager from Child Cancer Foundation was also present. The sessions were recorded for transcribing and then the recordings destroyed.

In line with our values of Whakapono and Tautiaki (belief and trust), and because we wanted to demonstrate through action our valuing of the voice of participants, each child received a $50 gift voucher. This included the two participants who withdrew after the first session. While a token of gratitude was important from the Foundation's perspective, our experience with our community is that many young people who access services actively want to 'pay it forward' through participation as ambassadors, fundraisers, lived experience speakers, mentors or other activities.

Results

The following analysis of the results was completed by reviewing the transcripts. Using a modified focus group methodology to collect the data, we facilitated small group discussions with participants who shared common characteristics or experiences that were relevant to the research topic. The goal was to gain insights through group conversation and then analyse the data for common themes. Notwithstanding this, there are some interesting outcomes that warrant additional research using different methodologies. These are discussed below.

Table One. Participants with a childhood cancer diagnosis by age and sex (anonymised coding N =24)

Code	Age	Sex	Code	Age	Sex
CA	7	Female	CM	8	Male
CB	6	Female	CN	9	Female
CC	7	Male	CO	13	Female
CD	7	Female	CP	10	Female
CE	6	Male	CQ	11	Female
CF	7	Male	CR	10	Female
CG	6	Female	CS	10	Male
CH	7	Male	CT	12	Female
CI	8	Male	CU	11	Male
CJ	6	Female	CV	13	Female
CK	6	Female	CW	9	Female
CL	6	Female	CX	13	Male

Table two. Sibling participants by age and sex (anonymised coding N =12)

Code	Age	Sex	Code	Age	Sex
SA	8	Female	SG	7	Female
SB	8	Female	SH	5	Male
SC	13	Male	SI	12	Male
SD	8	Female	SJ	11	Female
SE	6	Male	SK	5	Female
SF	7	Male	SL	11	Female

Many of the children's insights demonstrated 'the wisdom of children'. Child CA (F 7) expressed a deep love for learning and shared her excitement about sewing projects, including making a jumpsuit and a skirt for her doll. Her enthusiasm for these activities at such a young age was impressive. Child CE (M 6) described spring as a special time for plants, likening it to Christmas for them. This thoughtful analogy showed a unique appreciation for nature and the changing of the seasons. Child CF (M 7) shared his enjoyment of activities like shooting, biking and basketball. He also mentioned how his friend (who was spoken about often) supports him during his treatment, highlighting the importance of friendships in coping with challenges. Child CM (M 8) was open about the challenges he faces with his port access and how he finds it quite hard. His honesty about these difficulties and the support he receives from his family and specialists was touching.

Many of the insights reflected the children's creativity, resilience and the supportive environments they are part of, and also how they create their own mechanisms for coping. For example, Child CE (M 6) shared that his iPad is very important to him and helps him stay entertained and happy (describing it as an 'undying love' for his iPad). He also mentioned that taking deep breaths helps him calm down during stressful times. The children's resilience and the importance of supportive activities and relationships in managing their illnesses cannot be understated from the responses we received.

Key concepts which emerged during the sessions covered a surprisingly broad range of areas such as:

- Emotional support and coping mechanisms
- Many children mentioned the importance of family, friends, pets and soft toys in providing emotional support
- For siblings, special objects (such as toys and photos) were significant in helping them cope with their sibling's illness
- The importance of routine via activities like going to school, engaging in hobbies, and spending time with pets helped maintain a sense of normalcy
- Having projects like decorating a playhouse or collecting Polaroid photos provided a creative and engaging distraction for one child.

These concepts are explored in more detail on the next page.

