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**Education following a childhood cancer diagnosis in Aotearoa: Perspectives from children
and young people who receive support grants and their family/whānau**

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Teresa Catriona McKeever

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Abstract

Advances in medical treatment have improved the survivorship rates of children with cancer, making it increasingly likely that schools will encounter children who have or have had cancer. Previous research has shown that the availability of resources to support children experiencing learning challenges as a result of their cancer is limited. Child Cancer Foundation's Personal Development Grants are sometimes used to fund additional educational support that is not available through the Ministry of Education. This mixed methods study firstly examined the characteristics of children who have received a Personal Development Grant for education, before conducting qualitative interviews with a sample of children and young people who received grants and their caregivers. Interviews explored participants' experiences of the child's educational needs following their cancer diagnosis and the specific support provided. Quantitative analysis did not reveal any characteristics that could predict the likelihood of a child receiving a grant for educational purposes. Qualitative analysis identified four overarching themes; the overall impact of cancer on the family; gaps in the existing support provided through the education system; participants' Personal Development Grant experience; and, the participants' tendency to focus on the good. This study enables the voices of young people experiencing educational challenges due to their cancer diagnosis and their caregivers to be heard. Recommendations for practice include increased collaboration between families, school personnel and medical teams and promotion of inclusive practices such as Universal Design for Learning in classrooms.

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Throughout this research I was acutely aware of the children included in the study who have sadly lost their battles with cancer. I am not aware of their names, as the information was anonymised, but nonetheless they were constantly in my thoughts as I was writing. I would like to dedicate this thesis to their memories.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 18/34 (see Appendix B).

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Chapter 1 Introduction

As a result of advances in medical treatment, childhood cancer survival rates are increasing each year in Aotearoa, with 84% of children surviving for at least five years post diagnosis (Ballantine & the New Zealand Childhood Cancer Registry [NZCCR] Working Group, 2017a). As such, childhood cancers are now often considered to be chronic illnesses, rather than life threatening diseases (Yilmaz et al., 2014). While this increase in survivorship brings new hope, it also brings new challenges. Over 60% of survivors experience late effects from cancer and cancer treatment, which can affect children physically, cognitively or socially and may not become apparent for some years after treatment (Donnan et al., 2015). With an estimated 120 childhood cancer survivors being added to the population annually in Aotearoa (Yallop, McDowell, Koziol-McLain & Reed, 2013), it is becoming increasingly likely that the Ministry of Education (MOE) will receive requests to support the learning needs of this unique group of children. However, previous research has shown that children have found it difficult to access support through the MOE (Fraser, 2001) and that teachers do not feel adequately prepared to support children with chronic health needs in the classroom (Adams, 2018).

The Child Cancer Foundation (CCF) often supplements the support provided by the MOE to children who have or had cancer, through awarding funds in the form of a Personal Development Grant (PDG) for educational purposes, which is the focus of the present study. The literature review will examine research in the area of childhood cancer and education, focusing on the educational needs of children with cancer and the supports available in Aotearoa and overseas. The research component includes an exploration of the characteristics of children who received a PDG in comparison with those who did not, through quantitative analysis, followed by a series of qualitative interviews with children and their caregivers to explore their perspectives of the support received and the educational experiences of the child following their cancer diagnosis. As an ecological viewpoint has been taken throughout this

study, the support provided by the PDG and the child's educational experiences cannot be viewed in isolation, thus the remainder of this introduction will describe the context in which this research takes place.

Setting the Scene

A brief overview of childhood cancer. Childhood cancer can be viewed in distinct phases, each of which have unique challenges for the child and their family (Vannatta & Salley, 2017). The diagnosis itself brings emotional turmoil and unexpected change for a family, requiring parents to take in overwhelming amounts of new information and make quick medical decisions for their child. During active treatment, the child can experience a lot of physical pain and side effects from treatment, roles can change within the family and the family unit can be separated for long periods of time. Treatment type, intensity and length will vary across different cancer diagnoses; however, most children will be on active treatment for at least one year, which may include long periods of hospitalisation and outpatient care from home (Kazak & Noll, 2015).

The end of treatment can be a time where families feel they should be celebrating, but instead they can often experience anxiety (Wakefield, McLoone, Butow, Lenthén & Cohn, 2011). This may be due to reduced contact with the medical team (Tresman, Bailey, Brown, Skinner, & Fraser, 2016), concerns regarding the possibility of relapse or future late effects, and difficulties in getting back to normal routines (Vannatta & Spalley, 2017). The long-term survivorship period is seen as starting five years post diagnosis, and while many families can put cancer behind them, the concerns experienced at the end of treatment linger on for others (Vannatta & Spalley, 2017). Sadly, although survivorship rates have increased significantly in recent years, cancer is still the leading cause of death by disease for children in developed countries, and many children will move on to palliative care and pass away as a result of their cancer (Kazak & Noll, 2015).

An overview of childhood cancer in Aotearoa. Approximately 150 children aged between 0 and 14 years are diagnosed with cancer each year in Aotearoa (Ballantine et al., 2018). The survivorship rates are comparable to other developed countries, such as Australia, Canada and the United States (Ballantine et al., 2018). The most commonly diagnosed childhood cancers are leukaemias, which account for approximately one third of all cancers, followed by central nervous system (CNS) tumours which account for over 20% of cancer diagnoses (Ballantine & the NZCCR Working Group, 2017b).

The only demographics that appear to have any significant difference in the incidence of childhood cancer are gender and age, with males and children under the age of five being at an increased rate of a cancer diagnosis (Ballantine & the NZCCR Working Group, 2017b). A commonly used phrase amongst parents and professionals in paediatric oncology is that childhood cancer does not discriminate, meaning that it can affect families regardless of ethnicity or socio-economic status. This is evidenced through the data provided by NZCCR, which shows that the incidence of childhood cancer is comparable across ethnicities (Ballantine & the NZCCR Working Group, 2017b). Likewise, there are no statistically significant differences in the overall five- or ten-year survival rates across ethnic groups, socio-economic status or geographical location (Macfarlane, 2019). This may be partly attributable to the equity of access to free treatment and services to all children across Aotearoa (Douglas & Dockerty, 2007).

Aotearoa has two main treatment centres for childhood oncology – one at Starship in Auckland and one at the Childhood Haematology and Oncology Centre (CHOC) in Christchurch. In 2018, 66% of new diagnoses received initial treatment at Starship, and the remainder were treated at CHOC (Ballantine & the NZCCR Working Group, 2019). Approximately 50% of families will need to travel away from their home and community, causing an additional stressor for a family on top of the devastating news that their child has cancer. The whole

family experiences major disruptions to their regular lives, with one parent/caregiver often travelling to the treatment centre with the patient, leaving the second caregiver at home to care for siblings, continue working and so on (Keene, 2003). Both Starship and CHOC work closely with regional shared care centres across the country to have treatment carried out close to home as much as possible (Ballantine & the NZCCR Working Group, 2017b), but this is not always feasible due to individual treatment protocols and the location of specialist practitioners and services. No matter where the treatment occurs, the family unit will always experience some level of disruption, as an adult always has to be with the child in hospital. Often the parent/caregiver staying in hospital will have to give up work, causing a financial strain on the family (Patterson, Holm & Gurney, 2004). This can cause roles within the family to change, relationships can become strained due to physical distance, difficulties in communication and difference in coping mechanisms can arise, and it can be difficult to access usual support networks. Treatment plans can vary in length, from several weeks to several years, so families can remain in a state of stress and change for long periods.

Child Cancer Foundation. CCF was founded in 1978 by parents and health professionals to address the lack of support available to support families through the enormity of childhood cancer (Dawson, 2013). Over the years it has changed from a wholly voluntary organisation to a professional organisation. Currently CCF provides support to children aged 0 to 20 who have been diagnosed with cancer, and their families, across Aotearoa. Services are offered directly to the child with cancer and siblings under the age of 13, and to parents and families of children up to the age of 20. As the researcher of the present study, I have worked for CCF for over three years, including while this research was being carried out. During this time, I have developed a strong working knowledge of childhood cancer in Aotearoa and overseas, particularly with regard to the psychosocial impact on the child themselves and their families. The services offered by CCF at present include individualised support from a Family Support Coordinator, national programmes for parents and siblings to foster peer connections

and offer tools and strategies to support throughout and after their child's cancer journey, social connections at a regional level organised by volunteer Connect Groups, and grants such as the PDG, which is the focus of this study and explained in greater detail below.

CCF has a strong working relationship with the District Health Boards across Aotearoa, particularly in Starship and CHOC hospitals. Referrals to CCF mainly come from hospital social workers. CCF also works very closely with the National Child Cancer Network (NCCN), the governing body for child cancer in Aotearoa, who manage the NZCCR, a database capturing demographic and treatment information for all children under the age of 15 diagnosed with cancer since 2000 (Ballantine & the NZCCR Working Group, 2017b). Annual referral figures for CCF generally match the annual statistics from NZCCR, so it appears that most, if not all, children diagnosed with cancer in Aotearoa are referred to CCF.

Education during childhood cancer in Aotearoa. The MOE ensures that children can keep up to date with their education while in hospital and unable to attend regular school, through their three Regional Health Schools (RHS; MOE, 2014). The Northern Health School has its main centre in Auckland and services the top of the North Island, with its southern boundary spanning from Taranaki in the west across to Tairāwhiti in the east. The Central Regional Health School covers the remainder of the North Island, while the South Island is covered by the Southern Health School. Each school has a number of centres and teachers located throughout their regions.

The main target group for the RHS are children who are hospitalised for two or more weeks (MOE, 2014), which occurs in almost all paediatric oncology cases. There are no specific entry assessments required for children with cancer – a confirmed medical diagnosis is sufficient to receive educational support. Children remain on the roll of their regular school while they are enrolled with the RHS and RHS teachers maintain contact with the child's school as they provide educational services. They also keep in regular contact with health

professionals involved in their care and their parents/caregivers. Each student will have an Individual Education Plan with curriculum objectives that consider prior learning and achievement levels, alongside necessary modifications as a result of health or treatment courses. Contact with the RHS teachers may be face-to-face while the child is in hospital. In addition, some children staying at Ronald McDonald House in Auckland will be able to attend the classroom available there for children in years 1 through 8, providing opportunities for much needed social interactions. This class is more often attended by siblings staying at the house however, as the patient is often too unwell to attend. On discharge from hospital the student will normally work independently at home with scheduled teacher check ins by phone or in person, depending on their geographic location.

The School High Health Needs Fund (SHHNF) is another potential source of support for children returning to school while they are still on treatment (MOE, 2018a). This funding is focused on children who need medium to long term support (six weeks or more) and require assistance or supervision to manage their health needs in the school setting. Students with cancer are outlined in their examples of eligibility: “A student has cancer and suffers severe tiredness, headaches, nausea and vomiting” (MOE, 2018a). This funding is ideal for students receiving chemotherapy, which often requires long treatment periods at outpatient clinics (Armstrong, 2003), as it could help them to regain some sense of normalcy by returning to school (Bessell, 2001). The school staff would need to be open to implementing accommodations that may be required to fully support the student, such as shorter days at school, modifications to the curriculum or exceptions to school uniform rules to allow children to wear a hat or bandana if they have experienced hair loss (Wissler, 2003).

Both the RHS and the SHHNF provide essential services to children undergoing treatment for cancer, while they are in hospital and attending outpatient clinics. However, this support does not usually carry over to the post-treatment period and it can become even more

challenging to access necessary supports at a later stage, as Fraser found during interviews of parents of children with cancer (2001). At this point, if difficulties develop, former cancer patients do not have access to specific funding for additional resourcing at school and generally need to compete with other children who may have more recognised educational needs, such as autism or ADHD (affecting 1.4% and 1.8% of children under 15 in Aotearoa respectively; Ministry of Health, 2016).

NCCN held a meeting in May 2016 which brought together representatives from MOE, MOH and connected not-for-profits (including CCF) to discuss the current educational needs of children who have experienced cancer. From this meeting came a continuously developing project with several targeted working groups with the overall goal of pooling available resources, expanding on information available for families and improving the communication channels between all stakeholders. Several projects have been completed to date: a collaboration between psychologists from the MOE and MOH to develop the information regarding brain injuries now available on the Te Kete Ipurangi (TKI) website (MOE, n.d.); an update of the content available regarding education in childhood cancer on the Kids Health website (Paediatric Society of NZ, NCCN, MOE & CCF, 2018); and a research project due for completion in 2019, focusing on returning to social activities and education when cancer treatment is nearing completion (NCCN, n.d.). While these initiatives provide a more promising future for children with cancer, there are still gaps currently in the system. It is possible that these gaps are one of the reasons why families turn to CCF to fund educational support for their child at school.

The context for the current study. CCF PDGs are available for children aged 0 to 12 years who have or had cancer, siblings aged 0 to 12 years and parents or caregivers, to achieve their personal development goals. There are four PDG rounds annually, in line with school terms. Each application requires the family to complete a form, which is subsequently

reviewed by a committee made up of parents of former cancer patients, alongside representatives from the health and education fields. The committee is independent from the regular operational side of the organisation, with CCF management involved in an advisory capacity only.

Any activity that will potentially benefit the applicant educationally or developmentally will be considered by the committee. While the committee's role is to ensure the funds are going towards activities that are appropriate and achievable, flexibility is required within the guidelines to recognise the sometimes fleeting nature of childhood cancer, particularly with regard to children's PDGs. Grants are sometimes awarded to provide a sense of normality for the family, or purely for the purpose of fun and distraction from the child's illness, even when it may be unlikely that the funded programme will be completed, for example, a term of swimming lessons for a palliative child. As the chair of the PDG committee is often heard saying, a PDG should be for something that "makes the child's heart sing." PDGs generally are considered to be educational or non-educational in purpose. Examples of non-educational grants for the child with cancer include: sporting and recreational activities, such as surfing, horse-riding, dance or drama to promote confidence, provide social connections and to develop motor skills; and mobility aids or electronic equipment to assist those with physical challenges as a result of their cancer.

The present study is focused solely on PDGs that have been granted to the child with cancer for the purposes of education. These are normally requests for in school support from a teacher's aide or external support in the form of tutoring. In addition to the regular PDG application form, requests for educational support require additional information from the child's doctor, parents and school where possible. This enables the committee to make a well-informed decision, centred around the best interests of the child. Some children submit multiple applications to provide ongoing support, while, conversely there have been cases

where children were granted funds but did not use them, often as a result of changes in the child's health or treatment. In recent grant rounds, the committee have become reluctant to approve applications for external tutoring, following advice from health professionals that it is better for the child's wellbeing to have recreational or social activities after school, rather than extra schooling when they are likely exhausted. The organisation is also concerned that parents may request teacher aide support as they are unsure of alternative supports available and they would like their Family Support Coordinators to be better equipped to have more meaningful conversations with potential grant applicants about what might work best for the child, before submitting an application. Parents are asked to submit written feedback following completion of the funded activity or resource, however this is not always provided.

To date, there has not been any systematic review of the PDGs or feedback from families. With the ongoing collaboration between CCF, NCCN and the ministries of health and education to further the educational support available to children with cancer, the time is ripe to conduct a review of the PDGs that have been granted for educational support, and to explore the perceived benefits from the recipient's point of view.

Chapter 2 Literature Review: Childhood Cancer and Education

As a result of the improved survivorship rates of children with cancer, it is becoming increasingly likely that schools will encounter children who have or have had cancer (Boles et al., 2017; Wissler, 2003). However, as more children survive, resources and training for educators have failed to keep up with the learning needs of this group of students (Barkon, 2009). While most children will enjoy academic achievement on par with their healthy peers, others will experience challenges in their academic lives as a result of their cancer (Kuehni et al., 2012). This highlights the need to develop a firm understanding of how we can utilise the available research to best serve the needs of childhood cancer survivors in achieving academic success.

It is important to note that literature in the area of childhood cancer and education is somewhat limited in terms of quantity, which may be a result of the low incidence of childhood cancer in the general population (Helms et al., 2016). Researchers have also questioned the quality of available literature in the field (Thompson et al., 2015) and commented on the difficulty of comparing or applying findings from overseas studies due to differences amongst education systems (Lahteenmaki, Huostila, Hinkka, & Salmi, 2002). In addition, most of the research literature has come from the medical perspective rather than the educational perspective (Barkon, 2009). To this end, this literature review will firstly explore Bronfenbrenner's (1979) ecological theory and the area of childhood studies as two useful theoretical frameworks through which to view education and educational support for children with cancer. The remainder of the review will explore the educational journey of a child with cancer from diagnosis and subsequent reintegration back to school, through to post-treatment late effects that may emerge and associated supports available, or lack thereof. This will help to provide a greater understanding of the context in which a PDG application may be submitted.

Theoretical Framework

Ecological theory. Bronfenbrenner's (1979) ecological theory is viewed as a valuable framework when working with children and families in both paediatric psychology (Kazak, Alderfer & Reader, 2017) and educational psychology (Annan, 2005; Gutkin, 2012). Figure 1 depicts a model of the ecosystem for a child with cancer, which is a fitting model for the current research context as it has the capacity to incorporate all factors that impact on the child and their education following a cancer diagnosis.

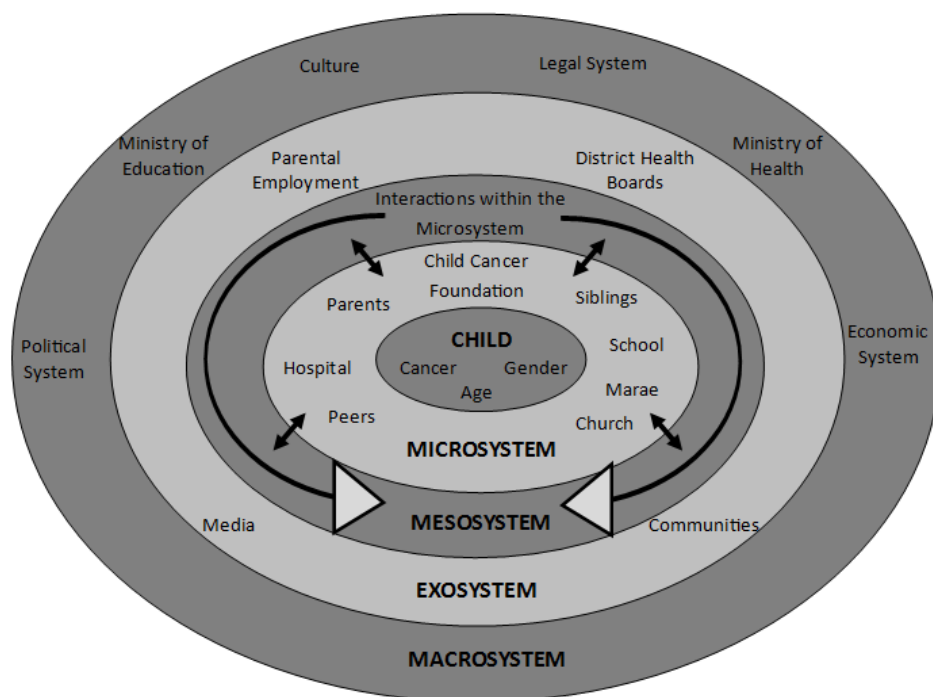


Figure 1: An ecological model applied to childhood cancer in Aotearoa, adapted from Kazak et al. (2017).

The young person with cancer is positioned at the centre of the ecosystem, surrounded by concentric systems which have varying levels of direct and indirect influence on the child. The first layer is the microsystem, which includes the young person's family, school, hospital and any other settings or people with a significant role in their immediate environment and experiences. During the early period post diagnosis, children have cited disruption to role functioning as their biggest stressor, which includes not being able to partake in everyday

activities such as school and family interactions (Rodriguez et al., 2012), both elements of their microsystem. It is important to note that the same research found child self-related levels of stress significantly lower than parental perceptions of the child's stress levels. Additionally, parents did not rate disruption to the child's role functioning as their child's biggest stressor. Both of these factors could potentially impact on the mesosystem, which is formed by the interaction between members of the microsystem. When looking at the educational needs and experiences of young people with cancer, the quality of interactions between parents, school personnel and the young person's medical team are of particular interest in terms of the impact on the child's learning and sense of belonging at school, and are often cited in the literature (e.g. Hay, Nabors, Sullivan & Zygmundet, 2015; Hermann, Thurber, Miles & Gilbert, 2011; Moffitt, 1985; Yilmaz et al., 2014).

The next layer, the exosystem, includes settings and structures that the child does not directly interact with, but which nevertheless have an indirect impact on them. In the current context, factors such as parental employment can often have a prominent indirect impact on the child, as one or both parents often have to give up work to care for their child during treatment, hence decreasing the familial income and often increasing parental stress (Patterson et al., 2004). The macrosystem refers to systems at a cultural, societal or political level, which influence beliefs and ideologies, in turn impacting on ecological environments. In the context of childhood cancer, cultural beliefs may impact on how a family understand and discuss cancer within the family (Kazak et al., 2017). Political and government systems may dictate where treatment for cancer takes place, for example there are now only two main paediatric oncology treatment centres in Aotearoa, resulting in 46% of children having to travel away from their home locality (Ballantine & the NZCCR Working Group, 2019).

In Bronfenbrenner's ecological theory, the child is "viewed not merely as a tabula rasa [blank slate] on which the environment makes its impact, but as a growing dynamic entity that

progressively moves into and restructures the milieu in which it resides” (1979, p. 21). This positions the child as an active agent in their own world, interacting with and influencing their environment in a reciprocal fashion. As such, it should logically follow that any research exploring a child’s experiences should include the child’s voice. However, research that includes the perspective of the child is limited when looking at the educational experiences of children with cancer (Molinaro & Fletcher, 2017). While some studies have been designed specifically to allow the child to speak directly about their own experiences, (e.g. Boles et al., 2017; Bruce, Chapman, MacDonald & Newcombe, 2008), others have relied instead on the accounts of parents or practitioners (e.g. Bruce, Newcombe & Chapman, 2012; Tresman et al., 2016). The perspectives of other members of the child’s ecosystem are valid and important in their own right, however they do not tell the whole story.

Childhood studies and the child’s voice in research. The field of childhood studies emphasises the immense value of including the child’s voice in a research context (Powell & Smith, 2009). Childhood studies sees childhood and, accordingly, research conducted with children, as a socially constructed phenomenon, where children have the right to be active participants in the research process, rather than having research done to them (Woodhead, 2015). Children are seen as responsible agents whose voice adds a unique contribution and perspective to their family and other systems around them, such as education and health (Smith, 2016). Lundy (2007) argues that enabling the child to have a voice is not sufficient on its own; the elements of space, audience and influence are also critical in order to act in accordance with Article 12 of the United Nations Convention of the Rights of the Child (United Nations, 1989). Article 12 states that the child has the right to express their view, and that their view must be given “due weight” (p. 5). Lundy’s (2007) model posits that firstly children need to be given the space to decide if they wish to participate or not, before having the opportunity to voice their thoughts, with support to express themselves if needed. Once they have expressed their views, their views must be communicated to an audience that has the

capacity to make changes based on what they hear. Lastly, the child's views must be taken seriously, with the ability to influence, rather than being a tokenistic exercise in participation; the child's voice must have the potential to become a catalyst for change. Taken from this viewpoint, the child's voice has the potential to have a powerful impact on the decisions that will affect them, at all levels of their ecosystem.

Powell and Smith (2009) have shown that, in spite of researchers being in agreement with the ideals of having children actively involved in research, they are often excluded when the topic is seen to be sensitive and/or the children in question are seen to be vulnerable. Children with cancer may be particularly susceptible to being viewed as vulnerable, with 15 to 25% of parents of children on treatment showing clinically significant perceptions of vulnerability and overprotective behaviour towards their child, (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp & Mullins, 2010) compared to 10% in a community sample (Forsyth, Horwitz, Leventhal, Burger & Leaf, 1996). This rate has shown to be even higher when looking at parents of children who have finished treatment, with 28% reporting perceived child vulnerability (Hogan, Ross, Balsamo, Mitchell & Kadan-Lottick, 2018). In research with this population, children with cancer are often perceived as "doubly vulnerable" (Boles & Daniels, 2019, p. 1), meaning that in addition to being minors, they have experienced significant challenges throughout their cancer treatment and beyond. Children could therefore be prevented from taking part in research by "gatekeepers" such as parents or medical professionals who may not allow researchers access to the child in order to protect them (Huang, O'Connor, Ke & Lee, 2014). However, Powell and Smith (2009) argue that not participating in research can cause the child more harm as they miss out on the potential benefits of being involved, such as empowerment or access to resources.

In a medical research environment, children have still cited positive experiences of participation even when there is no direct therapeutic benefit to them, such as knowing that

they are helping others, potential future health benefits, having fun and increasing their knowledge (Staphorst, Hunfeld & van de Vathorst, 2017). Boles and Daniels (2019) acknowledge that the child's views are essential to develop medical and psychosocial services and practices that are appropriate and meaningful for children with cancer, however they also recognise that participation in research may place an additional burden on children undergoing cancer treatment. As such, they encourage researchers to "weigh concern for the child's medical and psychosocial wellbeing with developmentally appropriate opportunities for children to describe their experiences, identify their needs, and express themselves while acting as participants" (p. 2).

This section has outlined the theoretical lens through which the current study will be viewed. The remainder of this literature review will focus specifically on the impact of a childhood cancer diagnosis on subsequent educational experiences of the child. While research which has also been conducted through an ecological framework will be featured prominently throughout this literature review, I will also reference research which has been conducted from the medical perspective, which is quite prevalent throughout childhood cancer research (Barkon, 2009). However, instead of using language that implies a deficit model, I will focus more on strengths and challenges, as this approach is more likely to build motivation and confidence in children (Smith, 2016). An ecological approach is also more conducive to the development of prevention and intervention strategies, rather than a focus on remediation (Gutkin, 2012). In addition, whilst the voice of the child is essential to include, an ecological framework values perspectives from all participants within the child's ecosystem, and so the voices of parents, medical and educational professionals will also be prominent throughout this review. It is important to recognise that siblings are also an important part of the picture, and they can have their own challenges at school following their brother or sister's cancer diagnosis (Lamb & Holley-Boen, 2016), however, this is beyond the scope of the current study.

The Impact of a Cancer Diagnosis on a Child's Schooling

Education during active treatment. The period following a childhood cancer diagnosis is rife with disruptions to everyday life. However, school can provide a sense of normality for the child in an otherwise changing landscape (Bessell, 2001; Niselle, Hanns, Green & Jones, 2012), offering the child a sense of comfort and support (Eaton Russell, Beaton, Lollis & Bouffe, 2016). It is therefore vital for contact to be maintained with school, teachers and classmates and for the child to participate in school life where possible, academically and socially (Bessell, 2001). The class teacher can help to reduce isolation for the child by enabling classmates to keep in touch through cards, letters, phone calls, messaging, emails or video calls (Wissler, 2003). Research has shown that this is just as important as keeping up to date academically, as children who were tutored or home-schooled while on treatment showed lower levels of social competence and emotional stability than children who remained engaged with their regular school or children who had not yet started school (Bessell, 2001).

Boles and colleagues (2017) explored the school experiences of children aged six to twelve, when still on active treatment. They interviewed the child themselves to enable their voice to be heard directly. School for the purposes of their research included hospital school, home tutoring services, parent-led home-schooling or regular school. The research team was interested in exploring the child's perceptions of school before and after their diagnosis, and what it means to them to be both a patient and a student simultaneously. Children expressed acknowledgement of the importance of school and education for their futures, however cited the difficulties that they experienced in completing schoolwork while on treatment. Barriers to schoolwork were not only caused by hospitalisation itself, but also by treatment-related symptoms such as nausea, vomiting, fatigue, pain or vulnerability to infection. These treatment-related side effects also interfered with their capacity to attend social events and out of school activities. Advances in technology have been shown to be of great benefit for

children while they are in hospital to allow them to keep in touch with peers and teachers along with acting as a tool to motivate and engage children with school and schoolwork (Niselle et al., 2012). Also programmes such as Monkey in My Chair may help to keep the child connected with their school while they are absent (Boles et al., 2017).

Root and colleagues (2016) feel that school-based psychologists are ideally placed to support with educational challenges and stressors caused by cancer diagnosis and treatment, recommending interventions in the following areas: videoconferencing with school for social and academic purposes; relaxation and guided imagery, written emotional expression, mindfulness and yoga, all for stress reduction; strategies to address needle phobia; reintegration into school and assistance in accessing relevant educational supports. Unfortunately, this support is not always available to children undergoing treatment, and while interviewing parents of children with brain tumours, Bruce et al. (2008), found that parents felt that it was up to them, as parents, to become advocates and to seek out support. The parents themselves recommended helpful strategies for others in similar situations, including the need to "be realistic and supportive, be persistent, make no assumptions, be attentive to siblings' wellbeing, involve children in the process, keep written records, and maintain consistent communication" (p. 336).

Returning to school. Parents may be disinclined to send their child back to school as they want to protect them and they perceive their child as more vulnerable than usual (Moffitt, 1985). This is often a rational fear, particularly when children are still on treatment, as lowered immunity makes them more susceptible to infection and everyday childhood illnesses, such as chicken pox, are potentially fatal. If the child has finished treatment, parents often report feeling a sense of abandonment, as they are now facing the next stage without the wraparound support of their child's medical team (Tresman et al., 2016). In interviews conducted by Bruce et al. (2008), parents of children with brain tumours reported concerns for

their child's physical safety returning to school. They spoke about their children having a "hidden" problem, which meant that people often did not acknowledge the difficulties encountered by their child as it was not physically visible. They also expressed concerns around the school's knowledge and awareness of their child's condition and the need for long term planning, academic support and communication.

The literature review by Hay and colleagues (2015) highlighted the essential role of the classroom teacher in normalising the school experience for children, ensuring that they reintegrate into school after treatment and succeed academically. However, teachers often do not feel that they have the skills or knowledge needed to support a child with cancer (Hay et al., 2015; Tresman et al., 2016). Despite the increasing survivorship rates of childhood cancer, the incidence of cancer in the general childhood population is still very low, and study samples have shown that none of the teachers in the study had ever encountered a student with cancer before the survivors in question (Lahteenmaki et al., 2002). Teachers have expressed fear of doing the wrong thing, and a general fear of cancer diagnoses (Tresman et al., 2016).

Research in the UK has shown vast differences in children's reintegration experiences, from the perspectives of parents, health professionals and teachers (Tresman et al., 2016). To address this, the researchers developed a school reintegration protocol, which includes a "School Passport" to guide the child through their journey, outlining expected timelines and the roles and responsibilities of professionals involved. All parties rated face-to-face meetings between health and educational professionals as highly valuable. The ability to define roles between the collaborative teams was deemed helpful and appeared to alleviate parental stress. While studies such as this provide recommendations around school reintegration, it is still not a standardised common practice internationally or in Aotearoa. However, it is an area that continues to garner attention, with a current longitudinal German study looking at the effects of a rehabilitation programme on children with brain tumours or leukaemia with regard

to school reintegration and psychosocial outcomes (Peikert, Inhestern & Bergelt, 2017) and a locally based study exploring returning to school and social activities for children with Acute Lymphoblastic Leukaemia in Aotearoa (NCCN, n.d.).

Psychosocial considerations. Psychological and social aspects of childhood cancer are apparent from the point of diagnosis for the child and their family, ranging from anxiety around treatment and the possibility of dying to concerns around school and peers (Nass, Patlak & National Cancer Policy Forum, 2015). Psychosocial considerations arise in research at all levels of child's schooling during and post cancer, particularly for children whose early development is disrupted by cancer treatment, where they miss out on early opportunities for social interactions (Boles et al., 2017). In interviews with survivors, some children spoke of loneliness and missing their peers while in hospital or learning at home, noticing differences between their current school setting and their regular classroom. Even when they were with others in hospital school, they said it was not the same and there was not adequate opportunity for social interaction (Boles et al., 2017). Although the Boles et al. study and that of Eaton Russel et al. (2012) showed that survivors viewed relationships with peers as important sources of support and reported positive peer interaction, many children also reported being bullied by their peers (Bruce et al., 2008; Eaton Russell et al., 2012; Lahteenmaki et al., 2002; Molinaro and Fletcher, 2017). This was supported by parent and teacher reports (Bruce et al., 2008; Upton & Eiser, 2006), highlighting the need for support from schools in terms of potential bullying in child cancer patients and survivors. Young people who reported significant difficulties with their peers said that it was often surrounding their appearance and their peers' lack of understanding of their disease (Molinaro & Fletcher, 2017). However, they also commented on the importance of siblings and friends in dealing with both academic and social challenges; all those who reported difficulties felt that they became stronger in the long run, despite how difficult it was for them at the time. Eaton Russell and co-researchers (2016) talk about "balancing grief and survival" which is a constant

attempt by both parents and survivors to counterbalance their feelings of grief caused by the illness by looking forward to the future and survival with optimism.

Similar themes have come through in other research, where children have been shown to fare just as well as, or even better than, their peers with regard to psychosocial wellbeing (Yallop et al., 2013) and have reported being optimistic and positive about life and future (Bessell, 2001). In addition, survivors are more likely to experience post traumatic growth (Kamibepu et al., 2010) and to show greater levels of resilience (Schepers, Okado, Russell, Long & Phipps, 2019; Tillery, Howard Sharp, Okado, Long & Phipps, 2015) than their peers. Research in recent years has seen a move away from viewing psychosocial outcomes of childhood cancer through a more negative lens, to focus on more positive impacts of cancer and post-traumatic growth (Zebrack et al., 2012).

Academic considerations. The majority of childhood cancer survivors are similar to their peers in terms of educational outcomes and they generally will continue to thrive and live prosperous lives as adults (Gerhardt et al., 2007), although their age at school completion is often greater than their peers, usually by just one year (Boman, Lindblad, & Hjern, 2010). This is usually because they are more likely to repeat a year at school or start school later than usual (Lahteenmaki et al., 2002; Yilmaz et al., 2014). However, some children are more likely than their healthy peers to experience academic challenges (Lahteenmaki et al., 2002; Yilmaz et al., 2014). A certain proportion of difficulties that a child may encounter may be explained through gaps in schooling, as it is extremely common for children to miss large chunks of schoolwork due to treatment regimens and feeling unwell. These absences can often continue post treatment for children with brain tumours, who often require ongoing hospital appointments (Upton & Eiser, 2006). However, children still on treatment have reported experiencing difficulties in memory or concentration, which appeared to be confusing for

them, as they did not associate it directly with other side effects of treatment (Boles et al., 2017), indicating that there may be something else at play.

Researchers in Aotearoa, Raymond-Speden, Tripp, Lawrence and Holdaway (2000), were interested in exploring how much of a child's academic challenges can be explained by school absences alone. To do this, they compared the educational outcomes of children with cancer with other children with chronic health conditions (asthma), including a control group of healthy peers. Their study showed that both children with chronic health conditions and children who had received cancer treatment scored lower than their healthy peers on measures of cognitive and academic functioning. However, on comparing the two test groups, it was also discovered that children with cancer scored significantly lower than their peers with asthma on the same measures, indicating that their difficulties were caused by something other than absence alone. While researchers caution that interviews and observations are also required to give a more holistic view of a child's experience at school (Long & Marsland, 2011), the study by Raymond-Speden and colleagues does indicate that late effects from cancer treatment appear to have a role in educational outcomes.