Special Moments

The significance of special moments and memories is substantial, and they play an essential role in a child's resiliency and identity as they go through their childhood cancer journey. Many children shared photos that captured special moments or memories, such as family gatherings, pets and personal achievements. These moments were often linked to feelings of comfort and happiness. The children also emphasized the importance of staying connected with friends and family, even (and possibly more so) during challenging times. Support from teachers and healthcare professionals was also highlighted as crucial, particularly by siblings who may feel less connected to their parents, and who may not have wanted to add to the perceived strain a childhood cancer diagnosis places on the wider family. The children involved in this study articulated an ability to find strength and support in their relationships with trusted adults, routines, and creative expressions helping them navigate the emotional challenges of having an illness or a sibling with an illness.

Importance of Whānau[4]

The children expressed the importance of family during the challenging nature of treatment. Of note, children identified how their families are present to offer emotional comfort and encouragement. For example, Child CB's (F6) family read the Bible together, which was an important source of support for them. Families also helped with practical aspects of the children's lives. Child CA (F7) mentioned that her Aunty helps her with sewing projects, providing a positive and engaging activity. Family members are often present during medical procedures and become part of the treatment team. For instance, Child CF (M7) mentioned that his Play Specialist helps him during port access with his family present, indicating that family and specialists work together to support him. And of course, families celebrate important milestones and events. For this cohort of young people, these celebrations are pivotal and essential for their resiliency and sense of normalcy, joy and identity.

Hospital

The children's experiences of hospital varied, but most experienced it as stressful and anxiety-inducing. For example, Child CJ (F 6) mentioned that her dad spent many nights in the hospital with her, indicating the emotional support she needed during those times. For their siblings, seeing them in a hospital setting was emotionally challenging. The presence of family members was, however, identified as crucial. Nurses and doctors also played a supportive role. Child SJ (M 11) mentioned that the nurses were very supportive of him during his brother's treatment.

Standing out in the group discussions was the role of special objects or toys. Children often brought toys or other items to the hospital to provide comfort. Child CA (F 7), for example, mentioned her rabbit (a soft toy which she has had since she was two) as a source of comfort when she was stressed or scared. Despite the challenges, some children found positive aspects in their hospital experiences such as positive relationships with parents and siblings making new friends both of similar ages and with older people such as nurses and doctors and other allied health professionals. Some children developed creative outlets yet to be explored, and finally, many described attitudes which they took pride in which demonstrated personal resilience and courage.

[4] *Whānau is the Māori language word for family.*

A Sibling's Illness

When asked to reflect on the illness of their brother or sister, unsurprisingly, children experienced stress and anxiety arising from their sibling's illness. For example, Child SJ (M 11) found it very hard to see his brother unwell, especially during significant events like birthdays. Child SG (F 7) mentioned the difficulty of watching her sister lose her hair and having to deal with a feeding tube, which was emotionally challenging for her. She went on to note that her sister's frequent hospital visits meant that she often missed her family members, affecting her sense of normalcy. Some children had to take on additional responsibilities at home, which could be both physically and emotionally demanding. In New Zealand research, Armstrong, K. notes that this can lead to siblings taking on practical and emotional support roles in the family[ix]. Hovland et al., and Brennan et al., note that this is not uncommon, discussing the maturation of siblings[x].