Late Effects of Childhood Cancer

Late effects have been described as unique challenges that arise as a result of cancer treatment (Bessell, 2001), which may be physical, cognitive or psychosocial in nature and may not emerge for several years after treatment (Donnan et al., 2015). It is important to note that not all children will experience late effects and many survivors may be similar to peers in terms of health and ability to participate in activities (Lahteenmaki et al., 2002). However, as the survivorship rates of childhood cancer patients have increased, so too has the incidence of late effects, in Aotearoa (Yallop et al., 2013) and overseas (Helms et al., 2016). Over 60% of child survivors will experience at least one late effect (Donnan et al., 2015) and, with an estimate of 120 additional survivors in the Aotearoa population each year (Yallop et al., 2013), the number

of children experiencing late effects within the education system is increasingly annually (Wissler, 2003). In a school environment, children experiencing late effects may have challenges with some or all of the following tasks: handwriting, spelling, reading vocabulary, math, concentration, attention, completing tasks on time, memory, processing, planning, organisation, problem-solving or social skills (Landier, 2013).

Due to the variety in cancer type, location in the body, treatment protocols, severity and individual reactions to treatment, it is difficult to predict who will experience late effects (Bessell, 2001). However, there are certain characteristics that increase the risk of a child experiencing late effects. The following risk factors increase the likelihood of developing late effects that affect educational outcomes:

- Being diagnosed at a young age
- Numerous or lengthy absences from school
- Learning difficulties prior to the cancer diagnosis
- Cancer treatment that:
 - affects hearing or vision
 - reduces energy levels
 - results in physical disabilities
 - involves treatment to the CNS (Landier, 2013).

Researchers have been exploring the links between these risk factors and learning challenges since the 1980s. For example, Mancini and fellow researchers (1989) found that children who received CNS irradiation for leukaemia were more likely to receive a diagnosis of a “learning disability” if they were three years or under at the time of treatment (50% of participants), than children over the age of three receiving the same treatment for the same cancer (who showed no evidence of having learning challenges). More recently, larger scale research internationally has compared national health and education records, so that the educational outcomes of children with cancer are considered in relation to their national peer group in the

general population. These studies have again provided links between certain conditions and the likelihood of experiencing academic difficulties. Children with CNS tumours or leukaemia are more likely to experience academic difficulties than the general population (Boman et al., 2010), particularly if diagnosed at a younger age (Andersen, Duun-Henriksen, Frederiksen, & Winther, 2017). Similarly, children with brain tumours have been found to perform at significantly lower rates than their peers in certain academic areas, such as reading, spelling and arithmetic (Ach et al., 2013). In addition, childhood cancer survivors are three times more likely than their healthy peers to access learning support services, and support is more likely to be needed for children who have been in remission longer (Lorenzi et al., 2009). However, on the contrary, some studies have failed to find a significant link between survivor's gender, diagnosis or age at diagnosis and their grades (Lahteenmaki et al., 2002).

At a more everyday level, children will have very different experiences of late effects. Taking brain tumours as an example, some children will recover quickly with very few side effects and others will have permanent damage such as visual impairments, and secondary issues such as strokes or epilepsy (Eaton Russel et al., 2012). Slow processing speed is common amongst children with brain tumours, and it can affect them in many ways in the educational environment: it can take them longer to respond to the teacher, take in information or follow instructions; it can affect their learning and decision making ability; they may be forgetful; they may find it hard to keep up with work; and, they may have trouble writing assignments or with maths (Barkon, 2009). Interviews with young people with brain tumours showed that they were quite aware of the areas that they struggled in, and what they needed to do in addition to peers to succeed (Bruce et al., 2008). Some were unaware of who could help them at school, however others described resource teachers, teacher aides and assistive technologies that were a great source of support. Having teachers who understood their needs and tailored supports to suit them was a very positive experience for some young people.

There is concern that teachers may not view cancer as a possible cause for academic challenges if the late effects manifest many years after the end of treatment (Barkon, 2009). Researchers stress how important it is for teachers to be more knowledgeable about childhood cancer, and for educators and parents to know that learning challenges occur commonly in survivors but may take some years to arise (Hermann et al., 2011). Teachers should also not assume that a child does not have the ability to complete a task because their processing speed is slow, and they need to understand that:

Many of the learning problems faced by survivors exist at the intersection of fatigue, processing speed and executive functioning, rather than in a particular or isolated academic area. This may affect different areas of academic functioning, and fluctuations may occur, resulting in different impacts on different days, (Barkon, 2009, p. 52).

Concerns have also been voiced about the children who are achieving within the average range, as they may be more problematic than others in that they will not raise attention (Lahteenmaki et al., 2002). However, they may be struggling with a drop in their cognitive level, they may be slower than before, they may be more forgetful, find it difficult to retain new information or organise themselves and their workload.

Long Term Educational Support for Children with Late Effects

While there is no guarantee that a child will or will not experience late effects, the research literature can be used to help predict the likelihood of a child experiencing them, which in turn can help to provide recommendations for teachers and parents to be aware of signs of late effects as a child matures, without causing undue alarm or hypervigilance. Raymond-Speden et al. (2000) recommended that children treated with CNS chemotherapy should receive regular neuropsychological assessments from diagnosis through to several

years post treatment to help identify cognitive concerns as they arise. More recent studies have been exploring the use of computer based cognitive training programmes for targeted early intervention (e.g. Butler et al., 2008; Kesler, Lacayo & Jo, 2011). Results have indicated significant increases in certain areas (e.g. processing speed, cognitive flexibility), but not in others (e.g. working memory or visual attention; Kesler et al., 2011) and parental reports of improved attention and academic achievement (Butler et al., 2008). Both research teams recommend further exploration of this area, as “the prospect of intervening to change this trajectory thus has tremendous significance—potentially affecting school services, family dynamics, vocational readiness and social services support” (Kesler et al., 2011, p. 101).

In Aotearoa, ongoing assessment for late effects is through the Late Effects Assessment Programme (LEAP), which was established in 2006 (Yallop et al., 2013). The LEAP team includes an oncologist, a nurse specialist and a clinical psychologist or neuropsychologist, all of whom have specialist knowledge and experience in late effects. Children transition into LEAP between three- and five-years post treatment and are invited to attend annual clinics, with the option to request more assistance if needed. Young people are usually discharged from the programme between the age of 18 and 21 years, but this will depend on their individual history and needs (Paediatric Society of NZ, Starship Foundation & NCCN, 2013). There are LEAP teams based in Auckland, Wellington and Christchurch and the teams also travel to other regional centres to provide a more equitable service. The primary purpose of the programme is to “provide an integrated systematic service that will assess and manage the medical, psychological and educational needs of CCS [childhood cancer survivors]” (Bartle, McDowell & Yallop, 2009, p.9). While the medical and health aspects of clinic are rated as the most popular reasons for LEAP attendance by both parents and survivors, the psychological and educational aspects are also rated as important by 63% of parents and 50% of young people, with the level of importance increasing with the age of the young person (Bartle et al., 2009). Each annual appointment includes a review with the clinical psychologist to assess

current functioning, which may lead to further educational assessment or intervention if the child or young person has experienced challenges in this area. At this point there may be a neuropsychological assessment, which will involve the child, their parents and their school (Paediatric Society of New Zealand et al., 2013a). The psychologist may request additional educational support through the MOE, the child's school, or not-for-profits such as CCF for children under 13, or CanTeen for teenagers.

While the late effects follow up support is offered more consistently and equitably in Aotearoa than other countries (Yallop et al., 2013), there is still a gap between hospital and school, particularly during that initial "return to normal" period post treatment. Contact with the health schools normally ceases once the child is well enough to return to their regular school full time and children do not normally attend LEAP clinics for at least three years post treatment. During this time, most researchers recommend the school psychologist or another designated liaison person as the optimal person to be involved in the reintegration of a child into school and subsequent tracking for late effects in the educational space (e.g. Harris, 2009; Hermann et al 2011; Wissler, 2003). In Aotearoa, as schools do not have dedicated psychologists, this role is likely to fall to a school's Special Education Needs Coordinator (SENCo) or the new Learning Support Coordinator roles due to be introduced in 2020 (MOE, 2019). Harris (2009) supports the use of the Eco-Triadic Model of educational consultation, which emphasises that a successful reintegration to school relies on the strength of the relationships between the consultant (proposed to be the school psychologist) and the other stakeholders (namely those at home, school, in the hospital and the individual student themselves). Harris provides a practical framework in the form of a checklist for use by the consultant in each relationship type, with a series of questions and considerations before the child returns to school, during school reintegration and in follow up periods.

Harris' (2009) model has a strong focus on the need for advanced preparation before the child returns to school and this theme is repeated in numerous articles on the subject. Gartin and Murdick (2009) stressed the need for teachers to fully prepare themselves, their classroom environment and other students before a child returns to the classroom, by familiarising themselves with the type of cancer, treatment, side effects, social and emotional requirements and possible late effects that may occur further down the track. This may include making adaptations to curriculum, classroom layout, or even their teaching style. In addition, they recommend that teachers explore their own feelings towards the child's cancer, including fear, anxiety and expectations of the child's ability. With this, it is also important that they have a baseline level of the child's ability, so they maintain focus on what the child can do and what their potential is, rather than thinking that they can't achieve because of their cancer. On a similar note, it is also important to encourage the child themselves to explore their current, and sometimes new, strengths and abilities, to better prepare them to adjust to any differences in academic ability following treatment (Herrmann et al. 2011). In addition, Molinaro and Fletcher (2017) highlight the need for schools to be aware of potential bullying and to develop supportive interventions for children during treatment and into survivorship, as almost 50% of participants in their study reported social difficulties, including bullying and distancing from peers.

Despite the need for teachers to be prepared for the return of a student with cancer, there are few or no training courses or information available for teachers (Wissler, 2003). Over three quarters of teachers surveyed in Aotearoa did not receive any initial teacher education training to prepare them to teach children with chronic illnesses, and almost half had not received subsequent professional development in this area (Adams, 2018). Although there are many exemplary pilot programmes and recommendations of best practice in the area of education during and after childhood cancer, very little appears to be implemented on a consistent basis. For example, Rubens and colleagues (2016) developed and piloted a School

Liaison Programme to target the educational needs of children most at risk for neurocognitive late effects, mainly those with CNS diagnoses or treatment. The school liaison coordinated support and communication between the child, parents, school and hospital, collating feedback from all parties alongside academic performance, which was monitored from the point of diagnosis on. Their study highlighted the benefits of such a role, but they acknowledged the difficulties of providing this on a consistent basis across treatment centres. Lack of funding and resources are often cited as reasons why further initiatives in this area are not supported (Butler et al., 2008).

Barkon (2009) recommends Universal Design for Learning (UDL) as one of the best strategies for academic success for children with cancer, where teachers "support learning rather than transmit knowledge" (p. 53). Three key principles of UDL are providing learning with multiple means of representation, multiple means of expression and multiple means of engagement, while enabling children to have choices in their learning. In addition, survivors should be encouraged to develop an awareness of their own learning styles and needs and learn the skills required for self-advocacy. A UDL classroom could lessen the impact on both the child and teacher if late effects were to emerge further down the track, other children in the class would also benefit from this style of learning, and funding may be more forthcoming as the outcomes are far more wide-reaching than for the small group of children with cancer. The MOE currently promotes the use of UDL in schools in Aotearoa because it benefits all children and enables equity for all learners (MOE, 2018b), an initiative which is promising for the future education of children with cancer.

One key recommendation that has consistently appeared in studies since the 1980s is the need for collaboration between the family, health practitioners and educators in a "dynamic, ongoing process" to keep up to date with changes in teachers, class and medical status (Moffitt, 1985, p. 6). The importance of collaboration has been emphasised by parents

(Bruce et al., 2008), health and educational professionals (Tresman et al., 2016; Vanclooster, Benoot, Bilsen, Peremans, & Jansen, 2018). However this does not always happen, due to various reasons, such as school or hospital policies, lack of guidelines in this specific area, lack of human resources or insufficient informational resources for teachers on the various needs of this unique group of children and strategies to support (Vanclooster et al., 2018).

In Aotearoa the communication between hospital and school is not consistent nationally. School visits to provide education and information to staff and sometimes students as well are generally conducted on an ad hoc basis, either by the oncology nurses or RHS staff and occasionally staff from CCF, but this is often limited by availability of workers or school location (Herbert, 2015). Specific information and resources are provided by charities, such as CCF's booklet "Back to school for students with cancer: Guidelines for teachers" (CCF, n.d.) and the Childhood Cancer and Education page on the Kids Health Website (Paediatric Society of NZ et al., 2018), but may not always be circulated amongst relevant educators. With regard to late effects, teachers spend significant amounts of time with their students, and so are in an ideal position to pass on any observable differences to parents, health professionals and colleagues, a vantage point that is wasted if they are not aware of what to look out for (Gartin and Murdick, 2009). Former research (Fraser, 2001) and anecdotal accounts from families, passed on through CCF Family Support Coordinators (Herbert, 2015) have indicated that, even if teachers are able to identify difficulties that may be caused by late effects, it is rare that children are eligible for additional support through the MOE. However, there appears to be a lack of recent research in this area.

CCF and the Current Research

As a collaborative partner with both the health and education sectors, CCF is interested in how the organisation can best support the child and their family as the child goes through their formal education. PDGs have been awarded for the purpose of supporting a

child's educational goals since 1991 (when they were known as ACG Scholarships; Dawson, 2013). As survivorship rates and subsequent late effects are continually increasing, CCF is interested in gaining a greater understanding of past and current grant recipients, in order to make more informed decisions for future planning. To this end, this thesis seeks to explore the characteristics of educational grant recipients in comparison to the wider population of children registered with CCF who were also eligible to apply for a grant but did not. While the research literature suggests that certain characteristics, such as age at diagnosis and cancer type, may increase the likelihood of a child experiencing challenges with learning and education (Ach et al, 2013; Andersen et al., 2017; Boman et al., 2010), the current study will be purely exploratory in nature, as it only focuses on one potential source of educational support.

The organisation is also interested in assessing if the support given is actually benefiting the recipients and if it is the best use of financial resources, particularly when the research literature points to a number of challenges in supporting the reintegration of children back to school (Harris, 2009; Hermann et al 2011; Wissler, 2003). Alongside providing data to enable the organisation to make informed decisions about educational grants, the interviews in the second stage of this research will give children and parents a voice regarding their educational experiences, which CCF can use to advocate for families' needs throughout the NCCN project and beyond.

To address the first and second concerns, the following research questions have been developed:

Research Question 1: What are the characteristics of children who have applied for a PDG for educational support through CCF?

Research Question 2: What are children's and caregivers' experiences of the child's educational needs following cancer diagnosis and the specific support provided through the PDG?

Chapter 3 Methodology

This chapter firstly explores the way in which the theoretical frameworks provided by Bronfenbrenner's ecological theory (1979) and the field of childhood studies have influenced the current research. Next, the research design and rationale for using a mixed methods approach are described, before outlining the overall ethical considerations and the method for each stage of the study.

It is hoped that this project will add to a field that is often described as having limited research, both in Aotearoa (Yallop et al., 2013) and overseas (Helms et al., 2016; Thompson et al., 2015). It is also hoped that this study will benefit:

- Participants, by creating an opportunity for their voice to be heard.
- Other children and families, by providing information that may be useful to them, and letting them know that they are not alone in the challenges they may face.
- Communities, through raising awareness of childhood cancer and the challenges that families can face, even after the child is "better", which in turn may increase the support available to families in their communities.
- Other professionals and organisations, who may be able to use this research to guide their own practice, both in Aotearoa and overseas.

Theoretical Framework, Research Design and Rationale

Ecological theory. As described above, Bronfenbrenner's (1979) ecological theory is viewed as a valuable framework when working with children and families in both paediatric psychology (Kazak et al., 2017) and educational psychology (Annan, 2005). The first two systems, the macro- and meso-systems, are the main focus of this study: Stage 1 utilised existing quantitative data to examine the characteristics of the child with cancer, while the interviews in Stage 2 explored the experiences of the child within their microsystem and the

interactions at the mesosystem level between the child's parents, school and hospital from a parental perspective. Although not the main focus of the current research, an awareness of the next two layers (exo- and macrosystem) was also maintained throughout all interviews. While the interview questions (Appendix A) were designed to elicit discussion of experiences at the micro- and mesosystem level, I was aware at all times that the experiences shared by the child and their parents may also have been impacted by factors within the exo- and macrosystem, and the parents were likely to be cognisant of at least some of these factors.

Childhood studies and the choice to involve the child directly in this research. The decision to involve child participants in the current study is supported by research in the area of childhood studies, as outlined in the literature review. Powell and Smith (2009) acknowledge that there are additional risks associated with having children involved in research, however these potential risks can be managed through a well-planned ethics application, the use of a researcher skilled in working with children and obtaining informed consent from the child, and other relevant parties. These considerations were taken into account when planning the current study. In addition, learnings from the emerging field of disabled children's childhood studies influenced my own thinking when approaching the interviews. Curran and Runswick-Cole (2014) reject the traditional way of viewing the futures of children with and without disabilities, where those with disabilities are seen in a deficit model focused on future concerns whereas "normal" children are expected to live independent, healthy and prosperous lives. Instead, they believe that all children, irrespective of disability, should be viewed as having childhoods and not seen in terms of either having or being problems. This approach was useful in terms of framing the interview questions, ensuring that the focus was on the children's abilities rather than deficits.

Mixed methods design. This research employed a mixed methods design in two stages. Mixed methods research is most commonly viewed within the paradigm of

pragmatism, which essentially is a practical approach to designing research that puts the research questions at the fore, rather than being restricted to one paradigm, such as positivism or constructivism (Punch, 2014). Mixed methods designs emerged following a realisation by social science researchers in the 1990s that using both quantitative and qualitative could add extra depth to research, that could not be achieved by using one alone (Punch, 2014). Through combining quantitative and qualitative methods, the researcher can draw on the strengths of both, while also minimising the weaknesses of each approach (Klassen, Creswell, Plano Clark, Smith & Meissner, 2012). The choice to employ a mixed methods approach in the current study was partly influenced by findings by Dumas and colleagues (2015). In their initial quantitative work, they found that women were more likely to be negatively impacted in terms of academic achievement as a result of childhood cancer, whereas male survivors tended to have higher levels of qualifications than the general population. In subsequent qualitative interviews, they were able to elicit the reason for this: the men interviewed revealed that they had been unsuccessful in attaining blue-collar roles because of physical limitations following their cancer treatment. Therefore, they turned to more white-collar roles, which required them to attain higher educational qualifications. This provides a useful example of how qualitative research has added extra depth to the information provided through quantitative analysis.

The current study was sequential in nature, with the quantitative component taking part in Stage 1 and the qualitative component in Stage 2 (Klassen et al., 2012). Stage 1 explored the characteristics of children who received a PDG for education through CCF in comparison to the characteristics of children who met the eligibility criteria for a PDG application, but did not apply for a grant, by conducting quantitative analysis of an existing data set. Stage 2 utilised the information drawn from Stage 1 to identify the children and caregivers who fitted the criteria to be invited to take part, described below. Stage 2 involved semi-structured interviews with parents and children to explore how the PDG was utilised, and the value of

that support. Interviews were recorded, transcribed and qualitatively analysed to elicit themes. Thus, Stage 1 provided the opportunity to take a more positivist stance by providing an objective description of the children's characteristics, while Stage 2 enabled a constructivist stance through exploring the perceived realities of children and caregivers' experiences of education during and after childhood cancer (Punch, 2016). It is hoped that this combination will provide a richer picture of PDGs for education than either stage could alone.

Ethical Considerations

This project was reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 18/34 on 25th July 2018 (Appendix B). My main priority in the application was to ensure that harm was minimized for all involved. To ensure cultural sensitivity of the project and interview questions, a Māori advisor was consulted prior to submitting the ethics application. Consent was not sought from individual families for Stage 1, as on registration with CCF, families consent to their deidentified information being used for research purposes. Before families were invited to take part in Stage 2 interviews, a CCF Family Support Coordinator was consulted to ensure it was appropriate to contact them. This minimised the harm caused by contacting a family whose child had relapsed, become palliative or died since being awarded a grant. To minimise the risk of children and parents experiencing discomfort in reflecting back on periods during their cancer journey, children had the option of having their parents present in the room with them during the interview, or elsewhere in the building if they chose to do the interview alone, so they were available for additional support if needed. Both child and parent participants were told that they could take a break if needed during the interview, or to end the interview at any time. I also planned on ending the interview early if the participant appeared to be overly distressed, but this did not occur. One interview was brought to a close however when the participant (Patrick) appeared to become

fatigued. Follow up support was offered through CCF's Family Support Team, but not required.

Additional precautions were taken to acknowledge the rarity and low incidence of childhood cancer in the general population. For example, less common cancer types were grouped under "other cancers." Identifying information, such as names, locations and specific cancer types were omitted from interview transcripts and subsequent quotes.

Method: Stage 1

Participants. Participant information for Stage 1 of the study was taken from the CCF client information database, Raisers Edge. Raisers Edge, fundamentally a database for fundraising, was adapted to fit the purpose of client management when first used by CCF in 2006. All children who have registered with CCF since 2006 have had their details recorded in the database, including personal details (e.g. date of birth, parental contact details); information surrounding their cancer diagnosis (e.g. date of diagnosis, type of cancer); and details of ongoing support provided by CCF (e.g. individual case notes from Family Support Coordinator contact, PDGs). Similarly, the details of children who were registered before 2006 and still had some contact with CCF were also added to the database.

For the current study, the population of interest were children who were eligible to apply for a PDG for educational purposes between the period of July 2013 and June 2018, which covers five full financial years. During this time frame, the first grant round was in July 2013 and the last grant round was in April 2018. Children were included if they were between the ages of five (the age when children start formal education in Aotearoa) and thirteen during this period (children are eligible to apply for a grant up until their thirteenth birthday). Therefore, children were included in Stage 1 of the study if they were a) born between July 2000 and April 2013; b) were under the age of thirteen at the time of cancer diagnosis; and c)

were diagnosed before or during the period of interest (July 2013 – June 2018). These criteria ensured that all children who could have applied for a PDG for educational support during the timeframe were included in analysis. The choice to include all children in the sample was to mirror the methods of previous researchers that included their entire research population in data analysis (e.g. Boman et al., 2010; Lorenzi et al., 2009). Participants were from across Aotearoa and there was a total of 1116 children in the initial report that was pulled from Raisers Edge in February 2019. Out of these, 46 were discounted from the final study sample, 11 because they had Aplastic Anaemia (a condition previously supported by CCF, but no longer listed under the International Childhood Cancer Classification), and the remainder because there was not enough information recorded regarding their diagnosis type or date to determine if they were eligible for inclusion. The valid sample consisted of 1070 children, with a mean age of 12 years, 4 months, an age range of 5 years 11 months to 18 years 8 months, and a gender ratio of 583 males to 487 females. Ethnicity data was initially collected but excluded from analysis as there was not sufficient data available. Ethnicity was not recorded for 15% of the sample and the majority of those with ethnicity recorded only had one ethnic group listed, which does not allow for the rich cultural heritage in Aotearoa, where over 25% generally identify with two or more ethnic groups (Butler, 2018).

The test group consisted of recipients of a PDG for educational support [n=75], while all other participants formed the control group [n=995]. The test group consisted of 47 males and 28 females, with a mean age of 13 years 6 months, ranging from 7 years 8 months to 18 years 6 months. The control group consisted of 536 males and 459 females, and the mean age of participants was 12 years 2 months, ranging from 5 years 11 months to 18 years 8 months.

Procedure. A report was pulled from the CCF database in February 2018 that included the following information regarding all children who met the eligibility criteria stated above:

- PDG for educational support equals yes or no

- If yes, the following information was also collected
 - Type of PDG (e.g. tutoring or teacher aide)
 - Date of PDG application
 - Percentage of approved funds that were utilised
- Primary cancer diagnosis
- Gender
- Date of Birth
- Date of cancer diagnosis
- Date of end of treatment
- Location (suburb and/or town)
- Ethnicity (later discounted due to insufficient information recorded)
- Deceased equals yes or no
 - If yes, date of death was also included
- Client identification (ID) number

Before preparing data for analysis, each participant was assigned a participant ID number and their location was coded in terms of District Health Board region. This was to enable easy identification of those who would meet the criteria for Stage 2. A copy of this information was saved electronically, password protected and accessible only to the researcher. A second copy, omitting the Raiser's Edge Client ID number and location was saved and this is the data that was used for analysis.

Data Analysis. Firstly, basic calculations were conducted using the child's date of birth to elicit each participant's current age, age at the time of diagnosis and, for children who received a PDG, age at time of PDG application. Descriptive statistics were collated for both groups and a logistic regression was carried out to ascertain if there were any predictive characteristics of the children in the test group. The dependent variable was if they received a PDG for education or not, and the independent variables tested were gender, cancer type and

age at time of diagnosis. As the dependent, or outcome variable (PDG grant), was categorical, it was converted to a dummy variable to fit the statistical analysis and coded to 0 for those who did not receive a PDG and 1 for those who had (UCLA Statistical Consulting Group, 2017). The research literature commonly cites children with leukaemias or CNS tumours as more likely to experience educational challenges than children with other cancer types (e.g. Ach et al., 2013; Andersen et al., 2017; Raymond-Speden et al., 2000; Wengenroth et al., 2015), so, for the purposes of regression, children were grouped together if they had leukaemia or CNS tumours and compared to children with other cancers. Again, dummy variables were used, with leukaemia and CNS tumours coded to 1 and all others coded to 0.

Prior to running the logistic regression, the data was tested for multicollinearity. Although there is no formal way of conducting tests during logistic regression in SPSS, it is recommended to conduct them using the collinearity statistics option through multiple regression (Pallant, 2011). This showed that there was no interaction between the three independent variables (Tolerance value > .1; Variance inflation factor < 10).

Method: Stage 2

Stage 2 utilised the data provided during Stage 1 to generate a list of potential interview participants. Data analysis revealed 21 children were granted a PDG for education in the Auckland area between July 2013 and June 2018 (the first criteria for inclusion). The decision to include children from Auckland was practical as that is where the researcher is based, and where the majority of CCF clients are located. When this list was explored further, nine children were removed from the potential interview pool, as they either had not utilised at least 50% of the grant funds, or the Family Support Team had deemed it best not to contact the family. The caregivers of the remaining 12 children were contacted (8 by email and 4 by post) by the CCF Admin Assistant and asked for permission for their details to be shared with

the researcher, who would in turn contact them to describe the study in more detail and invite the caregiver and their child to take part.

Follow up phone calls were attempted by the Admin Assistant for those who had not responded to the initial email or letter (11 out of the 12 contacted). Two potential participants were discounted due to out of date contact details (post returned, emails bounced back and/or phone numbers were no longer in service). Four caregivers responded positively and there was no response from the remaining six. Once agreement to be contacted was given, the researcher sent a letter with full information about the project for parents/caregivers (Appendix C) and consent forms (Appendix D) and combined information and consent forms for children and young people (Appendices E and F). Participants were contacted by telephone to tell them more about the study and to schedule a time to complete the interviews, if they were still interested. Out of the four caregivers with an initial positive response, three verbally agreed to take part in the interviews, so the overall response rate was 30%. All caregivers who agreed to take part gave their consent for their child to be involved, and also sought consent directly from their child.

Participants. Three young people (Patrick Starr, age 9, John Allen, age 17 and Molly Buttercup, age 10) and their caregivers agreed to take part in the interviews. To be respectful to John's age, all three will be referred to as young people instead of children from now on. At the time of interview, Patrick was in Year 4. He appeared to have a good sense of humour and engaged well with the interview, although seemed fatigued after a few minutes of talking. He was diagnosed with a rare brain tumour at the age of 14 months, which he still has now, and continues to receive treatment. John was in Year 12 at the time of interview. He appeared to be somewhat shy and quiet but was very polite and willing to be involved. He was diagnosed with a form of leukaemia at the age of three and a half. Molly was in Year 6 at the time of interview. Molly readily added comments throughout her mother's interview, however also

appeared a little shy when she was being interviewed independently. At the age of four, she was diagnosed with a different form of leukaemia to John. Thus, each young person had different types of cancer, which would have led to differing treatment plans and duration, hence resulting in different experiences for each young person and their family.

All three caregivers were female. Two were the mothers of the young people and one was the grandmother and full-time caregiver. To minimise the risk of participants being easily identified through their comments, all three will be referred to as caregivers for the remainder of this study.

Instruments. Two semi-structured qualitative interviews were designed for the purposes of the study, one for parents/caregivers and one for children/young people (Appendix A). The semi-structured style was adopted to allow for probing outside the set questions, which enables clarification and greater exploration of participants responses than what is possible in questionnaires or more structured interviews (Neuman, 2014). Caregiver questions focused on their child's cancer journey; the impact of cancer on their schooling; their child's engagement, achievement and social relationships at school; their experience of the PDG in terms of their perceived benefits of the support provided, the application process itself and suggestions for improving the process; and, other avenues of support explored. The child/young person questions focused on their likes and dislikes; school; their experience of the support provided through the PDG; and, any changes they would like to make at school or for other young people with cancer. The interview questions were piloted with a colleague, whose daughter had cancer and received a PDG for education in the 1990s.

Procedure. Interviews took place in May 2019, at a time and location convenient for the families. All participants preferred to be interviewed in their own homes. Before agreeing to visit a family's home, the researcher checked that there was a private space available without disruption for the duration of the interviews. Young people were given the option of

being interviewed alone, with their caregivers nearby, or with their parents in the room with them.

Before the interviews commenced, the researcher verbally reviewed the information sheets and consent forms, ensuring that all forms were signed, and all participants were happy to proceed. Patrick and Molly opted to be interviewed independently, with their caregivers nearby, while John preferred to have his mother present. As a result, the interview with John and his mother merged into a three-way conversation that lasted for 45 minutes. Patrick and Molly's interviews lasted for 12 minutes 30 seconds and 10 minutes 30 seconds, while their caregivers spoke for 30 minutes and 41 minutes 23 seconds respectively. Interviews were recorded and later transcribed in preparation for analysis. Molly and her caregiver accepted the offer to review their transcriptions; neither requested changes to be made. All other participants declined the opportunity to review their transcripts.

Data Analysis. The transcribed interviews were coded using thematic analysis, based on an inductive approach. This approach was chosen due to the sparsity of research in the area, as it allowed full exploration of the content of the interviews, without being limited by a particular theory (Braun & Clarke, 2006). The stages outlined by Braun and Clarke (2013) for coding and analysis were followed:

1. Reading and familiarisation. This includes highlighting particular items of interest.
2. Complete coding across the entire dataset
3. Searching for themes across the data
4. Reviewing themes and developing a thematic map to show the potential themes and subthemes and the relationships between them
5. Defining and naming themes
6. Writing up the final analysis

Chapter 4 Results and Discussion

This chapter will firstly explore the results from Stage 1 and discuss with reference to the literature. Next the analysis of the qualitative data from Stage 2 will be presented and discussed alongside the relevant research literature. This integrative approach is recommended in qualitative analysis as linking the analysis to research literature enables deeper development of the analysis as it happens (Braun and Clarke, 2013).

Stage 1: Results

Figure 2 shows the characteristics in terms of gender and cancer type of the sample in three groups; the overall sample; those who had received a PDG for education; and, those who had not. The characteristics are displayed as a percentage of occurrence within each group. Only 7% of the sample received a PDG for educational support. The overall mean age at diagnosis of the entire sample was 4 years 11 months, ranging from new-born babies to 12 years 11 months. The mean age at diagnosis of the group who received a PDG for education was 5 years 3 months, ranging from 1 month to 11 years 11 months. Lastly, the mean age at diagnosis of the group who did not receive a PDG for education was 4 years 11 months, ranging from new-borns to 12 years 11 months.

At first glance, Figure 2 suggests that males were more likely to receive a PDG for education, as well as children with leukaemia and CNS tumours. However, the logistic regression did not produce a good model of fit, according to both the Omnibus Tests of Model Coefficients ($p > 0.05$) and the Hosmer and Lemeshow Test, which requires a value of greater than 0.5 to support the model ($p < 0.05$; Pallant; 2011). Therefore, in this study, the characteristics of age at diagnosis, gender or type of cancer did not provide any predictive values as to whether or not a child received a PDG for education.

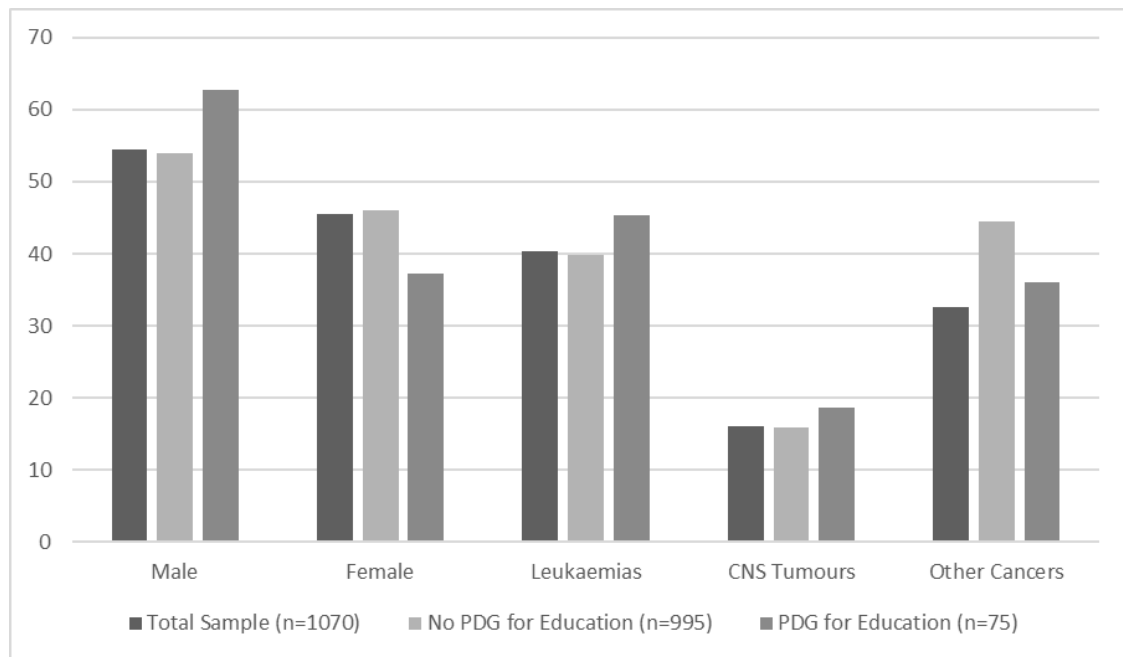


Figure 2: Characteristics represented as percentages in each group.