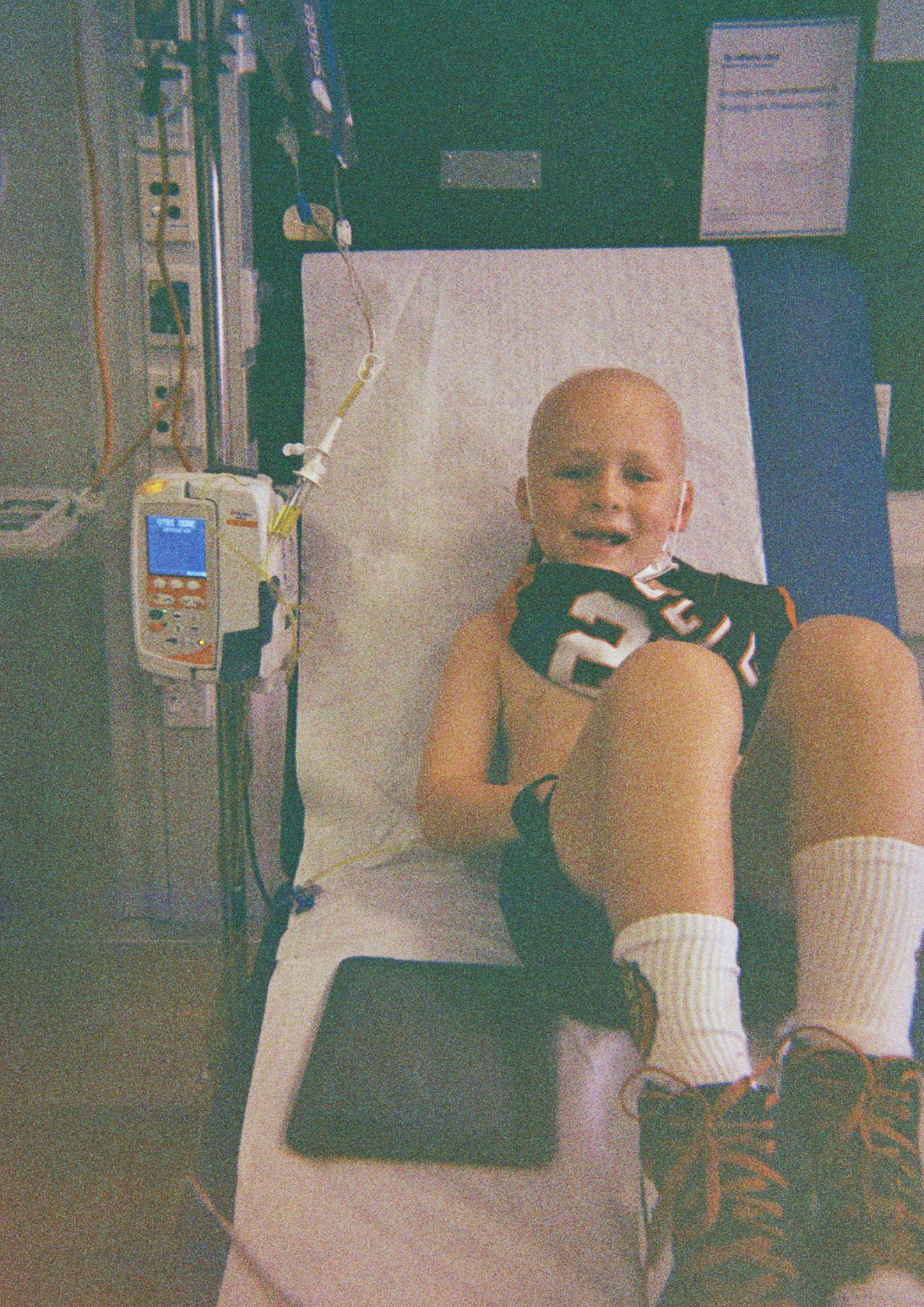
The need to protect their health and their sibling's health sometimes led to social isolation. Child SJ (M 11) mentioned, for example, that she could only see a few close friends during COVID 19 lockdowns. Despite the isolation, friends played a crucial role in providing emotional support. Child SI (M 12) and Child SJ (M 11) both highlighted the importance of their friends in helping them cope. It was also common for the children to mention pets who provided comfort and companionship, helping this cohort of children to at least feel less alone. Interestingly, the CI project itself allowed the children to express their feelings and experiences through photography, which was therapeutic; while this was not intended, it is interesting to note that the process had a positive impact for most participants and highlights the importance in the choice of Photovoice as a methodology.

It was clear from the sibling cohort data that their wellbeing was significantly impacted by their brother or sisters' illness, but they found various ways to cope and support each other through the challenges.