Of the children who were granted a PDG for education, two thirds had utilised the funds for tutoring, while 29% had received teacher aide support. Two children received both tutoring and teacher aide support, while one child used their grant for additional one on one support from their teacher.

The average age of children at the time of grant application was 9 years 6 months, with a range from 5 years 6 months to 12 years 10 months. The majority of children only received one grant for education (76%), while 21% received two grants and two children received three. Most children utilised all of their grant funds, with 72% having less than 10% of granted funds left unused. 9% did not use any of their grant funds.

Stage 1: Discussion

The characteristics explored in the current study did not provide any predictive value for future grant rounds. This is in contrast to larger scale regression studies which showed that certain cancer types and age at diagnosis helped to predict which children may experience educational challenges and/or need educational support in future (Ach et al, 2013; Andersen

et al., 2017; Boman et al., 2010). However other studies, such as Lahteenmaki et al. (2002) did not find any significant connection between the grades of survivors and the characteristics of gender, diagnosis, or age at diagnosis. While a good model of fit would have been useful for CCF in terms of planning future grant budgets, it is not surprising given the limitations of the information available. While the data were available regarding whether or not the children received educational support through CCF, there was no way of knowing if they had received support from other avenues. It is likely that those children with more significant learning challenges may have fitted in to existing funding structures and therefore did not need to apply for a grant through CCF.

The majority of children who received a grant did so for tutoring. This is particularly interesting given the recent shift away from funding external tutoring by the PDG committee and is an area that warrants further exploration to consider why families chose this form of support. In addition, almost one quarter of children received more than one PDG for educational support. This indicates an ongoing need, and calls into question the appropriateness of this type of support being funded by CCF, a not-for-profit organisation, rather than being provided through the MOE.

While the vast majority of children utilised all of the funds granted, almost 10% did not use any of the grant money. This could be due in part to the unpredictability of childhood cancer, where there could be sudden changes to the child's health status or treatment plan that would stop them continuing with their plans (Eaton Russell et al., 2016). However, this could also have been because the specific support applied for was not actually the right fit for the child at that time. This was unable to be explored further in the current study because Stage 2 discounted those who had used less than 50% of grant funding, as the main purpose was to explore the perceptions of the support provided. This issue has arisen in other studies of children with cancer, where non-completion rates of up to 40% have been found in children

participating in cognitive programmes (Butler et al., 2008). Again, future research could explore this area in more detail.

The dataset available also showed that, in addition to the educational grants, over the same period for the same sample population, 124 children had received grants for other personal development purposes. Examples include horse-riding, ballet classes or swimming lessons. This also included equipment such as laptops and devices that may have been primarily for school but were not included in educational grants as it was too difficult to ascertain if they had been required for educational support or simply due to the increase of Bring Your Own Device programmes in schools. In addition, 15 of the 75 children who received a PDG for education had also received a PDG for other purposes, during the same time frame.

The results from Stage 1 demonstrate the usefulness of mixed methods approaches to research, as the numbers alone do not allow for any further explanation or exploration of the data. This will be possible in Stage 2 through the qualitative data, with interview questions allowing participants to elaborate on the reasons why they applied for specific educational support types and the perceived benefits of the support received.

Stage 2: Analysis and Discussion

I chose to transcribe the interviews myself, as this enabled me to become immersed in the data and start the analytic process of familiarising myself with the data, highlighting initial themes at an earlier stage (Braun & Clarke, 2013). My analysis of the interviews resulted in four main themes with associated subthemes, as depicted in Figure 3. Overarching themes are displayed in boxes connected to their corresponding subthemes, displayed in circles. Related but separate themes are linked through dotted lines.

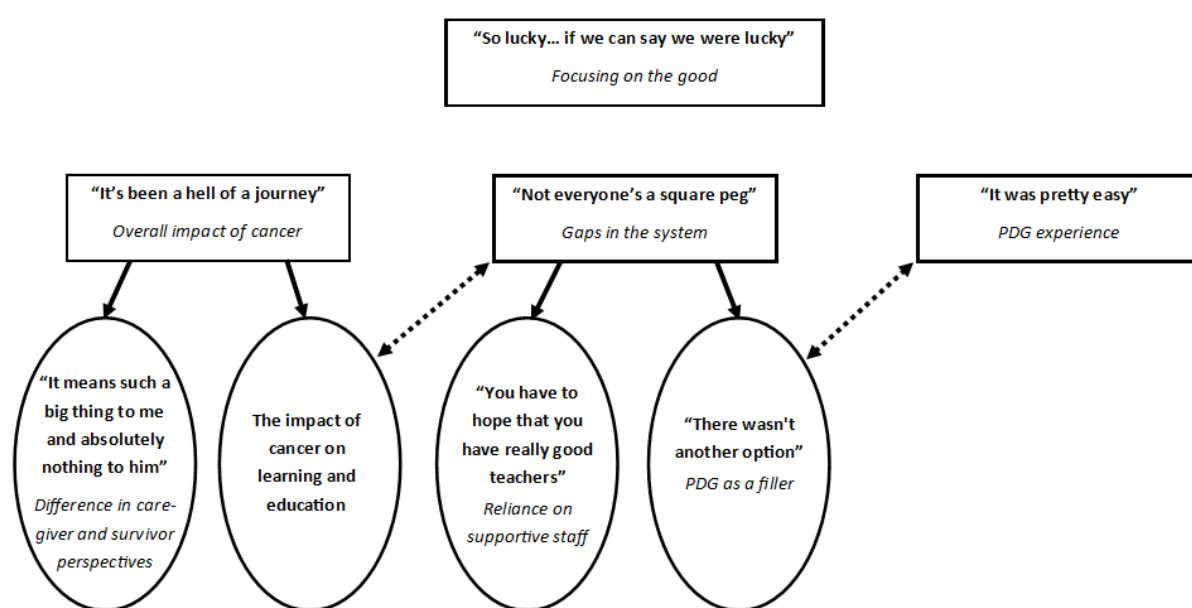


Figure 3: Illustration of the overarching themes and subthemes and how they relate to each other.

The first overarching theme "It's been a hell of a journey" examines the impact of childhood cancer on the child and their family in terms of the unpredictability and longevity of cancer treatment, the associated complications and late effects that may arise. These factors all occur within an already busy family life and, while the child is the person going through the treatment and illness, the emotional impact appears to be more heightened for the caregiver, which is explored in the subtheme "It means such a big thing to me and absolutely nothing to him." This wider impact of cancer needs to be understood before contemplating "The impact

of cancer on learning and education”, the final subtheme in this section, which, although a major focus of this study, was unable to be viewed in isolation.

The second overarching theme “Not everyone’s a square peg” is strongly related to the previous theme describing the impact of cancer on learning and education and highlights the rigidity of the system and difficulty to “fit” neatly into funding strands. Learning challenges are often not deemed severe enough to warrant additional support, although some teachers and schools are quite committed to increasing support where possible. The subtheme “You have to hope that you have really good teachers” explains how some schools and teachers will go above and beyond to ensure support is provided, however it is not standard across the system. The subtheme “There wasn’t another option” explores how the PDG played a very small, yet important part in the learning and educational experience of survivors, through temporarily filling the gaps in funding and support available through the education system.

The third overarching theme “It was pretty easy” focuses on the PDG process, and ways that it could be improved upon in future. This is strongly related to the previous theme “There wasn’t another option,” which outlines the reasons behind the PDG application.

The fourth and final overarching theme “So lucky... if we can say we were lucky” was an undercurrent throughout the interviews, shining through on some occasions, hence it is displayed above all other overarching themes in Figure 3. It describes how the families tended to focus on the good, despite all the challenges, and how the young people interviewed came across as strong, resilient young people with bright futures.

The themes identified demonstrate how an ecological viewpoint is helpful when exploring the educational experiences of young people with cancer and their families. The PDG acted as a conduit through which to open up wider discussions, which incorporated factors at each level of the child’s ecosystem. This allowed a greater depth of understanding

than would have been possible through a narrow lens focused solely on PDGs. Each theme will now be further expanded on and discussed in relation to the research literature.

“It’s been a hell of a journey.” While the focus of this research is on education, the most prevailing overarching theme was the enormity of the overall impact of a childhood cancer diagnosis on the young person and their family, as described by John’s caregiver as “a hell of a journey.” This journey must be explored in order to allow the reader to fully understand the context in which learning and educational interruptions or challenges may emerge, and to gain an insight into the perspective from which caregivers and survivors approach their individual situations and seek support, including through the PDG. This theme explores the way cancer affects already busy lives: it makes normal life almost impossible; it continues to have an impact, even after treatment is finished; it requires a good support network; and, it has a major financial impact. Two subthemes also became apparent through analysis: the differing perspectives of the caregiver and survivor and the impact of cancer on learning and education.

Cancer does not happen in a vacuum, rather it occurs amid an already busy family life. For example, Molly’s caregiver described how Molly “was in kindergarten education and I was working part time and I had just recently had a baby, so her sister was, well at that stage, she was eleven months old when Molly got first diagnosed.” The lead up to the diagnosis itself can take several months, with multiple doctor or hospital visits and numerous tests. In Patrick’s case, “he was fourteen months and diagnosed after a period of five or six visits to the GP with vomiting and headaches. Obviously, he couldn’t talk. Very, very sick by the time he was diagnosed.” For Molly, the diagnosis period was even more drawn out: “for the kind of ten, eight to ten months leading up to that [her diagnosis] she was having a number of different blood tests and things to try and ascertain what was actually going on.”

By the time the family hear the news of a cancer diagnosis, they have already endured a stressful period of uncertainty regarding their child's health and a diagnosis does not lessen that feeling of uncertainty, with frequent changes to treatment plans and durations, depending on cancer type, individual differences in response to treatment and heightened risk of developing complications and infection. A brief description of the experiences of the three families in this study will help to highlight the differences in treatment regimes based on cancer type.

John had the most common form of childhood leukaemia (and childhood cancer), but also the one with the longest standard treatment duration. He had a difficult time at the start of his treatment, contracting pneumonia twice early on, however following that his treatment plan went smoothly, with no major complications. He completed treatment at the age of seven, four years after commencement. Molly, who had another form of leukaemia, had a longer than anticipated treatment time, with unexpected delays and complications, resulting in extended periods of time in isolation, both in hospital and at home:

We were in hospital pretty much full time from around Christmas 2012 until April 2013... we came out of hospital in April... but she was still in isolation – at home, but in isolation at that point... and then she developed some lung complications which meant she had to have a further operation at the end of that year, in the December, 2013.

[Caregiver interview]

Patrick's journey has been even more complex and ongoing, as his brain tumour is still present, and he is still receiving treatment for it, over eight years later:

So they removed 40% of it [the brain tumour]. It was very large, it was the size of a grapefruit. So then we went through the whole journey, which we thought was going to be eighteen months and it's turned out we're still going all those years later, which

he is 9 now. So yea lots of chemo and radiation. Eventually. I think he's had about 7 or 8 brain surgeries thus far. [Caregiver interview]

Despite their individual differences, all three caregivers spoke about the toll of long durations in hospital, much of which was spent in isolation, which often needed to continue after returning home. This makes normal life almost impossible, with the uncertainty of treatment plans and the added risk of infection making it difficult to maintain routines as a family or plan ahead. This is aligned with comments from parents in other studies, where parents have cited the impact of uncertainty in treatment processes (Eaton Russell et al., 2016). The end of treatment did not signal the end of the cancer journey, with both Molly and John's caregivers talking about attending follow up appointments to monitor for late effects, the possibility of which they seemed to have a keen awareness of. At the age of seventeen, it has been ten years since John finished treatment and both he and his caregiver spoke with excitement about how his upcoming appointment with the Late Effects Assessment Programme team will likely be his last.

In Patrick's case, the effects of treatment were more profound, with his caregiver listing severe medical complications due to his tumour and subsequent treatment, such as deteriorating vision and neurodiversity due to the tumour itself, epilepsy as a result of a chemo trial and moyamoya following radiation, which she feels is:

Probably worse than the tumour... I mean his list of medical things is too long, but yea we've sort of got into a bit of a rhythm now. I still have to have my emergency bag packed. I tried to fight that and stopped doing it, and then I'd arrive in there with... no toothbrush (laugh) so I've given in and I've got the bag ready again. I never thought we'd still be doing this.

Lists of complications like these are unfortunately quite common with survivors of brain tumours, and, similarly to Patrick's caregiver, research participants often comment that they can be "worse" than the tumour itself (Eaton Russell et al., 2016).

Throughout all the upheaval, extended family can be a source of immense support, with grandmothers being of particular importance to the participants in this study. One of the caregivers interviewed is actually the young person's grandmother and has dedicated herself to the full-time care of her grandchild throughout treatment and beyond, another commended her own mother for assuming the primary caregiving role to enable her to work, while the third relied heavily on both grandmothers to support with siblings, especially when their sick child was in isolation in hospital: "we relied a lot on our, both our mothers. His came up from [location] and mine came down from [location]. And they looked after [youngest child] basically because she couldn't come in [to hospital] anymore." This again is in line with other studies, which highlight the important role extended family members can play in the cancer journey, particularly female members such as grandmothers and aunts, who quite often support with a caregiving role (Kelada et al., 2019).

Another aspect of the cancer journey which came up during all caregiver interviews was the financial impact on families, although this is not something that was dwelt on, nor something that the young people appeared conscious of. When Molly's caregiver was talking about how she appreciated additional supports from CCF, Molly appeared confused as to why they needed this financial support:

Molly: Petrol vouchers? Why did you get petrol vouchers?

Caregiver: Mmm, because when you're in hospital you're driving in and out, in and out a lot, everything is so expensive. And the food around hospital is so expensive, and yea. And you can't earn any money cos you're in and out of hospital, so yea.

This highlights one of several differences in the young person and carer experiences that became apparent throughout the interviews and is an important theme in its own right.

“It means such a big thing to me and absolutely nothing to him.” This subtheme stood out through comparison of the caregiver and young person interviews, as it became clear that they each had very different experiences of and ascribed very different meanings to the cancer journey. The young people were all very young at time of diagnosis and have vague recollections of that period in their life, while their caregivers could recall events from that time in vivid detail.

John’s caregiver explicitly acknowledged the vast difference between the experience of his cancer journey from her perspective as a carer and his perspective as a young patient:

I sometimes think that John has either blocked out that period when he had treatment, or he just has accepted that that was part of his life and it’s not worth talking about. It’s a huge thing for me. I can almost go day by day for that, you know, and sometimes I’m bemused by the fact that it means such a big thing to me and absolutely nothing to him! (laughs) you know, just it’s a strange thing. So, we’re talking about it now, and he’s just like why is it important to you guys.

The young people in this study were all quite young at the time of diagnosis (between 14 months and 4 years old), and all three commented at various stages that they couldn’t remember events about their treatment, such as going to school in hospital (Patrick), if they missed time at school because of cancer treatment (John) or starting school while still experiencing the physical effects of their cancer treatment (Molly). This corresponds with other studies, where children who were diagnosed before school age had very limited recollection of their cancer journey. For example, in a study by Molinaro and Fletcher (2017), many survivors interviewed had vivid recollections of the cancer treatment and side effects,

however those who were under four at the time of diagnosis reported limited or no memories of that time period. Some researchers have postulated that having cancer and being in hospital becomes a normal part of a child's everyday routine and is more readily accepted by them than by adults, especially for children diagnosed at a young age (Hammersley, Ford & Campbell, 2018).

In addition, none of the young people appeared to define themselves in terms of cancer, as they did not mention their illness when asked to describe themselves. They were not asked directly about their cancer initially, however, they were aware of the purpose of the research and that the interviewer was there to talk about their experiences because of their cancer. This is similar to findings from research on young people with chronic health conditions (including cancer), who described themselves in terms of being a "regular" young person, rather than someone defined by their illness (Yates et al., 2010). Molly's caregiver asked after her interview if she had spoken about her Beads of Courage® and Molly simply said that she hadn't wanted to talk about them. Her caregiver explained that Molly used to bring them to school quite a bit to explain her cancer journey to friends, but then she stopped. There was some debate between Molly and her caregiver as to the reason why she stopped, however, the sense that came through was that sharing her story through her beads no longer seemed to be important to Molly. Patrick's caregiver was similarly surprised that he couldn't remember going to school in hospital, when he seemed to love it at the time.

In stark contrast, as John's caregiver indicated above, the whole experience is still so clear and impactful for caregivers that they could almost recall it all day by day. From the terminology used throughout all three caregiver interviews, it is apparent that carers become immersed in the medical world, almost becoming oncology experts themselves through the knowledge acquired with regard to their child's individual cancer, treatment choices and effects, practical administration of medication and general information regarding how to keep

their child well through reducing infection risk. In essence, they are required to learn a whole new language, as John's caregiver said, "I could quote all his medications, I could quote all his side effects, like it's all gone now, but like I was some sort of like encyclopaedia robot thing." Molly's caregiver acknowledged the level of practical aspects required of her throughout treatment, but she was also quite aware of the emotional requirements:

So much organising going in and out of appointments, and just all the medical stuff that you're doing and trying to keep the house really, really clean and dust free and all that sort of thing. You know like? And just the sort of emotional work that you're doing all the time.

Similarly, Patrick's caregiver was cognisant of the emotional impact: "I think I've been through [trailed off] it's just been such a bumpy road. I think I'm well used to, I need to self-care along the way and all those things too." Throughout all the interviews, although their child was the one undergoing the treatments, the emotional impact seemed much greater and longer lasting for the caregivers. This may partly be because of the young age the young people in this study were at diagnosis, however, Molinaro and Fletcher (2017) found that caregivers' recollections of the difficulty of watching their child endure painful treatments with debilitating side effects were more emotionally charged than the survivors' accounts of the direct experience, even for older children and teenagers. In addition, other research has shown that parents tend to speak more about the bigger picture, focusing on more abstract and potential future concerns, whereas children were very much focused on their immediate environments and more concrete areas of concern (Bruce et al., 2008; Eaton Russell et al., 2016).

This differing perspective was also evident in discussions of how cancer affected the survivors' education and learning, which is the final subtheme under the overall impact of childhood cancer.

The impact of cancer on learning and education. The above themes have set the scene for the context in which the young person's educational journey unfolds, and in a sense, the lens through which both caregivers and survivors view their school experience. Accordingly, this subtheme will unpack the young person's and their caregiver's current views of school, the circumstances around which they started school, and their views around the social and academic aspects of school.

It's important to note that all young people reported liking school, their friends at school and their teachers. They all spoke of particular subjects that they enjoyed and, while they were able to articulate their specific areas of challenge, this did not come across as the defining feature of their school experience. All three were asked about what changes they would like to make at school, but none of them could think of anything they would like changed. As mentioned above, this implies that the young people answered questions about their schooling at an immediate and concrete level, and the overall feeling was one of positivity. While the caregivers were also positive in terms of their child's engagement and enjoyment at school, there was more of a focus on the bigger picture in terms of how cancer has impacted on their learning and education and all caregivers expressed current and previous concerns regarding their child's ability to reach their academic and social potential.

The three young people interviewed had all been diagnosed and started treatment before reaching school age. All three had interruptions to their early childhood education, however, were able to start primary school at a relatively similar age to their peers, perhaps a term or several months later. As such, Patrick (age 9), Molly (age 11) and John (age 17) would have started school approximately 4, 5 and 12 years ago respectively.

But she was cleared to go to, to start school at the start of the following year, so she was five and a half. And, it meant that she, yea, when she started school she was still

pretty skinny and didn't have much hair, but apart from that she, you know, was pretty keen to go and she coped with it really well. [Caregiver interview]

As this indicates, caregivers had justifiable concerns about their children starting school:

It was still scary because he was still undergoing treatment while he was at school and because there's so many kids there they can't say keep away from that kid, he's got a cold you know. But we just had to risk it. [Caregiver interview]

While John and Molly were able to start full time, with the odd day missed due to treatments or being unwell, Patrick started school part time and remained on that basis for quite some time.

At the start, the social aspect of school was more important to their caregivers than the academic side, with all caregivers expressing some level of concern regarding the impact that isolation may have had on their child. John's caregiver commented that "he couldn't go anywhere, whenever we went to Starship he was in isolation. So he couldn't mix with any of the other kids." Both Molly and Patrick enrolled with the Health School when they were unable to attend regular school and the social impact seemed more important than the academic side. Although there was no contact with other children, having the teacher come in lessened the reliance on the main caregiver, as Molly's caregiver said, "it was nice for her to just have a little bit of interaction with someone else rather than just me."

Fortunately, the missed opportunities for interaction with peers during periods of isolation and hospitalisation does not appear to have impacted the young people in this study's ability to make friends. John reported that he finds it easy to make friends and "Most of my form class I'm friends with, or have been friends with." Similarly, Molly has "lots of friends and they're in my class this year." Patrick also said that he is friends with all the boys and girls in his class "and I've got some other friends in another class." His caregiver did,

however, express some concerns about how his physical limitations have previously held him back from playing physical games with the boys at school, although that seems to be less of an issue now. His continuing medical conditions are also somewhat of a barrier to socialising outside school, as he is at risk of experiencing TIAs (mini-strokes) at any time, requiring his caregiver to be with him at all times.

After the interview, Patrick's caregiver shared a story about when he wanted to play ball with the boys in his class. The boys put limitations on him, saying that he could play, but if he dropped the ball a certain amount of times, then he had to stop. Patrick thought about this, decided he didn't want to play under these conditions and went off to do something else. His caregiver commented that he did not appear to be upset by this interaction but expressed how it was very difficult for her to witness it. Vannatta, Gerhardt, Wells and Noll (2007) noted how sometimes survivors who had intensive treatment affecting the CNS were unaware of their social challenges, which potentially could be a protective factor for Patrick in this sense, as he may not feel like he is being excluded in the way that his caregiver perceived him to be. Conversely, it is also possible that Patrick was aware of the likelihood that he would drop the ball and thought he was better off not participating, thus limiting opportunities for social interaction. Inclusive practices in schools could help to prevent this scenario from occurring, for example, teachers could employ adaptations to games during physical education (Lieberman, James & Ludwa, 2004), which may in turn encourage children to adapt playground games.

There were no reports of bullying in any of the interviews, although Patrick's caregiver spoke about having issues with questions from other young people about Patrick's scars from surgery:

A couple of the kids, because his scars are always so, yea we've had a few issues with that. Kids question things, but he just says oh well, that's just, you know, I'm brave,

I'm a warrior, you know, be proud. I always tell him be proud. Of your scars. It's your journey. He's a very caring boy himself, so, no, he's alright.

These reports are quite different to other research in the area, which shows that difficulties with peers and bullying is a significant issue for survivors (Lahteenmaki et al., 2002; Bruce et al., 2008; Upton & Eiser, 2006), especially those with visible effects following treatment for a brain tumour (Eaton Russel et al., 2016). Bessell (2001) found that children who were too young for school during treatment had significantly higher social competence than children who were home-schooled during treatment. This may help to explain the apparent social competence displayed by the young people in this study, although yet other research disagrees with this, indicating that bullying is more likely to occur in children who fell ill before school age (Lahteenmaki et al., 2002). The absence of bullying in the current study contrasts with earlier work in Aotearoa which indicated that bullying and peer avoidance were issues for young people with cancer (Fraser, 2001). Molly's caregiver commended her school on its' openness to diversity, so perhaps there is tentative support that the MOE's increasing focus on inclusiveness in schools is having an impact with this group of young people. This is an area that warrants further research, as other studies have not shown any notable difference in rates of reported bullying in schools in Aotearoa between 2001 and 2012 (Clark et al., 2013).

Differences in research outcomes may partly be attributable to the person taking part in the research. For example, Yilmaz and colleagues (2014) found that survivors were more socially introverted than their peers, according to teacher report forms. In this study, John's caregiver remarked that he may be perceived as introverted:

He's always been like this, very quiet, very calm. Almost to the point of shy and introverted. Not introverted though, when he's in the right, with the right people then he's outgoing. And at school he was always like the little quiet boy.

In this instance, it is understandable that someone who does not know John as well could potentially rate him as being introverted. His quiet, shy nature certainly came across during the interview process and he often looked to his mother to answer questions on his behalf.

Turning to the more academic impact of cancer on the current participants, initially all three young people appeared to keep up with their peers, however, as they grew older, their caregivers and teachers began to realise that they were experiencing some learning challenges in comparison with their peers.

Patrick's caregiver spoke about not yet knowing the "nature of the beast" when he was attending early childhood education, or even for the first couple of years at primary school: "You know it's alright when they're little and they're all little together, but then they start to develop and he gets left behind, which is what was happening last year, you could see it." Patrick is the only participant that has been kept back a year at school, but is also the one that has missed the most days at school due to ongoing treatment requirements:

He's repeating Year 4. So that's been a very good decision. He's had so much time off school, last year he had two big surgeries, both six week post op he wasn't at school and then just slowly part time, so you know, in the big scheme of things, we just decided, I decided that it would be best to take the pressure off him and it's been the best decision. [Caregiver interview]

The fact that Patrick repeated a year at school corresponds with trends found in large scale studies, where, although small proportions (less than ten percent) of survivors had repeated a year at school (Lahteenmaki et al., 2002), survivors were more likely than their healthy peers to repeat a year or start school later than normal (Yilmaz et al., 2014) and many had continued school absences post treatment (Upton & Eiser, 2006). Bessell (2001) found that survivors who had repeated a school year were more likely to report poor relationships with teachers, or

poor academic performance and some indicated that it added to their social difficulties, but luckily in Patrick's case, both he and his caregiver have reported positive outcomes to date. Patrick commented that he is friends with all the boys and girls in his class and his teacher is "quite nice and I like her very much because I like all the cool things and new things she ends up teaching us."

For Patrick it appeared that cancer had a direct influence on his challenges at school. He experiences some physical limitations, such as deteriorating vision, issues with balance and coordination and he fatigues easily. He also experiences cognitive and processing delays:

So one of the problems he has is multi-tasking. So it's like swimming, he struggles to breathe and kicking all at the same time. Same with learning. He's told a sequence of things, and you know, to type, then to print or to email, it all gets too much and his processing is not quick to absorb, then he gets anxiety because of the time frame. He needs more time anyway. [Caregiver interview]

This is comparable to other research on children with brain tumours, which showed they may experience neurological effects with vision or movement (Upton & Eiser, 2006). They also may be affected by a combination of slow processing speed or executive functioning and fatigue, resulting in it taking them longer to respond to the teacher, take in information or follow instructions (Barkon, 2009). Many children have additional supports at school following a brain tumour (Ehrstedt et al., 2016; Upton & Eiser, 2006) and Patrick is no exception, having received teacher aide support since the start of school.

Molly and John also experienced issues in processing. Molly's caregiver stated that "academically she has, and continues to have, (pause) just takes a lot longer to learn things than a lot of the other kids." Assuming this was due to late effects, they went back to the hospital, but did not get a definitive answer about the cause:

So we went, I talked to her oncologist about the learning stuff and, you know, whether, (sighs) because there aren't that many kids, and there isn't that much longitudinal data about the kind of treatment that she's had, he, the oncologist was like we don't know if this is treatment related. It may be, it may not be. There's a whole variety of things, like, the fact that she was out of school at what is like a developmentally crucial academic you know, crucial period of that sort of early childhood, early schooling kinda time. And so, it could be that, or it could be some of the treatment stuff, or it could be nothing to do with the treatment, it could just be actually, you know that that is something that she would have always had. You just, you don't have a control child, so you don't know (laugh) what it is. [Caregiver interview]

An assessment with an educational psychologist was organised for Molly through the hospital, but again, it did not provide the clear-cut answers that her caregiver sought in terms of identifying specific areas of need that could be targeted for learning support. In contrast, John received an assessment through the LEAP clinic, which highlighted that he may have difficulties in processing. The reality of this was described by John: "I do get challenges with essay writing or like, trying to get the information out of my head and put it on paper." His caregiver found it helpful for them to know exactly where his challenges were, so they could put supports in place to assist. While awareness of specific challenges may be beneficial, the reasoning behind the desire to have an assessment from the caregiver's point of view appears to resonate with the medical model, whereby a diagnosis helps to provide a treatment plan (Gutkin, 2012). This is useful in medical situations, and an understandable perspective from a caregiver supporting their child through years of medical treatment, however in educational and psychological areas, Gutkin (2012) argues that an ecological model is a much better framework. Interventions can take place at multiple levels, thus having the potential to impact on multiple young people, rather than just intervening at an individual level.

In spite of the difficulties that all three young people faced, the biggest academic challenge from the caregiver's point of view, was in accessing support to help them reach their potential, which is the topic of the next theme discussed.

“Not Everyone’s a Square Peg.” Aligned with learning and education is the parallel theme of rigidity within the system in terms of enabling successful reintegration to school or accessing learning support, the difficulty for childhood cancer survivors to “fit” into pre-existing categories and the gaps in the system. The subthemes further explored this through outlining how the families have relied on having supportive staff to ensure that their child’s educational needs were met and how their application for a PDG was because there didn’t appear to be another available option.

All young people in this study were diagnosed before they were of school age, with two actively attending early childhood education at the time of diagnosis, and the third starting while still receiving active treatment. All caregivers commented how early childhood environments were much more flexible than school in terms of high adult to child ratios, level of care provided and regular communication with teachers. Once it came time to start primary school, the schools did not appear to have processes in place to support children with high health needs and, as such, the support available to manage the unique needs of each child was quite varied. This is most apparent in Molly’s and John’s experiences. Molly’s caregiver reported that she “had some really, really, awesome teachers that first year, who were just, you know really looked after her.” She was able to have peace of mind when Molly was at school:

And were like, they would call me up “oh there’s something in the classroom” or “there’s chicken pox,” or, you know, they were really on to it. I pretty much dealt with the teachers only. And they were fantastic. Incredibly approachable. They were very like, “you be here if you wanna be here, you leave it to us if you want.” You know like,

they were really allowing me to, you know, drive how I wanted it to go. And I just really, the way they were so attuned to her, I just felt like I could really trust exactly how they were. It was really reassuring.

In stark contrast, John's caregiver felt that her concerns were not fully listened to by the school principal at the time of enrolment. Even though she went through the list of health-related concerns, the principal appeared more interested in small talk than in discussing John's requirements. Once he started school, she reported having very limited contact with his teachers:

No. no, at the normal parent teacher days, and that but [pause]. I don't recall anybody ever ringing me and saying you might want to come up and pick up John, we've got chicken pox in the school. And, as a teacher, I know that chicken pox is like every other week, someone's got it. But chicken pox could have killed him if he'd come into contact with it. But yea, I don't recall anyone ever ringing me and saying you need to come and get John, there's 6 kids come down with a tummy bug and it might be rhotavirus. Well, you know rhotavirus could have like, done him in as well. All that stuff, but I don't recall anybody ever doing that. Nobody rang me and said you better come and get him.

The comments from caregivers in this study suggest there is lack of knowledge, and sometimes also acknowledgement, of the severity of risk present for young people with cancer, which has been commonly cited in research on school reintegration after cancer (Vanclooseter et al., 2018). Patrick's caregiver speaks of this as a constant battle for her, as Patrick's individual needs are not being taken into account, as they don't neatly fit the existing criteria for support: "And that's I think the biggest challenge with the school system sometimes, is to realise not everyone's a square peg." Due to his visual deterioration and consequent sensory needs, Patrick has qualified for support under the MOE's Ongoing

Resourcing Scheme since preschool. This support is currently in the form of a resource teacher for vision and teacher aide support in the classroom. However, as the application was originally approved for his sensory needs, his health needs, which have changed significantly since preschool, have not been factored into his case. Therefore, the teacher aide hours allocated to him are not sufficient for in class support while he is at school.

I've got letters galore in support of him, right from the oncologists to neurologists to the consult liaison. They all say he needs to have someone with him to be safe, with these TIAs and things, I mean it could just happen just like that. But that's not taken, there's no provision for that in the application. There is if you've got a child that could run away, that's got autism or something, but a high-risk medical situation, no. So it is very frustrating when you're working within this very tight perimeter of their guidelines. And even though I supply all these letters of support from Starship, which are from the specialists and not just anybody, they don't really seem to use them.

[Caregiver interview]

This raises questions about the process and ties in with recollections of parents from other studies, where letters informing teachers of their child's needs were overlooked, resulting in the teacher not being fully aware of the young person's specific needs (Bruce et al., 2008).

While Molly had a positive experience starting school, her caregiver's earlier attempts to engage the support through the RHS were difficult, due to a lack of fluency between the processes of enrolling with regular school and with the RHS. The RHS requires that a student is enrolled in their regular school before being added to their roll, but as Molly had not yet started school, the staff at the primary school that she would eventually attend found it difficult to process her enrolment, not knowing when she would actually attend school:

I found it frustrating that I had to organise all of that. Like I was saying to the Northern Health School, I had tried, and nothing was really happening and I was like, can't, I don't understand why I have to keep doing this, can't you talk to them or explain it, like, because I felt like I was explaining stuff I didn't even really understand about their needs for the Northern Health School, and the school's needs and I was being involved but I didn't really understand the protocols behind either of them. [Caregiver interview]

The process took two to three months to complete, caused a considerable amount of extra strain for Molly's caregiver and she didn't feel like the quality of service provided to Molly was worth the effort taken to organise it. It must be noted however, that Patrick's caregiver had very positive feedback about their experience with the RHS.

All three young people in this study had very different experiences in terms of their reintegration to school following treatment, however all caregivers reported experiencing similar frustrations in terms of the gaps apparent in the system at this point in their journey. This variation of experience at the point of school re-entry has often been cited in the literature, with caregivers, teachers and health professionals all reporting quite varied and mostly inadequate experiences (Tresman et al., 2016; Vanclooster et al., 2018). Schools are often not aware of the processes that need to be followed and there can be little or no interaction between the school and hospital (Fraser, 2001).

The importance of collaboration between education, medical and family systems to support successful school reintegration has been stressed since the 1980s (Moffitt, 1985), however the experiences of the families interviewed in this study and other studies suggest that little progress has been made in this area to date (Bruce et al., 2008; Hay et al., 2015; Herrmann et al., 2011). In a review of the literature on school reintegration, Vanclooster and colleagues (2018) found that families, health professionals and educators all have similar

needs when supporting reintegration into school in terms of the communication and information sharing required, and, while all parties stress the value of collaboration, this may not always happen due to various reasons, such as restrictive school or hospital policies, or lack of specific guidelines, resources or strategies to inform teachers of the various needs of this unique group of young people. From the accounts of the caregivers in this study, there has not been a systematic way of sharing information between the MOE and MOH, and even the RHS appear to have enrolment policies that create obstacles for families. The caregivers often spoke of the importance of having supportive staff in school, to help them navigate these challenges, which was another subtheme that became evident through analysis.

“You have to hope that you have really good teachers.” This subtheme explores how positive school experiences seemed to rely on being fortunate to have supportive teachers, rather than the educational system ensuring that the young people had a positive experience.