Transitioning

Unsurprisingly, trusted adults and friends play a significant role in providing emotional and social support, and helping the children navigate the cancer journey with a sense of companionship and understanding. Children's teachers and classmates provide various forms of support during their treatments. Child CA (F 7) mentioned that her teacher from Northern Health School sometimes visited her at home and sometimes she went to the school. This personalised approach helped her continue her education despite her medical treatments, which she viewed as important. Teachers also provide emotional support by being understanding and accommodating the children's needs. For example, Child CA's (F 7) teacher engaged with her in activities she loves, like learning and sewing, which helped her stay motivated and positive.

Classmates, like Child CC's (M 7) friend, play a significant role in providing companionship and emotional support. The friend supported Child CC's (M 7) during his treatment, and they share common interests like basketball, which helped Child CC's (M 7) feel connected and supported. Classmates who are aware of the children's medical conditions were identified by the cohort as offering empathy and understanding, making the children feel less isolated. This support is crucial for their emotional wellbeing. Overall, the support from teachers and classmates helps the children maintain a sense of normalcy and provides both academic and emotional support during their treatments and afterwards. Returning to school and normal life after hospital stays was challenging and Child CJ (F 6) mentioned that her teacher helped her settle back into school. Providing teachers and classmates with tools to better support and understand the childhood cancer journey for both the child living with a cancer and their siblings can only help in improving the journey itself and the transition back to the 'new normal'.



Discussion

For all the children—those with childhood cancer and their siblings alike—hospital experiences were marked by emotional trauma and highlighted the importance of support systems, tools and relationships that provide coping mechanisms for managing the stress and disruption caused by illness. Based on the findings of this research with this cohort of children, the role of family is vital. Parents and siblings on the cancer journey improved the overall wellbeing of the child with a childhood cancer illness.

This resonates with other New Zealand and international research and suggests that supporting siblings provides benefits for them, the child with a cancer diagnosis, and the family as a whole. The degree of importance placed on soft toys and other special items (smartphones and iPads) mentioned by the cohort also provides an opportunity to undertake additional research by testing interventions that may support connection between siblings and improve the overall strength of the bond.

Similarly, the role of trusted adults in other key systems in a child's life, like teachers at school, provides an avenue for further exploration around how to enhance this support for children as they adjust to normalcy after their (or their sibling's) illness. Helping classmates understand the needs of children with cancer and their siblings will also benefit the children involved throughout all stages of the cancer treatment pathway and into survivorship.

Seven key themes from this study reinforce much of what we know as well as the existing literature. These themes raise key reflections and questions for the Foundation and other agencies and professionals working in childhood cancer to consider:

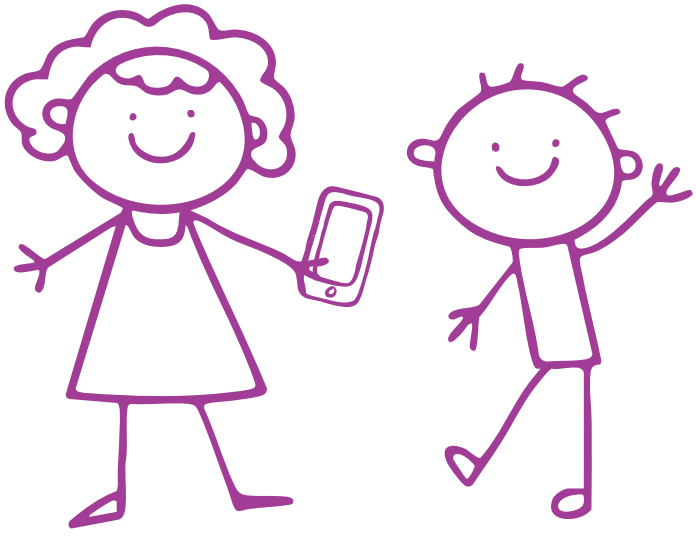
1. We should not view children in isolation from their whānau (family).
2. Children and families can still 'live well' with an oncology diagnosis. How well do we support families in doing this? Do we need to reframe how we talk about an oncology diagnosis (for example, 'living with childhood cancer')? This also allows for a transition to seeing oneself or one's family as an individual or whānau with lived experience, rather than being identified by the illness.
3. How can connection be maintained between school friends and siblings'? What initiatives can we invest in to support this? How do we support teachers in helping children maintain connection, as trusted adults in a child's life?
4. How do families live 'normally' again? What would investment in supporting families to do this look like? What would success look like?
5. Siblings are great observers. Are we helping them interpret what they see and supporting them through their feelings? Given the established importance of siblings in support and recovery, how do we increase care in this area? What would it look like? Do we need to be more active and inclusive in how we support siblings in particular? How can we foster additional inquiry into the role of siblings in the wellness of their brother or sister?
6. Do we need to look at how we support 'normalised activities' for both siblings and children with an oncology diagnosis? Normalised activities will vary from child to child. For example, a child in this study with a palliative diagnosis played piano, which his mother described as a stress management tool and focusing exercise.
7. How can we use existing resources such as soft toys, iPads or smartphones to provide better support initiatives? For example, do we provide a 'bring a friend' Online Antics session (in our online play and educational programme for children unable to attend school) or expand on sibling support programmes?

Conclusion

The data collected from the Creative Investigation Sessions primarily reinforced what we already know from our work with children and their whānau and reflects findings from the literature. The project team noted that the CI project allowed the children to express their feelings and experiences through photography, which, while not described by the children as 'therapeutic', was appreciated and helped them talk about and express their emotions in ways many of them had not had the chance before. This was particularly the case for the siblings. This was not intended, but it is interesting to note that the process had a positive impact for most participants and suggests there are benefits of continuing to undertake this type of exercise in a more programmatic way.

A novel finding was the importance of soft toys and electronic devices. The role of siblings in the wellbeing of the child with a childhood cancer diagnosis has been recognised in previous research and was highlighted in this study also. Both findings provide avenues and opportunities for exploring how to address these needs in future studies. While many parents and medical professionals exclude siblings from (age appropriate) information-sharing and general participation in healthcare decision-making, the findings of this investigation and in the literature (Dryden-Palmer et al., Brennan C et al. Armstrong K) suggest that inclusion and participation of siblings improves outcomes for the siblings, the ill child and the overall resiliency and adaptability of the whānau as a whole. It was more common for the CI groups made up of children with a childhood cancer diagnosis to mention their siblings as important sources of support and normalcy rather than parents. However, this is likely an effect related to differing expectations with what Rooth et al., describes as *the child's undemanding respect for parental care and adult competence*, while their expectations of their siblings involve more equity and personal agency.[xi]

The Foundation has attained valuable information which will allow us to include the voice of the children we work to support through a childhood cancer journey. This information has informed our strategic planning and led to the development of a new 'Super SIBS' Sessions programme for siblings. It also suggests that there is benefit in reinstituting parent and sibling camps with partners. The CI project has also provided a focus for future research investment. We anticipate undertaking a second CI series in the future. In doing so, we will look at how we can improve the photographic experience and output and expand the number of children we include. The outcomes also suggest that we improve our promotion and delivery of our online programmes such as *Online Antics* and *Super SIBS Sessions* as the children who participate both benefit from and enjoy participating.



References

[i] Walther, A., & Lüküslü, D. (2021). Who are the Young People Who Engage as Youth Representatives? Routes into Formal Youth Participation. *Youth and Globalization*, 3(1), 195-214. https://doi.org/10.1163/25895745-03010008

[ii] Dryden-Palmer, Shinewald and O'Leary (2024) Supporting siblings during the critical illness hospitalisation of a child: Learning from experience. Frontiers in Paediatrics. 12:1337491. Doi: 10.3389/fped.2024.1337491

[iii] Armstrong K, 2019 The unmet needs of siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand, Massey University of New Zealand

[iv] Hanlon A, (2025) Trauma Informed Care in Paediatric Oncology, Child Cancer Foundation, 2025 www.childcancer.org.nz

[v] Gass, K., Jenkins, J., & Dunn, J. (2007). Are Siblings relationships protective? A longitudinal study. Journal of Child psychology and psychiatry. https://doi.org/10.1111/j.1469-7610.2006.01699.x

[vi] https://publichealth.jhu.edu/center-for-health-equity/photovoice

[vii] Hanlon A, (2025) Trauma Informed Care in Paediatric Oncology, Child Cancer Foundation, 2025 www.childcancer.org.nz

[viii] Dryden-Palmer, Shinewald and O'Leary (2024) Supporting siblings during the critical illness hospitalisation of a child: Learning from experience. Frontiers in Paediatrics. 12:1337491. Doi: 10.3389/fped.2024.1337491

[ix] Armstrong K, 2019 The unmet needs of siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand, Massey University of New Zealand

[x] Hovland W, Hean S 2021, the quality and developmental pathways in sibling relationships: a qualitive study of Norwegian Children admitted to child welfare service care; Child and Family Social Work 2021; 26:559-571

[xi] Rooth, H., Forinder, U., Piuva, K., & Söderbäck, M. (2020). Being a child in the family: young children describe themselves and their parents. *Journal of Family Studies*, 29(1), 1–14. https://doi.org/10.1080/13229400.2020.1860112

Appendix One

Consent Form for Children Research Title: Gathering the children's voice to support service delivery.

Researcher's Names: Kerry Price and Rachel Painer

I have read the participation information sheet and have had the opportunity to ask the researcher any further questions I may have had.

I understand that my child's(children) participation in this research is voluntary, and I may withdraw may child at any time from the study without affecting services I may receive from the Foundation in any way.

I understand that the risks to me are minimal in this study and have read the information sheet and asked any questions I may have about any risks.

I understand that my child(ren) will be involved in two individual, 30 minute online recorded focus groups and that my child(ren) will take photographs outlining their lived experience. These photographs will used to focus the discussion and highlight areas of importance or significance to my child(ren).

I understand that Child Cancer Foundation will provide disposable cameras, and a return envelope to have the film developed but that the photos taken will remain the property of my Child(ren). While my child(ren) will retain ownership I consent to the Child Cancer Foundation using the photos in the report and for promotional purposes.

My name, my child or children's name will not be used to identify comments or work in the study unless my child(ren) are selected to provide specific feedback or vox pops, but this will only be done with my express permission prior to use or publication. This may include a photograph of my child(ren)

If I have any concerns or complaints regarding the way the research is or has been conducted, I can contact the Privacy Officer, Child Cancer Foundation, privacy.officer@childcancer.org.nz. (The Privacy Officer is a separate role and not related to the research in anyway).

By signing below, I am consenting to (please tick):

- ☐ Participating in a series of focus groups with the lead researcher and Play Specialist.
- ☐ Having each 30 minutes online session recorded the Play Specialist asking my child(ren) about their photographs and lived experiences.
- ☐ Having copies of photos used for reporting purposes of their lived experience (the photographs will only be of their work and not of my child unless I give express consent later).
- ☐ I understand that information will be used for a report on children's voices and possibly other published materials such as briefs on the Child Cancer Foundation Website, social media and in strategic planning and I consent for it to be used in this manner.

I give permission for my child(ren) _____ to participate in this research.

Parent/Guardian Signature _____Date_____

Child's Name (please print) _____

Child's/Children's signature _____Date_____

I understand that by participating in this research project on children's voices the Child Cancer Foundation as a token of the value that they ('the Foundation') place on the information provided by my child(ren) will provide each participant who successfully completes the project with a $50 voucher of their choice.

0800 424 453 • info@childcancer.org.nz • childcancer.org.nz

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