We have already seen through the differing experiences of Molly and John starting school, how some schools and teachers will go above and beyond to ensure their student is being supported, but there are no clear processes to ensure this happens across the board. Molly’s caregiver was quite forthcoming in her praise for the way the teachers and school supported Molly by identifying areas that she was struggling in and proactively including her in additional support services where possible, such as Reading Recovery and small group work in maths and spelling. However, she was also very cognisant that the support provided was dependent on the individual teachers:

For any kids with any kind of different learning styles that aren’t catered for in a traditional sort of school setting, it just means you have to hope that you have really good teachers and really good support that recognises differences and then cater accordingly. And I mean she’s had some fantastic teachers and then some teachers who are just ok. [Caregiver interview]

In contrast, John's caregiver initially felt frustrated when an assessment at the hospital suggested he had difficulties with processing, as she felt this should have been picked up and addressed earlier at school. However, she did mention several subsequent supports that were put in place to support his learning, such as Reading Recovery and small group instruction. Both John and his caregiver spoke positively about his current teachers, who are very supportive:

His teachers all there all know that he's got a processing problem. And so, quite often if it's time to do an assignment, if an assignment is due, he will have done most of the work but they're all aware that he is, he might have been struggling and they'll say to him I'll be in the classroom on such and such a lunchtime if you want to come in and we'll go over it, so they've all been really good. And he usually doesn't need much help, you know, just usually finishing stuff. [Caregiver interview]

In Patrick's situation, his caregiver attributes his success at school this year to his teacher, who "is fantastic. We're managing without a teacher aide in the afternoons." This is an important achievement as former teachers had been unable to manage Patrick without a teacher aide present and, as the funded hours only covered him for the mornings, his caregiver had to pick him up early from school. This also occurred in instances where the teacher aide was unable to attend work: the teacher would call his caregiver and ask for Patrick to be picked up and taken home. The MOE is strong in its stance for inclusive education, guided by national legislation such as the Education Act and international conventions such as the United Nations Convention on the Rights of the Child (MOE, 2018c). However, in Patrick's situation it appears that the processes in place at his school did not allow him to fully exercise his right to be at school. Other studies that have explored teachers' perspectives have indicated that they often do not feel adequately prepared to teach children with additional health and learning needs (Adams, 2018; Bessell, 2001; Hay et al., 2015). Thus, it appears that the teachers were

also be placed in an unfair position, as the system did not seem to support them to enable Patrick to attend school full time. This is an example of the impact of factors across each level of Patrick's ecosystem.

The caregivers' interviews all indicated the importance of teachers' ability to recognise and cater for their child's unique needs, however the interviews with the young people themselves highlighted another vital skill; the ability to engage young people in learning. All three young people gave positive examples of teachers who made learning fun through games and interesting activities, and they all shared an appreciation of the additional supports given to them at school. For example, Patrick likes his teacher "thinking up some cool things that are different to teach us," while Molly values the opportunity to be in smaller groups for learning as "you didn't have to wait that long" to receive support from the teacher.

Other studies have similarly highlighted the importance of teachers for a successful school experience (Bessell, 2001; Hay et al., 2015). Some families have reported positive and constructive school practices, however, others have commented that teachers need constant reminding, or may be unwilling or unable to comprehend the additional supports needed (Vanclooster et al., 2018). As childhood cancer has a relatively low incidence in the general population, it is important to remember that most teachers will not have had former experience in teaching a student with cancer (Lahteenmaki et al., 2002) and may feel ill informed (Hay et al., 2015) or be fearful of doing the wrong thing (Tresman et al., 2016). Thus, moving forward, as discussed above, it is vital that processes are put in place to ensure that all stakeholders are working collaboratively to provide equity of support to all young people.

Researchers recommend that the support provided should be a "dynamic, ongoing process" to keep up to date with changes in teachers, transitions between classes, developments in medical status or manifestations of late effects (Moffitt, 1985). While the current study showed that the educational needs of the young people were ongoing as they

progressed through school, the resources available to support were not as apparent. For all three families, this is where the PDGs came in.

“There wasn’t another option.” The final subtheme in this section focuses on how, at the time of PDG application, all three caregivers did not feel that they had any other funding sources available to them.

As noted above, Patrick was already receiving funding from the MOE, but it wasn’t enough to have teacher aide support available in his classroom for the full day:

If I wanted him to be at school he needed someone with him so I had to try to get the money, which is where Child Cancer Foundation came in... It was emotionally exhausting because I, you know it was just another battle for me, and you know he couldn’t be at school, I mean now that’s actually illegal. They have to be at school, the school can’t say that. But of course I didn’t know. (pause). [Caregiver interview]

His caregiver felt that the only other option available would have been home-school, but she was aware that that would not be supportive of her wellbeing, or Patrick’s developmental need to learn and socialise with his peers. She was extremely appreciative of the funding, although did not feel that she could morally request more funding to support his education from CCF. She did receive further funds for another term from another community group, however she again didn’t feel that was right and so began advocating for additional funding through local MPs.

For both John and Molly, their learning challenges were not considered severe enough to qualify for additional funded support within school. Their caregivers shared an awareness of the need for the regular support services provided in school to be accessible to all young people and expressed a sense that they had exhausted their portion of that avenue of support.

Molly's teachers had commented that they had tried everything they could within school, but she was still struggling, which is why her caregiver initiated the assessment:

I was thinking there is government funding if your child has particular things, so that's where I was sort of going with getting the ed psych review, I was thinking well then if they're like yes, she has dyslexia, it would be like, OK so then we could get this teacher aide, or whatever... and then because she didn't neatly fall into a particular thing, they were like there is no funding available for a child that (laughs) is a little bit on all of these levels. And, so, yea, that's, for us, why the personal development grant was a great option because there wasn't another option. It didn't feel like there was another option. [Caregiver interview]

In this case they chose a tutoring programme following a recommendation from a friend.

Molly is released from school once per week in the morning ("so your brain's fresh") to attend the hour long session, which has a strong focus on spelling and Molly has found that "it helps with my reading and writing, cos I know how to spell that word." Both her caregiver and teacher have noticed a marked improvement following the sessions, particularly with regard to her reading, with her caregiver commenting that "she was at a Year 1 level when she was in Year 4 and now she's in Year 6 she's right on level." The funding from the PDG covered the costs of tutoring for most of the first year, and the family have chosen to continue since, funding it themselves.

In a similar vein, John's caregiver spoke about how there didn't appear to be any other funding options available for him, as he was just slightly below his peer group, so his difficulties were not deemed significant enough to warrant additional supports. He completed tutoring after school for almost two years and both John and his caregiver noticed an improvement, with his school reports indicating that he was achieving on par with his peers. His medical team and caregiver had some concerns that he may become fatigued by attending tutoring

after a full day at school, but neither John nor his caregiver noticed any negative effects. His caregiver was extremely appreciative of the grant, as she did not feel that she would have been able to afford it herself or find another way to fund it.

Parents interviewed in other studies have also turned to community organisations to supplement school-based supports (Bruce et al., 2008) and numerous studies have highlighted the great need for parents to become advocates to ensure that their children receive adequate and timely support services (Fraser, 2001; Rubens et al., 2015; Tresman et al., 2016). For all three caregivers it appears that the PDG helped to fill a gap in the educational support available to their children through the MOE or other sources.

“It was pretty easy.” While the PDG was a major focus of this research, it ended up as just a very small part of the overall picture of the lives of these young people and their caregivers since their cancer diagnosis. All caregivers fed back that it was a relatively easy process, with appreciation of the support given by their respective Family Support Coordinator with completing the application. As Patrick’s caregiver commented: “I know [Coordinator] helped me with the process, because I was snowed under big time with just the journey, the uncertainty. So she was just so good you know she really helped me out.”

One caregiver commented that she heard about the grant from another parent, rather than directly from CCF, which she found strange, although recognised this may have been because they were still in hospital at the time, and it may have been mentioned at a later stage. She made some suggestions for improving the process such as being more proactive in telling families about it; offering additional supports to complete the application for families who may be less literate or for who English is a second language; and, having an information sheet with ideas about the types of grants that people have applied for.

“So lucky... if we can say we were lucky.” Throughout all the interviews and the discussions around challenging situations, an overwhelming sense of positivity shone through. The caregivers often eluded to a strong sense of gratitude, even during tough times. For example, John’s caregiver commented that they were lucky he contracted pneumonia at the start, as it resulted in him receiving an immunity booster, which aided a smooth progression of his treatment plan. Molly’s caregiver was grateful for her daughter’s earlier medical condition, as that meant they were more aware of her health and caught the cancer almost as it developed, while Patrick’s caregiver felt gratitude that she could support him: “I mean he’s such a beautiful child, his nature and he’s very insightful and you know it’s actually quite a privilege for me.” During the interview with Patrick, this description came to life, as he demonstrated a great sense of self awareness in terms of naming his own strengths and challenges; an appreciation of the support that he was receiving at school; and, a great sense of humour throughout.

John’s mother spoke about the immense pride she feels for her son, for the way he has calmly and quietly dealt with his cancer journey and continues to put in the extra effort required to complete schoolwork and achieve academically: “he knows that he’s got to be proactive in doing it. But it’s not holding him back, you know. I’m really proud of him.” John used few words in his responses to interview questions, but still displayed a depth of awareness of his own strengths and a commitment to seek help to support in areas of challenge. Likewise, Molly was very articulate in describing her own strengths, challenges and what supports she needs to help her achieve at school. She also showed great determination and perseverance through her love of reading and writing. As her caregiver commented:

She really is someone who is always very very willing to give stuff a go. And even when she was finding it very, very difficult to read, she persevered right through, and that’s what I mean, she was forever getting certificates from the teachers, like you

know for Molly for persevering with her learning, for persevering with her learning (laughs). Because she really did, and I know that that's an amazing bonus, because I think, you know, kids can get really turned off learning if it's difficult, if they have the kind of personality that wants to be able to succeed at something straight away. Yea. So, yea I think that's like a gain, her personality, she is good with that sort of stuff.

In recent years, there has been an attempt to shift the trend from focusing on the negative impact of childhood cancer to exploring the positive outcomes (Zebrack et al., 2012). Findings have shown that post traumatic growth is evident in both survivors (Kamibeppu et al., 2010; Tillery et al., 2015) and parents (Turner-Sack, Menna, Setchell, Maan & Cataudella et al., 2016), with both groups showing elevated levels of resilience in comparison to peers (Schepers et al., 2019). The notion of being lucky has also come up in other studies, with parents and survivors recognising that they are often much better off than others and expressing gratitude towards those that supported along the journey (Eaton Russell et al., 2016). Many survivors also recall positive memories from their experiences, with a main recollection being the strength and love that they felt from those caring for them, while, in line with the present study, caregivers recall the resilience that survivors showed (Molinaro & Fletcher, 2017). While this may show signs of post traumatic growth due to their cancer experiences, it is difficult to ascertain the cause, as the participants in Molinaro and Fletcher's study or the current study, may have been more optimistic in general, which may naturally lead to a higher likelihood of being positive during their cancer journey. The current findings are also aligned with views from the field of childhood studies, which promotes a shift away from deficit models of disability to view all children as simply having childhoods (Curran & Runswick-Cole, 2014).

Summary of Findings

The quantitative analysis in Stage 1 addressed the first research question by giving an overview of the characteristics of children who had applied for a PDG for educational support. Slightly more males than females received grants and numbers were higher for children with leukaemia and CNS tumours, although none of these findings were statistically significant. The qualitative component enabled a deeper exploration of the PDGs and addressed the second research question through interviewing young people and their caregivers about their experiences of the young person's educational needs following a cancer diagnosis and the specific support provided through the PDG.

Throughout the interviews it became apparent that educational experiences could not be viewed in isolation, particularly from the caregiver's point of view, and a wider lens was needed to firstly gain an understanding of the overall impact of a childhood cancer diagnosis on the young person and their family. All three young people experienced various challenges with their learning and were quite cognisant of them, yet this did not appear to impact their enjoyment of school, with all three expressing positive views on school, their teachers and friends. While much of the discussion was focused on the child's micro- and meso systems, there was some recognition of factors at the exo- and macro-levels by caregivers as they reported difficulties with accessing adequate support for their children at a systemic level within schools and more broadly within the MOE. All three caregivers applied for a PDG because they did not feel they had other funding options available. The supports provided through the PDG were viewed as beneficial by all participants and caregivers reported that the application process was straightforward. In spite of the challenges faced by the participants, the overwhelming sense at the end of the interviews was one of positivity and hope for the future, aligning with a childhood studies perspective.

There were some limitations to this study, however the findings may be useful to families and professionals working with children with cancer and can be used to guide future research. This will be discussed further in the next chapter.

Chapter 5 Conclusion

The current study sought to describe the characteristics of young people who received PDGs for educational support and to explore the experiences of a small subset of these young people and their caregivers in terms of educational needs following a childhood cancer diagnosis and the support provided through the PDG. The findings presented above indicate that the PDG played a small, yet important part in the learning and educational experiences of these three survivors, through temporarily filling the gaps in funding and support available through the MOE. This chapter will explore the implications for practice generated from the research findings and put forward recommendations for future research. Firstly, however, the limitations of the current study must be acknowledged and discussed.

Limitations

The most obvious limitation to the current study was the small sample size for the qualitative component. While the views of the three young person and caregiver pairs offer valuable insight into the educational experiences following a cancer diagnosis for these three families, the findings cannot be generalised. This is a common limitation in the field of childhood cancer (e.g. Bessell, 2001; Boles et al., 2017; Eaton Russell et al., 2016; Yilmaz et al., 2014) and may in part be due to the low incidence of childhood cancer (Helms et al., 2016). The response rate (30%) was low for this study, and I could have made more of an attempt to follow up with non-responsive families, however it was more important to me to balance their needs and ensure there was not undue pressure on anyone to take part, as recommended by Boles and Daniels (2019). The decision to only interview families based in Auckland limited the perspectives to those who lived in urban areas, close to the main treatment centre. Experiences may have been very different for families in rural communities, or smaller urban locations and expanding the geographical location may have increased the sample size.

Additionally, all the caregivers interviewed were female, adding to the already existing underrepresentation of fathers in similar studies (Eaton Russell et al., 2016).

The sample size for the quantitative analysis in Stage 1 was large, however this was also limited by focusing on a singular source of educational support. Children in the test group may have received educational support through other means external to CCF, and perhaps a survey asking about various sources of educational support would have added additional weight to the findings.

The retrospective nature of interviews creates another limitation, as accounts are dependent on the participant's memory, which may wane over time (Molinaro & Fletcher, 2017). However, other research has suggested that retrospective accounts add value as participants no longer feel the intense distress of the early treatment period and have had time to reflect on their experience, thus being able to provide greater insight (Cox, 2018). In the present study the latter was likely to be the case for the caregivers, while the young people interviewed only had vague recollections of their time in hospital and early schooling, although all had some memory of the support they received through the PDG. The fact that all three young people in this study were under the age of four at time of diagnosis would have had a big impact on their ability to recall events, so future research could benefit from a wider range of diagnosis age amongst participants. There is also the possibility that the proximity of the caregivers may have influenced how freely the young people spoke in their interviews, and vice versa (Boles et al., 2017). However, none of the adult interviewees appeared to be reserved in their responses. The young people came across as slightly more restrained in their responses, but this appeared to be more due to shyness rather than caregiver presence. To counteract this, perhaps it would have been better to conduct the interviews over two sessions, to build greater rapport with the young people, as suggested by Boles and colleagues (2017).

The very nature of qualitative analysis means that there is always an element of researcher bias, which I addressed through discussions to reflect on how my own knowledge and experience may impact on my analysis and by analysing one set of caregiver/young person interviews in conjunction with my supervisor. These steps enabled me to be reflexive in my analysis, which can act as a type of “quality control” in qualitative research (Braun & Clarke, 2013, p. 37).

Implications for Practice

The importance of collaboration between the family, the school and the medical team was highlighted throughout the interviews, and has been one of the main recommendations from many research studies over the past 30 years, yet is still not widely implemented (e.g. Moffitt, 1985; Fraser, 2001; Hay et al., 2015; Herrmann et al., 2011). The ongoing collaborative projects being led by NCCN, as described in the introduction above, provide hope that progress will be made in this area in Aotearoa. However, there are certain areas of responsibility that do not naturally sit within any existing role. Numerous studies have suggested the benefits of having a school liaison person, who would coordinate the collaboration and information sharing between all parties and help the family navigate their way through the system (Bruce et al., 2008; Herrmann et al., 2011; Tresman et al., 2016; Vanclooster et al., 2018). This likely would have been a valuable support person to have for the families in the current study, negating the reliance on proactive and supportive staff to ensure that the process ran smoothly for each child at school. Thus, a position like this is worthy of further exploration for future NCCN working groups in conjunction with the MOE, as it may be possible that this responsibility could sit with the new Learning Support Coordinator roles being introduced (MOE, 2019). Collaboration and improvements made at these outer levels of the child’s ecosystem will enable members of their microsystem to ensure the child’s right to a quality

education is upheld and parents can become members of a collaborative team together with school and hospital staff, rather than being positioned as advocates for their child.

All caregivers in the present study believed that their child's educational challenges were a result of late effects from their cancer and subsequent treatment. This adds further support to the recommendations mentioned throughout this paper that parents and teachers should have an awareness of the possibility of late effects, with teachers being in an ideal position to monitor any changes over time (Gartin and Murdick, 2009). However, it is important to note that, despite the challenges faced, each of the young people in this study displayed a remarkable insight into how to overcome their barriers. Therefore, it is important for teachers and parents to strike a balance between being aware of potential late effects and being overly vigilant and anxious about their potential manifestation.

Throughout the interviews there appeared to be a tendency by the caregivers to think that a teacher aide could be a solution, if funding was available, however it was not clear if the caregivers were aware of the role and purpose of a teacher aide. The MOE (2017) has information available on the TKI website regarding the role and purpose of a teacher aide, however this may need to be made clearer to parents. In addition, many of the difficulties described by the caregivers and young people could be managed through inclusive classroom practices such as UDL. This is already being promoted by the MOE (2018b) however, more could be done to encourage schools to adapt UDL classrooms and minimise the need to seek external support. In addition to supporting existing difficulties, a UDL classroom would ensure that the teacher is prepared for any future challenges as late effects emerge (Barkon, 2009). It would also help to foster positive peer relationships, reducing the risk of bullying occurring. In future, CCF staff members could encourage caregivers to have more in depth conversations with their child's school about the possible support available, before submitting a PDG application.

Thus far in this write up, three of the four elements of Lundy's (2007) model have been achieved: the young people were provided a space to participate, they voiced their thoughts, and their views have been communicated. Lastly their voice needs to have the ability to make a difference. The overwhelming voice that came through from all three young people interviewed was one of positivity. These young people have not allowed cancer to define them, nor allowed their challenges with learning stop them from participating in, enjoying and achieving at school. Thus, their voice can help to alleviate some of the concerns that caregivers and professionals may have about the future of these young people. Parents can also take some relief in the knowledge that, although the experience may have been traumatic for them as caregivers, it does not always have a traumatic and long lasting impact on children, as appears to be the case in the present study, and in previous research (e.g. Molinaro & Fletcher, 2017). These findings are consistent with other research studies which indicate that cancer often becomes part of a "normal" childhood, particularly for those diagnosed at a younger age, and children can be much more accepting of this than adults (Hammersley et al., 2018). Other studies have gone even further to suggest that children with cancer can often become more resilient than their peers in the long term (Schepers et al., 2019; Tillery et al., 2015). In this regard, CCF Family Support Coordinators could use the findings from the present study and other research literature to reassure parents who may be anxious about the long-term psychosocial impact on their child.

As mentioned above, the current study raises a question about the role of CCF in funding educational support. Bessell (2001) commented, "The education system needs to assist teachers to provide an appropriate education for each of these children" (p. 357). In Aotearoa, the Education Act (1989) states that all children have a right to education, irrespective of any special educational need and this is also seen as a fundamental human right in the United Nation's (1989) Convention on the Rights of the Child. In line with this, the New Zealand Curriculum Principle of Inclusivity "ensures that students' identities, languages,

abilities, and talents are recognised and affirmed and that their learning needs are addressed” (MOE, p. 9). Thus, responsibility for educational support lies within the MOE. However, from the caregiver accounts above, they do not appear to feel that appropriate education or adequate support is readily available through schools at present. It is also apparent that the support funded through the PDG was perceived as beneficial by caregivers and young people alike, and caregivers expressed immense gratitude to CCF for the support. Therefore, it would be unethical for CCF to discontinue PDGs for educational support at present, however as an organisation it is recommended that this is their eventual goal. To get to this point, they should continue to partake in and/or fund collaborative projects through NCCN and advocate for the educational needs of children with cancer to be adequately met. When a caregiver discusses an application for educational support with their Family Support Coordinator, they should firstly ensure that all other avenues of support have been exhausted through the school and MOE, assisting with advocating if necessary. One of the benefits of the PDG for caregivers appeared to be the level of choice that they and their child had over what type of support was funded, which is also a goal of the PDG committee. This control can still lie with the family, however discussion around the benefits of more social and recreational activities may help parents make a more informed decision about what activity they apply for.

Directions for Future Research

UDL has been emphasised throughout this study as a potential solution that has the possibility to support both prevention of and intervention in educational challenges following childhood cancer. It would be beneficial to study the impact of UDL on a child with cancer, taking the perspectives of all stakeholders into account. Alongside listening to the perspectives of the child with cancer, their teacher, parents and medical team, the child’s classmates could be involved, to explore any impact on them. It would also be beneficial to

investigate the ability for a UDL classroom to support children with other needs, for example those who are palliative, siblings of children with cancer, or bereaved siblings.

This study highlighted several areas that warrant further research internally in CCF, that would also be of interest to the wider field of childhood cancer and education. To complement Stage 1, a survey could be distributed to members of the population to ascertain any other educational supports they may have received from other sources and run regression analyses to test for predictability of characteristics. The findings from the present study could be utilised to develop a survey to assess the impact of educational grants going forward. The current study only interviewed grant recipients who has used at least 50% of funds awarded. Interviews with those who used less than 50% of their funds would help to identify barriers to completion, and further assess the suitability of PDGs for educational purposes. The majority of PDGs were awarded for recreational or social purposes and follow up research with those families could explore the benefits of extracurricular activities on a child's development.

It is hoped that the findings from this study and future research will encourage educational systems in Aotearoa and overseas to continue to promote more inclusive education options such as UDL that will meet the needs of all learners, including children with cancer, thus allowing grants such as the PDG to truly be for something that makes the child's heart sing.

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Appendices

Appendix A: Interview Schedules

Interview Schedule: Parent/Caregiver

- Can you tell me a little bit about your child and their cancer journey
 - Probe: when were they diagnosed, how old were they at the time, what was their diagnosis, are they still on treatment/when did they finish treatment?
- What impact did cancer have on their schooling?
 - What year were they in when they were diagnosed/what year are they in now?
 - Did they miss much time at school?
 - How did the school respond to the diagnosis
 - What support did you receive from the school
 - What was communication like with the school
 - Have they changed schools since their treatment started?
 - Have there been any delays to their education (e.g. being held back a year) following their cancer diagnosis?
 - Were they enrolled with the health school?
- How would you describe their engagement with school and their school work:
 - Before cancer diagnosis (if applicable)?
 - During their cancer treatment?
 - Now?
 - Probe: what support did the school provide around this?
- How would you describe their achievement at school:
 - Before cancer diagnosis (if applicable)?
 - During their cancer treatment?
 - Now?
 - Probe: what support did the school provide around this?
- How would you describe their relationships with classmates?
 - Before cancer diagnosis (if applicable)?
 - During their cancer treatment?
 - Now?
 - Probe:
 - What support did the school provide around this?
 - Do they have many friends/many close friends at school?
 - Did they keep in touch with friends when they were in hospital? If so, how?
 - Have you noticed any difference in their ability to make and keep friends at school since their diagnosis?
- Is there anything else you'd like to say about the support received at school?
- Turning now to their Personal Development Grant, what year were they in at the time of application?

- Could you describe the support that was provided to your child with PDG funding.
 - Probe: what did this look like in practice?
 - If it was a teacher aide: how did they work with your child, what was their main focus of support, what was their role in the classroom?
 - If it was external tutoring: when/where did it take place, what was the main focus?
- Why did you apply for a PDG?
 - Probe for specific concerns regarding education and existing support
 - how did you know what to ask for?
 - what did you ask for and why did you decide to ask for that?
 - How did you find the application process?
- What were your expectations at the time of application?
 - i.e. what results did you want to see for your child?
- What impact did the PDG have on your child?
 - Probe: Do you feel that your expectations were met – why/why not?
- How would you say the support benefited your child?
 - Probe for improvements in: academic performance (test results, completion of work, teacher reports, school reports), engagement, attendance, friends, socialisation with peers. being part of the school community, fully participating at school and in extra-curricula activities
 - If it did not benefit, probe for reasons why not (e.g. wrong type of support, too early or too late in development?)
- Looking back, do you feel that a different form of support would have been more beneficial?
 - If so, what?
- When the PDG funding ended, did your child have ongoing educational needs?
 - If yes, how have these needs been met?
 - i.e. are they still receiving the same or similar support?
- Has your child received any educational support from other sources?
 - If yes, what support and from what sources?
- Did you explore other avenues of funding instead of a PDG?
 - If yes, what options were explored? What was the outcome? If declined, why?
- What suggestions do you have for CCF that might improve the PDG process?
- Is there anything else that you would like to share with CCF about your child's PDG experience?
- Is there anything else that you would like to share about your child's school, learning and/or friendships since their cancer diagnosis?

Interview Schedule: Child/Young Person

- Tell me a little bit about yourself
 - How old are you?
 - What are your hobbies/friends?
- Tell me about school. Good things? Things that you like the best? Things you would like to change? What helps you to learn? If you could wave a magic wand at school what would school look like?
- What was school like:
 - before you had cancer?
 - When you were being treated for cancer/in hospital?
 - What is it like now?

Probe for more detail (e.g. did you like your school, teachers, friends, what was/is your favourite subject?)
- Your parents/caregivers have told me about the (support type) that you had in (year).
 - Please tell me what you can remember about this
 - Probe for more detail (e.g. who supported you, when/where did it happen, did you like it, was it easy/difficult?
 - Did you help to make the decision about what to apply for?
- Do you feel that (support name) helped you at school?
 - For teacher aide support: How did (teacher aide's name) help you? What was it like having them at school?
 - For tutoring support: How did it help you? What was it like having a tutor?
 - Probe for more detail (e.g. helped catch up/ keep up with other students, made things easier to understand, improved school work/grades, helped make friends)
- If you could wave a magic wand and get some extra help at school, what would that look like for you - and for other kids who have cancer?
- Is there anything else that you would like to tell me about (support name)?
- Is there anything else that you would like to tell me about school?

Appendix B: Ethics Notification



Date: 25 July 2018

Dear Teresa McKeever

Re: Ethics Notification - NOR 18/34 - Working Title: An exploration of the ongoing educational needs of, and support for, children with cancer in New Zealand

Thank you for the above application that was considered by the Massey University Human Ethics Committee: Human Ethics Northern Committee at their meeting held on Wednesday, 25 July, 2018.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Associate Professor Tracy Riley, Dean Research
Acting Director (Research Ethics)

Appendix C: Information Sheet for Parents/Caregivers



MASSEY UNIVERSITY
INSTITUTE OF EDUCATION
TE KURA O TE MĀTAURANGA

An exploration of the ongoing educational needs of, and support for, children with cancer in New Zealand

INFORMATION SHEET

Dear Parents/Caregivers,

Kia Ora. My name is Teresa McKeever and I am completing a research project for my thesis as part of the requirements for the degree of Masters of Educational Psychology at Massey University. You may recognize my name. I have been the Programme Development Coordinator at the Child Cancer Foundation since 2016. I have chosen to conduct my research on the educational needs of children with cancer, as it is an area I have become increasingly passionate about since starting this role.

I am inviting you to take part in this study. Please read the information below, and if you have any further questions, I can be contacted using the details below.

What is the project about?

The Child Cancer Foundation provides Personal Development Grants (PDGs) that provide education support for children. I am interested in finding out how the grants are used by families. I would like to know more about:

- the characteristics of children who have applied for educational support through a PDG, and;
- how useful the support has been for children and their families

In the first stage of the project, I will be looking at the characteristics of children who applied for a PDG for educational support since 2013, using existing information held by Child Cancer Foundation. The information provided for this part of the study will not include any names or identifying information.

In this second stage I will be interviewing parents and children about their experience of the specific support that was received. Questions for parents will focus on how effective the support was and whether or not your expectations were met. There will also be the opportunity for more general discussion surrounding your child's educational needs following their cancer diagnosis and other supports that were available. Interviews with children will involve talking to them about their experience of school before and after their cancer diagnosis, and their experience of the support provided.

Invitation to take part

I would like to invite you to take part in this study. If you agree to be in the study I will interview you and your child about your experiences. You and your family have been selected to receive this invitation because:

- your child has received a PDG for educational support within the last five years
- at least 50% of the funds given for the PDG have been used, and;
- you live in or within driving distance of Auckland

I am hoping that six families in total will take part. At this stage I do not know the names or any other information of families that are receiving this invitation and I will only know this information if you agree to be contacted by me. It is your choice to participate in this study. If you choose not to participate this will not have any impact on the support that you receive from Child Cancer Foundation.

What will happen if I agree to take part?

If you are interested in taking part, please let me know by contacting me on the details listed below. I will contact you to organize the interviews. The interviews can take place at a time that is suitable to you, either at your home or at the Child Cancer Foundation Family Place, wherever you and your child will feel most comfortable. You will be asked to sign a consent form for you and your child to be interviewed. I will also have a consent form for your child to sign. Consent will also be discussed with you and your child prior to starting the interview.

The interviews should take about 90 minutes in total. Parent/caregiver interviews may take 45-60 minutes, and child interviews may take up to 30 minutes, depending on their interest and age. Some time may also be needed to answer any questions that you or your child may have and to allow some time for me to build rapport with your child so that they feel comfortable talking to me, particularly with younger children. If you would like to seek further support or further discuss your experience, you will be directed to appropriate support services through the Child Cancer Foundation.

Interviews will be voice recorded and later transcribed. You will have the option to view and approve your interview transcription before it is included in the study. Your child will also have this option. Quotes from the interviews may be used in reports but will not include any identifying information.

All information from the interviews will be stored securely and will be accessible only to myself and my supervisors. The combined summary of data from your interviews and the interviews of other respondents may be shared with the Child Cancer Foundation to aid further research, however this will not include any information that identifies you or any other participants in the research. Data will be held securely for seven years, at which point it will be disposed of securely.

On completion of the study, you will be sent a summary of the results, either by email or post. A summary report will be given to Child Cancer Foundation, which may be included in Sharing Magazine or other publications. In addition, the results may be published as part of my thesis, at professional conferences or in scientific journals. No identifying information will appear in any publication.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *decline to answer any particular question;*
- *withdraw from the study (at any time until end of June 2019, when the findings will be written up);*
- *ask any questions about the study at any time during participation;*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher (for instance for purposes of whakapapa);*
- *be given access to a summary of the project findings when it is concluded.*
- *ask for the recorder to be turned off at any time during the interview.*

Ethics Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 18/34. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Chair), Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz

Project Contacts

If you would like to take part in this study, would like further information or have any questions, please contact either myself or my supervisors:

Teresa McKeever, Graduate Student, Massey University
(09) 303 9978 || 021 838 142 || Teresa.McKeever.1@uni.massey.ac.nz

Dr. Wendy Holley-Boen, Lecturer, Massey University
(09) 414 0800 ext. 43535 || W.Holley-Boen@massey.ac.nz

Dr. Jude MacArthur, Senior Lecturer, Massey University
(06) 356 9099 || J.A.MacArthur@massey.ac.nz

Thank you for taking the time to read this information,

Kind Regards,

Teresa McKeever

Appendix D: Consent Form for Parents/Caregivers



MASSEY UNIVERSITY
INSTITUTE OF EDUCATION
TE KURA O TE MĀTAURANGA

An exploration of the ongoing educational needs of, and support for, children with cancer in New Zealand

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interviews being sound recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

I agree that my child may participate in this study under the conditions set out in the Information Sheet.

Review of interview transcript (please select one of the following):

I would like the opportunity to read and amend the transcript of my interview ☐

I do not want to receive a copy of the interview transcript and agree that extracts from the interview may be used in reports and publications arising from the research ☐

Signature:

Date:

Full Name - printed

Full Name of child -
printed

Relationship to child

Page 1 of 1

Appendix E: Combined Information and Consent Forms for Children/Young People



MASSEY UNIVERSITY
INSTITUTE OF EDUCATION
TE KURA O TE MĀTAURANGA

An exploration of the ongoing educational needs of, and support for, children with cancer in New Zealand

INFORMATION SHEET



Kia Ora,

My name is Teresa McKeever and I am studying Educational Psychology at Massey University.

As part of this I have to do a research project and would like you to help me with it please.



What is the project about?

I would like to interview you to ask you some questions about school – what it was like before you had cancer, what it was like when you were in hospital and what it's like now. I'm also interested in talking to you about the support that you got through a Personal Development Grant from Child Cancer Foundation – this may have been a teacher aide in school or tutoring outside school.

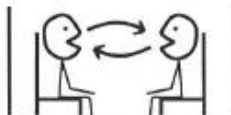
I hope that I will be able to use the information that you tell me about your experience to help other children with cancer when they go back to school.

Who else is taking part?

I will also talk to your parents/caregivers and to five other children who have had cancer and their parents/caregivers.



What will happen if I agree to take part?



Your parents/caregivers will let me know when and where I can talk to you – it might be at your house or at the Child Cancer Foundation Family Place beside Starship.

The interview with you will take up to 30 minutes. Your parents/caregivers can be in the room with you or you can talk to me alone. I will also talk to your parents/caregivers.

I will record our conversation and write down what you said afterwards. You can have a copy of what you said if you want, and you can share this with your parents/caregivers.



I might use some of the things that you say when I write up my report, but I will not use your name – you can make up a name for me to use instead if you like.

You do not have to answer my questions if you don't want to. You can also ask to stop the interview at any time.

Do you agree to talk to me about school and the support you received? Yes No

Signature: _____

Date: _____

Ethics Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 18/34. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Chair), Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz

Appendix F: Combined Information and Consent Forms for Younger Children



MASSEY UNIVERSITY
INSTITUTE OF EDUCATION
TE KURA O TE MĀTAURANGA

An exploration of the ongoing educational needs of, and support for, children with cancer in New Zealand

INFORMATION SHEET



Kia Ora,

My name is Teresa McKeever. I am a student at Massey University.

For my homework, I am talking to children and their parents about what school was like after you got cancer.



I am interested in what you think about the help that you got with your school work.

This might have been from a teacher aide in school or a tutor outside school.

I would like to record our conversation.
I will write about what you tell me.



I won't use your real name so nobody else will know that I am writing about you.
You can choose your own made-up name if you like.



If we do talk about school together, you can tell me that you don't want to talk about school anymore.

Your parents/caregivers can sit with you when you talk to me, or you can talk to me on your own.

Is it ok with you if I talk to you about school?

Yes



No



Signature: _____

Date: _____

Ethics Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 18/34. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Chair), Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz