

An Oncology Education Program:
Parents' perspectives

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DECLARATION


This report contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this report contains no materials previously published except where due reference is made.

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PART A: LITERATURE REVIEW

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Abstract

While most children are now surviving a diagnosis of cancer, a number of psychosocial impacts of the disease are becoming increasingly apparent, including poorer schooling outcomes. Given that schooling is such an integral context for child development and an important component of overall adjustment to illness, a number of researchers have highlighted the need for intervention. However, the development of schooling interventions for children with cancer is arguably limited by a lack of research that investigates the impact of cancer upon school adjustment and, importantly, the modifiable factors that may influence this process. This review proposes a theoretical model of school adjustment that offers a framework for exploring these gaps, and in particular, for examining potentially modifiable system-level factors. Schooling interventions that have been documented in the literature will be discussed in relation to these system-level factors. Findings of this review have direct implications for the future development of schooling interventions for children with cancer that are evidence-based.

School is an important part of a child's life. It has been referred to as the "work" of childhood, providing an opportunity for the social, emotional and cognitive development necessary for completing the childhood phase of development, and for building the foundations of adult life (Harris, 2009; Leigh & Conklin, 2010; Lum, Donnan, Wakefield, Fardell & Marshall, 2017; Thompson & Gustafson, 2009; Varni, Katz, Colegrove & Dolgin, 1994). The school environment provides children with a safe and familiar framework and opportunities to create connections, be productive, achieve success, be independent, learn to cope effectively, build self-esteem and form an identity of oneself as an important member of society (Baysinger & Heiney, 1993; Leigh & Conklin, 2010; Rabin, 1994; Vitulano, 2003). In terms of a socio-ecological approach, school is one of the most influential microsystems upon a child's development (Bronfenbrenner, 1994).

However, for children with chronic illness, a number of obstacles to normal school participation exist, resulting in poorer schooling-related outcomes. Compared to their peers, children with a chronic illness are more likely to fall behind academically and to become socially isolated, and less likely to achieve important educational milestones (Bell et al., 2016; Brown, 2002; Maslow, Haydon, McRee & Halpern, 2012; Pini, Hugh-Jones & Gardiner, 2012; Thies, 1999; Tollit, Sawyer, Ratnapalan & Barnett, 2015). Emotional, developmental and behavioural conditions that impact schooling also occur at a rate higher in this group, compared to those without a chronic illness (Casey, Brown & Bakeman, 2000; Donnan et al., 2015; Shaw & McCabe, 2007).

Children diagnosed with cancer appear to be at particular risk, due to the severity of the condition and the invasiveness of its treatment. Compared to children without cancer, children with cancer have a higher likelihood of grade repetition (Barrera, Shaw, Speechley, Maunsell & Pogany, 2005; Bessel, 2001; Bonneau et al., 2011; Roberts, Robins, Gannoni & Tapp, 2014), fewer close friends (Barrera et al., 2005), poorer academic outcomes (Barrera et al., 2005), and are at higher risk of failing to attain educational qualifications and employment (Lancashire et al., 2010; Maule et al., 2017; Mitby et al., 2013). Research suggests that around 40-60% of children with cancer experience ongoing problems with schooling related to their diagnosis (Barrera et al., 2005; Donnan et al., 2015; Roberts et al., 2014), and given that over 500 Australian school-age children per year are diagnosed with cancer (Australian Institute of Health and Welfare, 2017), the number of students at potential risk of schooling problems and poorer long-term outcomes is not inconsequential.

The psychosocial outcomes for children who have survived cancer have only more recently come into sharper focus as, due to an improved prognosis for most types of childhood cancer, the disease is now typically regarded as chronic rather than fatal (Barrera et al., 2005; Donnan et al., 2015; Harris, 2009; Mavrides & Pao, 2014; Weiner, Hersh & Alderder, 2010). The shift to a chronic illness framework has important ramifications for the way in which treatment 'success' may be viewed, as outcomes other than survival also become significant (Bessel, 2001; Ellerton & Turner, 1992; Rynard, Chambers, Klinck & Gray, 1998; Varni et al., 1994). In the clinical setting, objectives for care are beginning to widen in scope, with psychosocial and longer-term considerations becoming important inclusions to standards of childhood

cancer care (Wiener, Kazak, Noll, Patenaude & Kupst, 2015).

However, although there is a growing body of research highlighting the poorer schooling outcomes for children with cancer, not all children with cancer experience schooling related problems (Barrera et al., 2005; Donnan et al., 2015; Roberts et al., 2014) and the reasons for this are largely unknown. We know little about the process of school adjustment for children with cancer, and in particular, the modifiable factors that may influence the impact of illness-related factors upon schooling and facilitate better schooling outcomes. The identification of such factors is an important underpinning for future evidence-based interventions. There is also very little research that has investigated the mechanisms and outcomes of interventions that already exist to facilitate the maintenance of schooling for children with cancer.

This review aims to address these gaps by considering the impact of wider, system-level influences upon school adjustment for children with cancer. A model of school adjustment for children with cancer has been developed (Figure 1), in order to provide a framework for the review and present what is currently known. Each element of the model will be discussed, with a particular focus on the potentially modifiable systemic factors that may influence school adjustment. Schooling interventions for children with cancer that have been documented in the literature and that target such modifiable factors will also be explored.

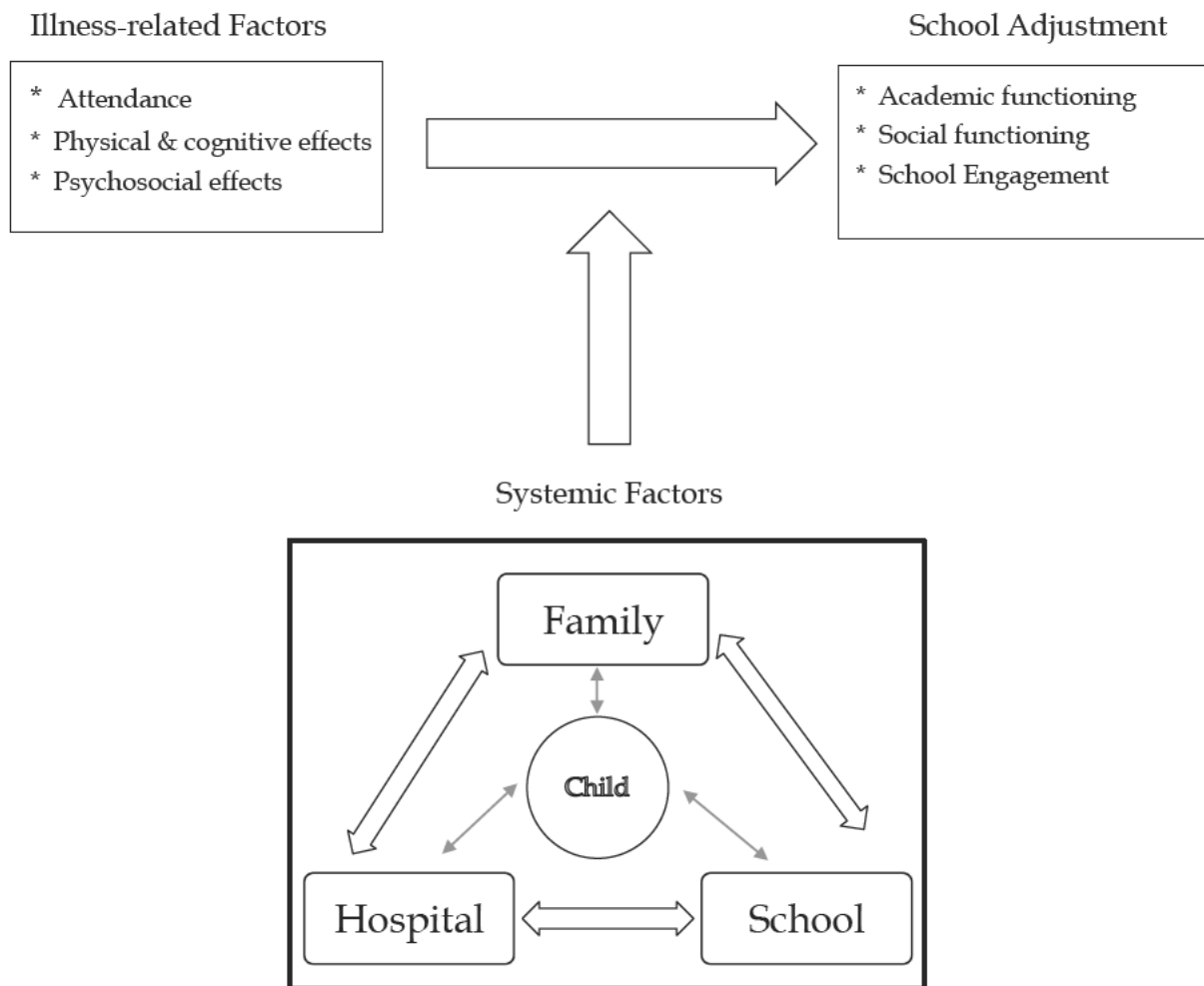


Figure 1. Model of school adjustment for children with cancer.

SCHOOL ADJUSTMENT AND ADJUSTMENT TO ILLNESS

As schooling is such a fundamental context for children, the extent to which children’s schooling is affected by cancer is likely to influence their overall adjustment to illness (Katz et al., 1989; Harris, 2009). Additionally, participation in schooling, independent of illness-related effects, has been suggested to exert a protective influence over a child’s adjustment to their illness. Schooling during treatment can play a normalizing role, allowing a

focus on something productive, and providing opportunities to socialize with peers (Bessel, 2001; Georgiadi & Kourkatas, 2010; Leigh & Conklin, 2010; Libman, Sherrod & Weyant, 2017; Mavrides & Pao, 2014; McLoone et al. 2013; Wakefield et al., 2010). It also been suggested that attending school can facilitate hope for children with cancer, affirming the probability that they will live to use the skills being developed at school (Baysinger &Heiney, 1993; Eiser, 1998; Georgiadi & Kourkoutas, 2010; McLoone et al., 2013; Moore et al., 2009). School adjustment can therefore be considered a significant component of overall adjustment. However, while theoretical models of adaptation to chronic illness in childhood acknowledge socio-ecological factors generally, the relationship between schooling factors and adjustment has not been well explored.

The Risk and Resilience model by Wallander and Varni (1998) proposes that a number of risk and resilience factors explain individual difference in adjustment to childhood chronic illness. In this model, school is included within the wider category of 'Socio-ecological factors', social and environmental resilience factors that facilitate adjustment, both directly and through their effect upon the way that the child experiences stress within their environments. The model does not consider the influence of schooling individually, however Wallander and Varni (1998) do propose that returning to school as soon as possible facilitates rehabilitation and adjustment for children. They also suggest that while perceived social support from classmates may have direct and independent effects on adjustment to illness, low perceived classmate support is a vulnerability factor (Wallander &Varni, 1998).

The Transactional Stress and Coping model by Thompson and Gustafson (2009) uses an ecological-systems framework, and views childhood chronic illness as a stressor to which both the individual and family systems attempt to adjust. This model proposes that adjustment occurs as a function of biomedical, developmental and psychosocial processes that mediate the relationship between illness and demographic parameters and adjustment. Within this model, school is suggested as a domain in which children with chronic illness are at increased risk for adjustment difficulties. Difficulties in school adjustment and performance are suggested to be a function of both direct (primary) effects of the illness & treatment, and indirect (secondary) consequences of illness such as fatigue, absenteeism, and psychological stress (Thompson & Gustafson, 2009).

Within these general models of adjustment to childhood chronic illness, participation in schooling is viewed as both adaptive and a potential source of risk. Although school is highlighted as a context that may influence the impact of illness on adjustment, the models do not facilitate a more detailed exploration of the unique relationship between illness and schooling adjustment, and it remains unclear which particular elements of schooling influence adjustment and how. These general models of childhood chronic illness also do not specifically consider the impact of cancer, which may have a more dramatic impact on schooling than many other chronic illnesses. While these models inform the development of a framework with which to explore the process of schooling adjustment, a more fine-grained analysis of the impact of cancer on schooling and the socio-ecological factors that may

influence this is required for the development of schooling interventions that are evidence-based.

DEFINITIONS OF SCHOOL ADJUSTMENT

In order to consider the experience of schooling and its role in adjustment in more detail, it is first important to define which schooling-related outcomes best represent whether a child is well-adjusted at school. While historically, school adjustment has been equated purely with academic performance, the construct is now increasingly operationalised as a combination of a variety of schooling-related elements that are likely to better capture the full schooling experience (Ahn & Lee, 2016; Baker & Siryk, 1984; Betts, Rotenberg & Trueman, 2013; Ozdemir, Cheah & Coplan, 2017; Perry & Weinstein, 1998; Ratelle, Duchesne & Guay, 2017; Troop-Gordon & Kuntz, 2013). Taken together, the literature suggests that school adjustment comprises three major components; academic functioning, social functioning and engagement. However, while school adjustment is likely to be a useful concept to explore outcomes for children with cancer, it is noted that school adjustment has primarily been studied in normative contexts, for example when typically developing students begin school or transition to high school. Gaps in our understanding remain regarding school 're-adjustment' for children with a chronic illness. As a result, we know little about the factors that predict individual difference in school adjustment for children with cancer.

PREDICTORS OF SCHOOL ADJUSTMENT

While the process of school adjustment has not been well addressed in the

context of childhood cancer, we do know that children with cancer face multiple barriers to normal participation in school. Review of the literature suggests that the main effects of cancer on schooling broadly fit into three categories; poor attendance, the physical and cognitive effects of cancer and its treatment, and the psychosocial effects of cancer and its treatment. Each of these illness-related categories are likely to affect the academic, social and engagement domains of school adjustment.

Poor attendance

Lengthy hospitalizations, regular appointments, disease-related symptoms and treatment side-effects, such as isolation, mean that the ability to attend school is undoubtedly a significant obstacle to school adjustment for children with cancer. (French et al., 2013; Sexson & Madan-Swain, 1993; Thies, 1999). A review by Vance and Eiser (2002) found that children with cancer miss more school than children with other chronic conditions. Donnan et al. (2015) found that over 40% of Australian children with cancer in their study missed more than 6 months of school. French et al. (2013) found that in their large sample, absenteeism in children with cancer was twice as high as the general population, and 33% of children with cancer attended less than 10% of the school year, a particularly high-risk group for long-term effects. Higher absenteeism has been found in childhood cancer survivors for at least 2 years after diagnosis (French et al., 2013; Lum et al., 2017). Not being able to attend school for long periods is likely to affect all domains of school adjustment. Grade repetition, a typically low level occurrence, also appears of much higher likelihood for children with cancer (Barrera et al., 2005; Bessel,

2001; Bonneau et al., 2011; Roberts et al., 2104), with significant further ramifications for school adjustment.

Physical and Cognitive impacts

The physical and cognitive effects of cancer and its treatment are likely to impact school adjustment both directly, through the child's capacity for academic work and social interaction, and indirectly, through their effects on a child's psychological wellbeing. Physical effects of cancer and its treatment may include fatigue, weakness, nausea, headaches, nosebleeds, lowered immunity, impaired mobility, and changes in hearing, vision, motor functioning and appearance (Chekryn, Deegan & Reid, 1986; Donnan et al., 2015; Weiner et al., 2010). Cognitive changes are particularly likely to be experienced by those diagnosed with a Central Nervous System tumor, or who have received treatments that affect the brain such as radiation, high dose methotrexate or cytarabine, or intrathecal chemotherapy (Armenian et al., 2010; Lund, Schmiegelow, Rechnitzer & Johansen, 2011). Further complicating the physical and cognitive effects on school adjustment is the possible emergence of late effects (Armenian et al., 2010) meaning that, similar to the observations made of students with a traumatic brain injury by Ylvisaker, Hartwick & Stevens (1991), the profile of strengths and needs for students with cancer may continue to change for many years, and therefore school adjustment may fluctuate long-term.

Psychosocial impacts

The psychological and social impacts of cancer are also likely to challenge school adjustment. Changes in self-concept, loss of peer contact, activity

limitations, loss of confidence, peer reactions, changes to social skills, and an uncertainty about changing needs are all likely to contribute to poorer social functioning for children with cancer (Brown, 2002; CanTeen, 2015; Tollit et al., 2015). Barrera et al. (2005) found that survivors were more likely than controls to have no close friends, and Chekryn, Deegan and Reid(1986) found that the most salient fear for children with cancer at school was peer rejection. Vance and Eiser(2004) found that children with cancer were reported by peers and teachers as more sensitive and isolated than their peers. Physical change, including limb amputation, hair loss, fatigue and facial swelling, and subsequent feelings of difference are particularly likely to impact peer relationships, as they are related to increased distress, a lowered sense of belonging, and exclusion from class and other activities (Alvarez et al., 2007; Chekryn et al., 1986). Other psychological factors such as anxiety, poor coping, reduced independence, low self-efficacy, low self-esteem, learned helplessness and despair may also be associated with more difficult school transitions and school disengagement (CanTeen, 2015; Emerson et al., 2016; Fottland, 2000; Tollit et al., 2015; Vitulano, 2003).

THE MICRO- AND MESO-SYSTEM FACTORS INFLUENCING SCHOOL ADJUSTMENT

Whilst research has focussed upon the illness-related factors that influence schooling outcomes, it is likely that the relationship between childhood cancer and school adjustment is more complex. As illustrated by the model used for this review (Figure 1), it is suggested that the impact of cancer upon school adjustment is influenced by the characteristics of the systems to which a child

belongs. This notion is consistent with a socio-ecological approach, which posits that the developing child must be considered in the context of their relationships with their environments (or microsystems), and the linkages between these environments (or mesosystem) (Bronfenbrenner, 1994).

Contextual factors are an integral component of general models of adjustment to childhood chronic illness (Thompson & Gustafson, 2009; Wallander & Varni, 1998), and the school, family and healthcare systems have been emphasised as the systems most likely to influence the adjustment of children with chronic illness (Brown, 2002; Power, 2003). However, as Brown (2002) points out, the mechanisms and impacts of these system-level influences upon adjustment have been poorly examined. Particularly, there is little research exploring the influence of children's systems upon their school adjustment.

The Family Micro-system

The family system has a profound influence upon outcomes for a child with cancer (Brown, 2002). Ahn and Lee (2016) suggest that family characteristics are more predictive of a child's adjustment to illness than illness-related characteristics, and Emerson et al. (2016) found that parental perceptions of their child's health predicts school re-entry success, above and beyond other markers of physical wellbeing. Within the family-school-hospital triad of microsystems, the family represents the most constant context for their child, and Diedrick and Farmer (2005) propose that the family should form the core of this triad. However, while the family system may be considered the most important influence, this system is also arguably the most under stress. Few

studies address the schooling-specific concerns and needs of parents of a child with a chronic illness such as cancer (Klibenstein & Broom, 2000).

Helping maintain their child's schooling, in addition to managing a chronic illness, is exhausting and demanding for parents (Ievers-Landis et al., 2001).

This is important to note as parents' own experiences and perceptions are likely to influence the extent to which they are able to support schooling. A number of parental factors have been linked to child school adjustment problems, including maladaptive beliefs about cancer, worry about infection, worry about death and relapse, fatigue, poor coping, poor self-efficacy, emotional distress, withdrawal and changed academic priorities (Anthony, 2003; Donnan et al., 2015; Georgiadi & Kourkoutas, 2010; Hullman et al., 2010; McLoone et al., 2013; Thompson et al., 2015; Weiner et al., 2010).

Behaviour management and parenting style may also be influenced by feelings of anxiety and guilt, with overprotection, overindulgence and separation anxiety being typical consequences of high vulnerability beliefs (Ahn & Lee, 2016; Hullman et al., 2010; Rabin, 1994; Weiner et al., 2010).

Parents will commonly modify their pre-illness expectations of achievement, independence and responsibility for their child (Weiner et al., 2010). School may come to be perceived as a dangerous environment by both parents and children, which is likely to influence engagement, attendance and functioning (Rabin, 1994). Indeed, parental concern about decreased immunity has been cited as one of the most frequent reasons for school absence (McLoone et al., 2011; Sexson & Madan-Swain, 1993).

The School Micro-system

Features of the school system will also have influence on the impact of cancer on school adjustment. As previously discussed, school has the potential to play a normalising role, an important protective function. School provides a familiar routine and opportunity for normal development, and is perhaps the only context that can offer respite from the sick role (Sexton & Madan-Swain, 1993; Weiner et al., 2010).

However, research suggests that teachers typically have little training in the area of chronic illness and do not feel prepared to manage children with chronic illness in the classroom (Brown, 2002; Klibenstein & Broome, 2000; Leigh & Conklin, 2010; Sexton & Madan-Swain, 1993). Teachers may hold preconceived ideas about cancer and experience personal reactions to the diagnosis (Sexton & Madan-Swain, 1993). They may also feel unable to appropriately protect the child from infection, address questions from other students and handle medical issues such as emergency events (Sexton & Madan-Swain, 1993). Unprepared teachers may be less likely to challenge the child, hold unrealistic expectations, underreport problems, may be overly sympathetic, overprotective or over-reactive, and may lack understanding of neurocognitive changes, all of which may interfere with the self-confidence and school adjustment of the child (Brown, 2002; Rynard et al., 1998, Sexton & Madan-Swain, 1993). Pini, Hugh-Jones and Gardner (2012) found that an 'intolerant' attitude of teachers was reported by adolescents with cancer as a major reason for school absence.

Another consideration is a school's resources, and capacity to provide

additional support to students with cancer (Bruce et al., 2012; Donnan et al., 2015; Lum et al., 2017; Sexson & Madan-Swain, 1993). While the school should play an important role in assisting children to accept and adapt to their limitations by developing an individualized plan (Brown, 2002), Thies (1999) suggests that children with chronic illness, with often changing needs, fall between the gap between regular and special education, and a lack of accommodation from the school often leads to poorer outcomes. Perry and Weinstein (1998) highlight that what is described as child maladjustment may be better attributed to poor interactional processes between the child and their school system.

Research regarding the impact of school peers is mixed. Many challenges to maintaining a supportive peer group exist for a child with cancer, including frequent and prolonged absences, peer misunderstandings, and peers' own feelings of fear and vulnerability (Ellerton & Turner, 1992). Peers may worry that cancer is contagious, or be reluctant to accept a student who is 'different' (Sexson & Madan-Swain, 1993). Children with cancer may consequently feel excluded, segregated and ridiculed by peers (Klibenstein & Broome, 2000), which is likely to have a detrimental effect on school engagement and functioning. However, classmates may be viewed as fundamental source of support too, and the maintenance of friendships may act as a buffer, easing the stress of transition (Brown, 2002; Chekryn & Deegan, 1986), and thereby facilitating school adjustment.

The Hospital Micro-system

The hospital system is one of the most necessary support systems for

children with a chronic illness (Balling & McCubbin, 2001). Due to frequent, lengthy periods in hospital during the active treatment phase, the hospital will often become a predominant context for children with cancer. However, whilst the hospital plays an obvious role of providing medical treatment, it may also facilitate school adjustment by emphasizing the importance of schooling and encouraging school contact, maintenance and timely re-entry (Sexson & Madan-Swain, 1993; Pini et al., 2012).

Sexson & Madan-Swain (1993) suggest that schooling problems may arise from the healthcare team being ambivalent or unclear in their messages about the necessity to return to school. The healthcare team may also view academic progression as the primary goal of schooling, thus homebound study as a valid alternative, which neglects other important aspects of school attendance (Sexson & Madan-Swain, 1993). However, overall there is very little research that explores the potential role of the hospital in promoting school adjustment.

The Meso-system

While the family, school and hospital microsystems all influence the school adjustment of children with cancer, the potential contribution of each alone is limited. Research suggests that successful school adjustment for children with chronic illness requires a collaborative partnership between all three systems (Pini et al., 2012; Rynard et al., 1998; Sexton & Madan-Swain, 1993). In particular, communication has been suggested as the most important function of the mesosystem, alleviating concerns of both parents and teachers (Leigh & Conklin, 2010; Pini et al., 2012; Rynard et al., 1998). Given that schooling

for a child with cancer may occur across a variety of contexts, including the hospital, home and school, communication is likely to be particularly important and may facilitate continuity and a shared message.

In sum, features of the family, school and hospital systems appear to exert significant influence upon school adjustment for a child with a chronic illness such as cancer, however more research is required to better understand which features are most influential. While many individual, illness-related factors that impact schooling are not readily modifiable, there appears potential for interventions to be developed that target a child's micro- and meso-systems to facilitate school adjustment.

INTERVENTIONS TO PROMOTE SCHOOL ADJUSTMENT

Across the literature, there is an increasing recognition of the need to include school intervention as a standard, protective level of care for children with cancer (Georgiadi & Kourkatas, 2010; Leigh & Conklin, 2010; Mavrides & Pao, 2014; McLoone et al., 2013; Thompson et al., 2015; Varni et al., 1994; Weiner et al., 2010). However, despite this recognition, there is little evidence supporting the effectiveness of school intervention programs, and few interventions have even been described in the literature, especially within an Australian context. As a result, school support is not universal for children with cancer (Libman et al., 2017).

A recent meta-analysis by Helms et al. (2016) found that schooling interventions were associated with significant effects for enhancing academic achievement, lowering depression levels, increasing knowledge among peers

and creating a more positive classroom attitude towards the child with cancer. The meta-analysis also found a tendency for intervention to decrease behavioural problems and increase social competencies for the child with cancer. However, only 6 studies met inclusion criteria for this meta-analysis, 3 of which evaluated school re-entry programs directed towards the child and 3 that were classified as peer education programs. None of the included studies were Australian.

Reviews by Thomson et al. (2016) and Vance and Eiser (2002) examined 17 and 42 studies respectively. Both reviews found that schooling interventions increased teachers' knowledge about cancer, led to more positive teacher attitudes, increased teachers' confidence, and improved the knowledge and attitudes of peers. However, both Thompson et al. (2015) and Vance and Eiser (2002) suggest that the impact of intervention on the child with cancer is less consistent across studies, and that evidence regarding the impact on parents is also very limited. These findings are similar to that of an earlier review by Prevatt, Heffer & Lowe (2000).

On the basis of their review, Thompson et al. (2015) developed a psychosocial standard of paediatric oncology care, which recommends that all children should receive schooling intervention. However, consistent with observations of other researchers (Helms et al., 2016; Lum et al., 2017; Prevatt et al., 2000; Vance & Eiser, 2002), they caution that methodological and conceptual weaknesses across studies, such as small sample size, mean that the evidence is currently of low to very low quality, and therefore while the outcomes of interventions appear promising, the conclusions that can be

drawn about their effectiveness are limited. Thompson et al. (2015) recommend that interventions should include a well-trained oncology team member to coordinate communication between the family, school and healthcare systems, and that, at a minimum, interventions should provide information about the disease and its impact to schools.

Lum et al. (2017) suggest that while research shows general support for schooling intervention, there is little evidence to support the effectiveness of any individual component, and no Australian interventions have been documented that meet the standards set out by Thompson et al.(2015). Lum et al. (2017) posit that as long as no national policies for meeting the educational needs of children with cancer exist, the needs of children and families will continue to go unmet and teachers will remain uncertain of their role.

As noted by previous reviews, there is currently no clear evidence regarding which specific components of schooling intervention for children with cancer are effective and thus little evidence is available to guide practice (Helms et al., 2016; Lum et al., 2017; Thompson et al., 2015; Tollit et al., 2015). The majority of interventions that do exist appear largely ad hoc, with minimal theoretical underpinning and unclear intended outcomes. However, it is apparent that the majority of schooling interventions found within the literature do target what may be considered micro- and meso-system factors, such as the preparation of teachers, the preparation of peers, collaborative planning, and the establishment of linkages between family, health and school systems (Bruce, Newcombe & Chapman, 2012; Ellerton & Turner, 1992; Katz et al.,

1998; McCarthy, Williams & Plumer, 1998; Northman, Ross, Morris & Tarquini, 2014; Rynard et al., 1998; Worchel-Prevatt et al., 1998). Although limited, the literature supports the notion that better preparing the systems surrounding a child with cancer, and facilitating collaboration between these systems is key.

The inclusion of a school liaison appears particularly beneficial. In reference to the model used for this review (Figure 1), the school liaison element can be viewed as targetting school adjustment through its effects upon the mesosystem. The specific role of the liaison differs across studies, including provision of medical information and resources, education, assessment, advocacy, monitoring, and support, however, all interventions describe an education or health professional that facilitates communication between family, school and hospital systems (Bruce et al., 2012; Ellerton & Turner, 1992; McCarthy, Williams & Plumer, 1998; Northman et al., 2015; Rynard et al., 1998; Worchel-Prevatt et al., 1998). Studies of interventions involving a school liaison component have documented a number of parent- and teacher-reported positive outcomes including less absenteeism, stronger academic success, improved social integration, an improved capacity to understand the child (Bruce et al., 2012), good adjustment behaviourally and academically (Rynard et al., 1998), program satisfaction, academic success, improved parent-school communication, better understanding of the child's learning needs, and a higher likelihood of a formalised academic plan (Northman et al., 2015). However, no studies have provided a more objective assessment of outcomes.

While a number of micro- and meso-system factors have been addressed by schooling interventions reported in the literature, they have not been approached in a systematic way, and a number of potentially modifiable system-level features that influence school adjustment remain unaddressed. The majority of interventions have focussed upon the school system, meaning there is limited information regarding family perspectives and outcomes, and the role of the hospital system has been particularly neglected. Little research has considered objective academic outcomes, despite the fact that academic achievement has been found to be a concern for children themselves (McCarthy, Williams & Plumer, 1998). While a few studies (Georgiadi & Kourkoutas, 2010; Worchel-Prevatt et al., 1998) provide a more socio-ecological model of schooling intervention for children with a chronic illness, to date such models have not been empirically tested. The framework provided in this review therefore provides a number of avenues for further research.

CONCLUSION

This review has explored what is known about the impact of childhood cancer upon schooling, and particularly, how system-level factors might influence this relationship. Using a model purposively developed in order to explore the literature in a systematic way, a number of child, family, school and hospital factors that influence the experience of schooling have been highlighted. The literature regarding schooling intervention has also been explored. Overall, this review has found that there are a number of system-level influences upon the schooling experience for children with cancer that are likely to affect their

school adjustment. These influences are important to consider, as whilst illness-related factors such as lengthy hospitalization and physical effects are largely unavoidable, features of the systems surrounding the child, such as the knowledge of teachers, the preparation of peers, the confidence of parents, the schooling-related messages provided by hospital staff, and the communication between systems, are potentially modifiable. Although there is currently minimal evidence for the efficacy of such interventions, the beneficial impact of addressing such factors is nonetheless promising. Further research is warranted to determine which elements of intervention are most efficacious, and to more reliably evaluate the experiences and outcomes of schooling intervention. However, it does appear that better informing and preparing the systems surrounding a child for their return to school and facilitating ongoing communication between systems may provide the best chance of successful school adjustment.

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PART B: RESEARCH PROJECT


An Oncology Education Program: Parents' perspectives.

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perceptions, education



Abstract

Objectives: *This study aimed to explore parents' perceptions of a hospital-based schooling intervention for children with cancer.* **Research Approach:** *A qualitative design using semi-structured interviews was employed.* **Participants:** *Nine parents whose children had participated in the intervention program were recruited.* **Methodological Approach:** *Parents participated in a semi-structured interview. Interviews were transcribed verbatim and analysed thematically.* **Findings:** *Six major themes were identified: Experiences with program components, The bigger picture of the program, Communication, A burden of responsibility for parents, Other sources of support, and Perceived impacts of cancer on schooling.* **Interpretation:** *Parents valued the focus upon schooling and perceived a number of aspects to be beneficial. Parents also highlighted challenges, including a lack of communication and individualized planning, and a burden of responsibility.* **Implications for Psychosocial Oncology:** *Findings suggest that schooling is important to families and should be a fundamental psychosocial consideration. The schooling-related needs of parents should also be addressed.*

A diagnosis of cancer is a forceful interruption to a child's schooling, with a number of implications for their adjustment, development and wellbeing. Children with chronic illness have poorer school-related outcomes, both academically and socially, and children diagnosed with cancer are at particular risk (Barrera, Shaw, Speechley, Maunsell & Pogany, 2005; Donnan et al., 2015; Lancashire et al., 2010; Roberts, Robins, Gannoni & Tapp, 2014). While an improved prognosis for most childhood cancers means that the long-term, psychosocial impacts of the disease are becoming important considerations for care, little is known about the experience of schooling for families of a child with cancer. Further, although recommendations for supporting the schooling of children with cancer exist (Lum, Donnan, Wakefield, Fardell & Marshall, 2017; Thompson et al., 2015), few hospital-based interventions have been described or explored within the literature, especially within an Australian context. As a result, little evidence is available to guide clinical practice.

The Oncology Education Program is a hospital-based schooling intervention developed at the Women's and Children's Hospital (WCH), South Australia. The program has been delivered universally to children treated for cancer at the WCH since 2015, and appears relatively unique in its inter-disciplinary, theoretically-based approach that targets not only children but also the systems surrounding them. This study will explore the experience of participating in the WCH Oncology Education Program, from the perspectives of the parents whose children have been involved.

The impact of cancer on schooling

Cancer and its treatment are likely to impact schooling outcomes via three main illness-related pathways; impaired school attendance, physical and cognitive effects, and psychosocial effects. Children with cancer miss more school than children with

other chronic conditions, and absenteeism can remain a problem for at least 2 years (Donnan et al., 2015; French et al., 2013; Vance & Eiser, 2002). An array of illness-related physical, cognitive and psychosocial factors may also affect the schooling experience, including lowered immunity, fatigue, activity restrictions, anxiety, changes in appearance, impaired attention and memory, reduced independence, and reduced self-esteem (Donnan et al., 2015; Prevatt, Heffer & Lowe, 2000; Wakefield et al. 2010; Weiner, Hersh & Alderfer, 2010).

Each of the three core domains of school adjustment may be affected by cancer, including academic functioning, social functioning and school engagement (Perry & Weinstein, 1998; Sexson & Madan-Swain, 1993). Compared to children without cancer, children with cancer have a higher likelihood of grade repetition (Barrera et al., 2005; Bessel et al. 2001; Bonneau et al., 2011; Roberts et al., 2014), fewer close friends (Barrera et al., 2005), poorer academic outcomes (Barrera et al., 2005), and are at higher risk of failing to attain educational qualifications and employment (Lancashire et al., 2010; Maule et al., 2017; Mitby et al., 2013). In an Australian study by Donnan et al. (2015), most parents reported at least one long-term impact upon schooling.

As school is such a significant context for children, school adjustment is likely to influence overall adjustment to illness. School is one of the only contexts able to offer respite from the sick role, therefore returning to school early and attending regularly serves an important normalising function that may facilitate adjustment to illness (Mavrides & Pao, 2014; Leigh & Conklin, 2010; Prevatt et al., 2000; Worchel-Prevatt et al., 1998). However, given this added importance of schooling for children with cancer, their schooling adjustment has arguably not received the research

attention that it deserves. We know little about the factors that may predict individual difference in schooling adjustment and what may help or hinder this process.

Schooling Interventions

A recent meta-analysis by Helms et al.(2016) found that schooling intervention for children with cancer was associated with significant effects for enhancing academic achievement and lowering depression levels for the child, increasing knowledge among peers and creating a more positive classroom attitude towards the child with cancer. A tendency to decrease behavioural problems and increase social competencies for the child with cancer was also found. However, only 6 studies met inclusion criteria, 3 of which evaluated school re-entry programs directed towards the child and 3 that were peer education programs. None of the included studies were Australian.

Reviews by Thompson et al. (2015) and Vance and Eiser (2002) examined 17 and 13 studies respectively. Both reviews found that schooling interventions improved teachers' knowledge, attitudes and confidence, and the knowledge and attitudes of peers, however both reviews found inconsistent evidence regarding the impacts for the child with cancer and their parents. Despite suggesting that evidence is currently limited by poor methodology, Thompson et al.(2015) nonetheless developed a psychosocial standard of paediatric oncology care, which recommends universal schooling support.

In an Australian context, a review by Lum et al. (2017) found no Australian interventions that address the standards outlined by Thompson et al.(2015). They also suggest that it remains unclear which components of intervention are most effective. However, in support of Thomson et al.(2015), Lum et al.(2017) posit that

findings are promising, and highlight the vast potential of intervention in facilitating academic performance, school engagement and peer relationships, improving teacher knowledge and classroom support, and improving graduation and mental health outcomes. Lum et al.(2017) propose baseline requirements for Australian schooling intervention (Table 1).

Table 1: Baseline requirements of the proposed Australian school re-entry guidelines (from Lum et al. 2017).

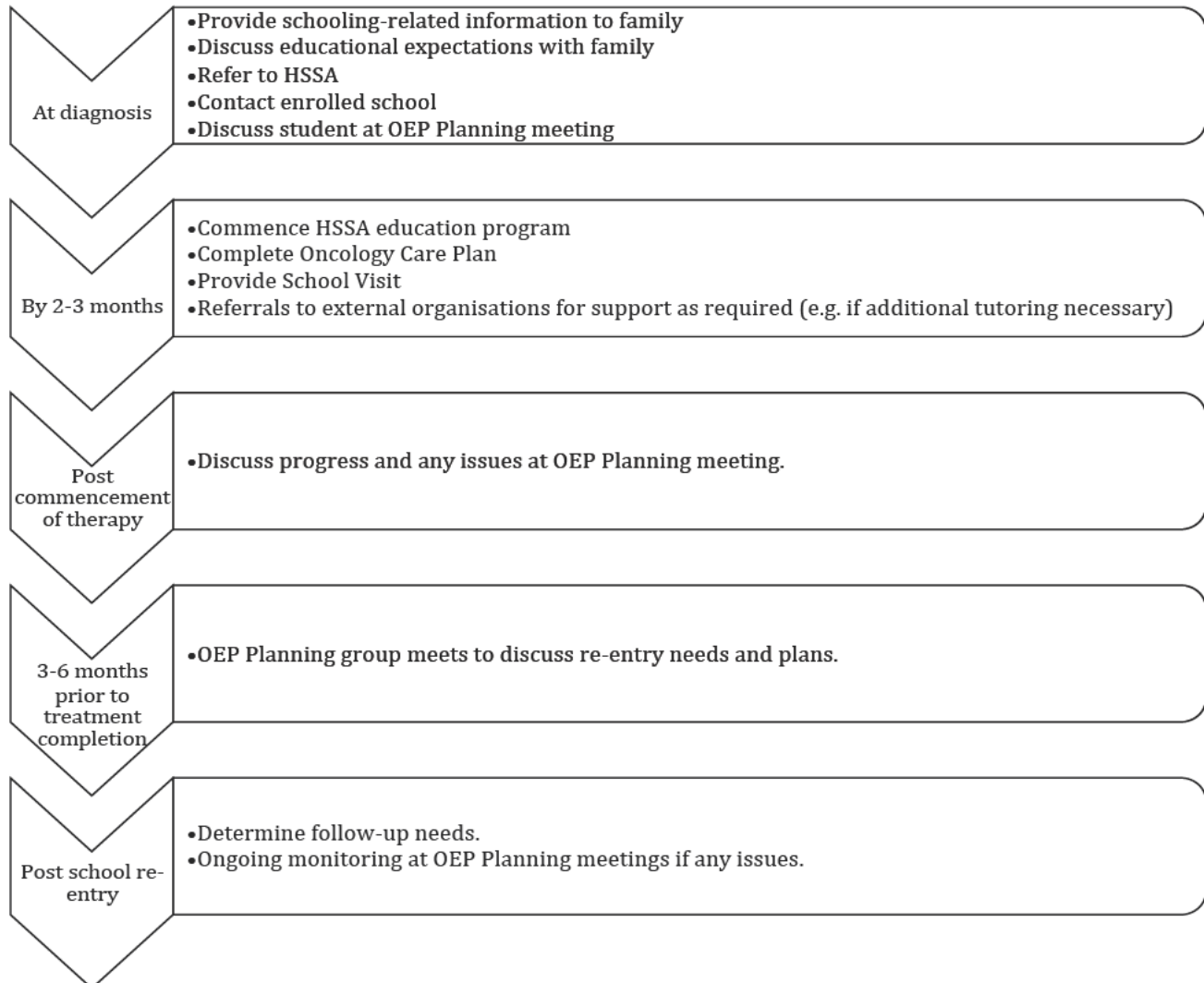
Health and education professionals caring for children with cancer need to...
<input type="checkbox"/> Provide a continuing, flexible education program in hospital or home
<input type="checkbox"/> Assign a paediatric oncology team member as the hospital-based liaison officer
<input type="checkbox"/> Assign a school team member as the school-based liaison officer
<input type="checkbox"/> Establish a collaborative learning support team to regularly meet, involving family, school and hospital personnel
<input type="checkbox"/> Develop an individualised education plan that is available to all school and hospital staff
<input type="checkbox"/> Develop an individualised health plan that is available to all school and hospital staff
<input type="checkbox"/> Transition the child to school as soon as possible
<input type="checkbox"/> Maintain communication between school, family and hospital
<input type="checkbox"/> Provide resources for teachers to understand the illness, its educational implications and how they can be managed at school
<input type="checkbox"/> Educate classmates about cancer and its implications
<input type="checkbox"/> Monitor academic functioning annually throughout school enrolment
<input type="checkbox"/> Monitor psychosocial well-being annually throughout school enrolment
<input type="checkbox"/> Identify and monitor high-risk students (e.g. CNS treatment)
<input type="checkbox"/> Give special consideration to transition periods (e.g. progressing from primary to high school)
<input type="checkbox"/> Provide information regarding legally bound educational support
<input type="checkbox"/> Have in place, if necessary, a special palliative care plan for the student, their peers and teachers

In sum, while there is general support for schooling intervention for children with cancer, the level of evidence remains low. There have been no recent, comprehensive Australian interventions described. Interventions found within the literature appear largely ad-hoc in their development, with minimal theoretical underpinning and a lack of documentation evaluating the effectiveness of each component separately (Helms et al., 2016; Lum et al., 2017; Thompson et al., 2015; Tollit, Sawyer, Ratnapalan & Barnett, 2015; Prevatt et al., 2000; Vance & Eiser, 2002). The lack of consistency in program target (e.g. child, teachers, peers), aims, components, and outcomes across studies also mean that synthesis of the literature is difficult. As a result, while there is growing recognition of the need to incorporate schooling intervention in childhood cancer care, there are no evidence-based approaches available to guide practice (Libman, Sherrod & Weyant, 2017; Lum et al., 2017).

The Oncology Education Program

The Oncology Education Program is a hospital-based schooling intervention currently delivered to all children treated for cancer at the WCH, the only tertiary centre for paediatric oncology in South Australia. The program was developed by clinicians to address an identified gap in service provision for children with cancer, and in particular, respond to an earlier study by Roberts et al. (2014) that found a significant proportion of children treated for cancer at the WCH had repeated a grade. The Oncology Education Program aims to prioritise schooling during treatment, in order to facilitate school engagement, academic and social outcomes. This includes supporting children to maintain positive links with their school post-diagnosis, and to successfully transition back into school as soon as medically able.

Interdisciplinary planning and review groups have been formed across education, medical and psychology departments. A program pathway was developed (Figure 1).



HSSA- Hospital Schools South Australia
OEP- Oncology Education Program

Figure 1: *The Oncology Education Program (OEP) pathway*

The educational program within the Oncology Education Program is delivered by Hospital Schools South Australia (HSSA), based at the WCH, and consists of several flexible, individualized components to address both educational and social

needs, while in hospital, at home and at school. An additional, interdisciplinary component is a school visit, attended by a School Liaison Nurse and HSSA representative. A description of these components is provided in Table 2.

Table 2: Oncology Education Program components

OEP Component	Description
Face-to-face teaching	<ul style="list-style-type: none"> Aims to engage students in targeted learning tasks to assist in their progress while unable to attend their enrolled school. Provided in the HSSA classroom and on the wards (at the bedside or in the playroom).
Learning online	<ul style="list-style-type: none"> WebEx used as the online platform to participate in face-to-face HSSA teaching sessions, individually and/or in groups. WebEx can also allow students to connect with their class via video conferencing. Through Learning Online students are able to participate in lessons and/or engage with peers socially.
Learning@Home	<ul style="list-style-type: none"> Aims to continue and consolidate a student's learning progress while at home and not able to attend their enrolled school. Learning packs are sent home in the mail. Maintains students' connection with their key teacher from HSSA and normalises their day by engaging in learning tasks.
Connecting Kids	<ul style="list-style-type: none"> Aims to maintain students' relationships and connections with school friends, and encourage engagement in fun writing activities. Maintaining connection likely to ease the transition back to school. Adapted to suit different ages and interests; <ul style="list-style-type: none"> For preschool and junior primary students connection with friends is facilitated through two identical soft toys retelling events to each other. For primary students a scarf or jumper of the child's favourite sporting team is often used. Middle and senior secondary students typically prefer to use their own school's IT platform, personal emails and phone texting to stay connected.
Waiting Room Visits	<ul style="list-style-type: none"> Face-to-face teaching and/or contact and support from HSSA teachers provided while children are waiting for treatment or appointments.
School visit	<ul style="list-style-type: none"> A school liaison nurse and HSSA representative visit the student's enrolled school to provide school staff with disease and treatment related information. An information pack provided, including an Oncology Patient Care Plan, a letter template for informing the school community about the risk to the student of infectious disease, relevant community support services, tutoring options and WCH contact information.

HSSA- Hospital Schools South Australia.

In addition to addressing individual schooling needs, fundamental to the Oncology Education Program is a bigger-picture, systemic approach. This approach is based on the socio-ecological premise that a child's school adjustment is best facilitated by considering their environments (microsystems) and the linkages between these environments (the meso-system) (Bronfenbrenner, 1994; Brown, 2002). As recognized by models of adjustment to childhood chronic illness, such as the Risk and Resilience model (Wallander & Varni, 1998) and the Transactional Stress and Coping model (Thompson & Gustafson, 2009), social and environmental factors affect adjustment in addition to illness-related factors. For example, the preparedness of teachers, resources of schools, reactions of peers, beliefs of parents, and the message conveyed by the hospital system are all likely to affect a child's school adjustment (Klibenstein & Broome 2000; Leigh & Conklin, 2010; McLoone, Wakefield & Cohn, 2013; Anh & Lee, 2016; Weiner et al., 2010; Pini, Hugh-Jones & Gardner, 2012). Examples of system-level change addressed by the Oncology Education Program include oncology unit culture change to value schooling, bridging the separation between medical and education departments, improving consistency in practice, and improving hospital-school communication. Regular multi-disciplinary meetings facilitate continuing development, collaboration and monitoring.

While many individual, illness-related aspects of cancer that impact schooling are not readily modifiable, The Oncology Education Program theoretical model (Figure 2) proposes that supporting the systems surrounding the child, and improving collaboration between these systems, will improve schooling experiences and outcomes. In other words, the impact of illness-related factors upon school adjustment is likely to be moderated by features of the systems to which children

with cancer belong, and the degree of connection between these systems. However, whilst such an ecological theoretical underpinning has been suggested within the literature (Brown, 2002; Georgiadi & Kourkoutas, 2010; Power, DuPaul, Shapiro & Kazak, 2003; Worchel-Prevatt et al., 1998), it has not yet been well explored, and further information is required regarding how families appraise the support they receive from the systems involved in schooling with a cancer diagnosis.

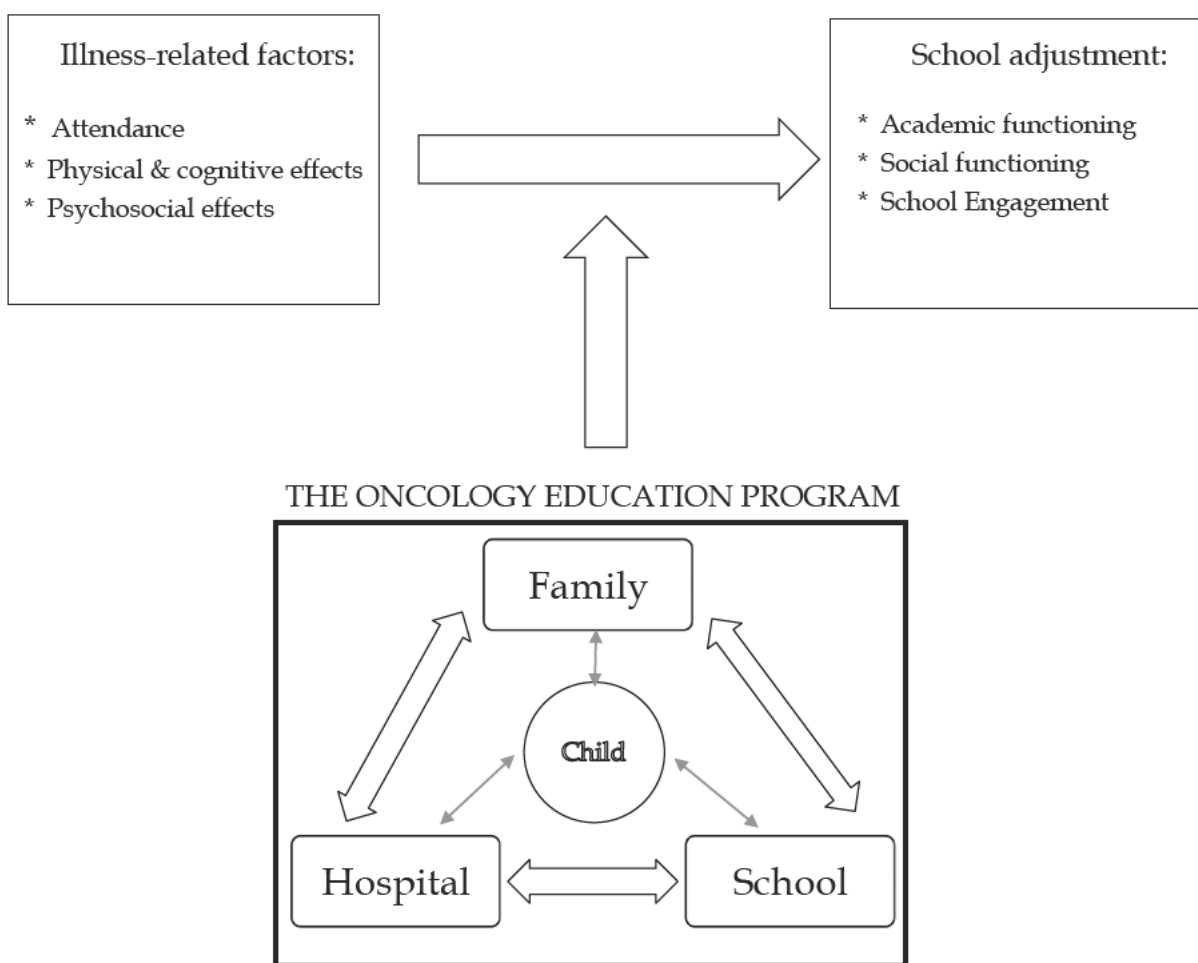


Figure 2: *The Oncology Education Program theoretical model*

OBJECTIVES

This study aims to better understand the experience of participating in the Oncology Education Program, including parents' views about the program and its components, and their perceptions of impact. Further, given identified gaps in the literature, the study also seeks to develop a better understanding of the school adjustment process for children with cancer, including its facilitators and barriers.

More specifically, this study aims to;

- 1) Understand the experience of being involved in the Oncology Education Program, from parent perspectives.
- 2) Explore parents' perceptions of the impact of the Oncology Education Program.
- 3) Explore parents' perceptions of the school adjustment process for children who have participated in the program, and what factors influence this adjustment.

The results of this study will provide parent perspectives of the program to service providers, in order to inform future development of the program and respond to family needs. Information about a specific Australian school intervention will also contribute to bridging an identified gap in the literature.

METHOD

Research Approach

A qualitative design using semi-structured interviews was employed. This design was chosen to facilitate a rich understanding of families' experiences. Qualitative

methodology is best suited to exploring subjective experiences and is particularly useful when less is known about a topic (Creswell, 2009), such as schooling intervention, an identified gap in the literature. Consolidated criteria for qualitative research (Tong, Sainsbury & Craig, 2007) were addressed.

Recruitment and sampling

This study was approved by the Women's and Children's Health Network Human Research Ethics Committee, and the South Australian Department for Education Research Unit. Parents of children with cancer were identified and recruited by nursing staff of the Michael Rice Centre for Haematology and Oncology (MRCHO) at the WCH. Parents were eligible to participate if they were fluent in English, and if their child was of school or kindergarten age during treatment (3-18 years), had undergone treatment for any type of cancer at the WCH between May 2015 and March 2018, and were currently in the 'maintenance' phase of treatment, or completed treatment.

Recruitment took place between September, 2018 and January, 2019. All parents who met eligibility criteria (N= 106) were provided with information about the study and invited to participate. Originally, nursing staff met with potential participants face-to-face and collected written consent to be contacted from those who agreed to participate. These parents were then contacted by the primary researcher, who further explained the study and their participation, and provided an opportunity to ask questions. However, after 4 months of recruitment only 12% of potential participants (N=13) had been approached by recruiting nursing staff, and so an amendment to ethics was sought and granted enabling all remaining participants (N=93) to be contacted by recruiting staff by mail. The remaining 93 families were mailed a

participant pack that explained the study and invited their participation. Those that expressed their interest were then contacted by the primary researcher.

Basic, unidentifiable demographic data was collected for those families who declined to participate.

Data collection

A semi-structured interview guide was purposively developed to gain insight into the experience of participating in the Oncology Education Program and schooling with cancer. The interview guide was based on a review of relevant literature and included open-ended questions exploring program components, facilitators, impacts, barriers and gaps. Examples included *“What is your understanding of the Oncology Education Program?”*, and *“Could you tell me more about what it was like when your child returned to school after treatment?”*

Interviews were conducted by the principal researcher, a Provisional Psychologist, either face-to-face at the WCH or by phone, depending on parents' preference.

Interviews lasted for an average of 47 minutes (M=46.6, SD=9.23). With parents' permission, all interviews were audio recorded.

Demographic and medical information pertaining to each child (e.g., gender, type of cancer, age at diagnosis, phase of treatment) was collected in order to provide information about variables that may affect the schooling experience. This information was collected using parent-report, and supplemented using hospital medical records. In order to provide a measure of engagement with each Oncology Education Program component, program participation for each child was collected from HSSA records.

Data Analysis

Interview data was examined using thematic analysis, a method for identifying patterns of meaning (Braun & Clarke, 2013). In accordance with the process described by Braun and Clarke (2013), interview data was transcribed verbatim, followed by familiarisation and the subsequent development of codes, themes and subthemes. Codes and themes were developed by the principal researcher, then coded data was reviewed by the co-authors and themes were discussed and agreed upon. During analysis of the final three transcripts, no new themes emerged, suggesting that data saturation had been reached.

FINDINGS

Participant characteristics

Of the 106 families approached to participate in this study, 20 parents initially consented. Of these, 9 parents from 8 families eventually completed an interview, including 8 mothers and 1 father, a response rate of 7.6%. The majority of parents did not respond to the mailed information pack, and the majority of those who initially consented did not respond to follow-up contact to arrange an interview.

Brief demographic information for each participant's child with cancer is displayed in Table 3. To protect anonymity, diagnoses, rural/remote location and schooling type have not been linked with individual families.

Table 3: Demographic information for children with cancer

Parent	Child	Gender	Years of age (School grade) at interview	Years of age (School grade) at diagnosis	Amount of schooling missed (approx.)
Parent 1 (Mother)	Child 1	F	6 (1)	5 (Rec)	>6 months
Parent 2 (Mother)	Child 2	F	9 (3)	6 (Rec)	>6 months
Parent 3 (Mother)	Child 3	F	9 (3)	7 (1)	>6 months
Parent 4 (Mother)	Child 4	M	8 (3)	7 (2)	>6 months
Parent 5 (Mother)	Child 5	M	6 (1)	3 Relapse at age 6 (Rec)	3-4 months
Parent 6 (Father) Parent 7 (Mother)	Child 6	M	8 (3)	5 (Rec)	>6 months
Parent 8 (Mother)	Child 8	M	6 (2)	1 Relapse at age 5 (Rec)	1-2 months
Parent 9 (Mother)	Child 9	M	15 (10)	12 (6)	>6 months

Rec= Reception (first grade of schooling in South Australia)

Acute Lymphoblastic Leukemia was the most common diagnosis, accounting for 50% of children. The weighting of this diagnosis is approximately representative of all eligible participants, of whom 43.9% had a child diagnosed with ALL. Other diagnoses included Wilm's Tumour, Hodgkin's Lymphoma, Acute Myeloid Leukaemia and Spinal cord tumour. The gender of children of participating families (62.5% male) was representative of the total eligible sample (61% male). Seventy-five percent of children in this study attended a public school at the time of diagnosis.

The average age of children with cancer in families who participated was 8 years

(M=8.34, SD=2.97), and age of diagnosis 6 years (M=6.5, SD=2.45). The majority of children (75%) were of Primary school age (5-12 years) at diagnosis, compared to Pre-school (<5 years, 12.5%) and High school (13-18 years, 12.5%) age. Whilst this pattern is somewhat representative of the proportions of all eligible families (47% Primary school age, 33% Pre-school age, 20% High school age), families of Primary school children were nonetheless over-represented in this study. Rural or remote families were also more heavily represented in this sample (50%) compared to rural/remote families within the larger sample of eligible participants (16%).

Engagements with each component of the Oncology Education Program are displayed in Table 4. All families participated in at least one component. On average, children participated in 44 HSSA engagements during their treatment, most commonly Face-to-face teaching on the ward. Five parents (62.5 %) reported having a school visit.

Table 4: *Student engagement with Oncology Education Program components, based on Hospital Schools SA records*

	Face to Face		Connecting Kids	Learning @ Home	Waiting Room	Learning Online	School visit	Total engagements
	Class-room*	Ward						
Child 1	1	39	Y	6	8	1	Y	57
Child 2	1	41	N	1	0	0	N	43
Child 3	4	39	Y	3	4	46	Y	98
Child 4	0	25	Y	3	2	5	Y	37
Child 5	0	2	Y	0	1	0	Y	5
Child 6	0	39	Y	2	6	0	N	48
Child 8	0	0	N	0	0	0	Y	1
Child 9	0	45	N	0	6	8	N	59
Average engagements per child (M, SD)	0.75 (1.92)	28.75 (18.07)		1.88 (2.10)	3.38 (3.07)	7.50 (15.84)		43.5 (31.04)

* Classroom= Hospital Schools SA classroom, located on-site at the Women’s and Children’s Hospital

Themes

Six major themes and 11 subthemes were identified from interviews with parents (Table 5).

Table 5: Themes and subthemes

	Theme	Subtheme
1	Experiences with program components	<ul style="list-style-type: none">- <i>Face to Face</i>- <i>Connecting Kids</i>- <i>Learning @ Home</i>- <i>Waiting Room</i>- <i>Learning online</i>- <i>School liaison visit</i>
2	The bigger picture of the program	<ul style="list-style-type: none">- <i>Parent understanding</i>- <i>The message - Schooling is important</i>
3	Communication- Not proper 3-way	
4	A burden of responsibility for parents	<ul style="list-style-type: none">- <i>The school takes a backseat</i>- <i>What's the plan?</i>- <i>A lack of resources</i>
5	Other sources of academic and social support	
6	Perceived impacts of cancer on schooling	

Theme 1: Experiences with the Program Components

Face-to-Face Teaching

All families except one participated in Face-to-Face teaching during treatment. All these parents valued the fact that schooling was maintained in hospital, and felt that participating in schooling activities was both normalising and a positive distraction for their child. Most parents commented upon the flexibility of teachers and the

enjoyment of their children. One parent discussed that Face-to-Face teaching was instrumental in avoiding her child having to repeat a grade:

The school was pretty quick to decide she'd have to repeat Reception, because they said she'd missed too much school....and so they [HSSA] visited her and helped with that, getting her up to a level that the school wanted. (Parent 2)

However, many parents appeared to have some expectations of Face-to-Face teaching that were not met. Parents indicated they would have liked more frequent visits, more dependable scheduling and individualised programming that better met their perceived academic needs for their child:

There wasn't really enough continuity....like, you need to do this and I will check on it....It was too optional, and when things are optional kids choose not to do it. (Parent 9)

Connecting Kids

The purpose of this component appeared understood and appreciated by parents. For some, 'Connecting Kids' was reported as the only contact the child had with their class whilst absent. All families had a name for their soft toy and it was discussed fondly:

....we got text messages from families taking [stuffed toy] places and it sat at her desk.... The teacher said they talked about her [Child 3] nearly every day at school, that she still felt like part of the class. (Parent 3)

It seems that the way in which this component had benefit for children varied depending on factors such as the child's school grade and phase of treatment, how it was implemented by the class teacher, and timing within the school year:

The only contact that happened, and that was at the end of the year, was the teacher did that Connecting Kids....But the teacher ran that so that the kids got it for a week, each kid in the classroom. So she [Child 1] didn't get that until the end of the year. (Parent 1)

Learning @ Home

Parents reported that receiving Learning @ Home packages in the mail was a source of excitement and distraction for their child, although some felt that these weren't frequent enough.

She got these in the school holidays, it was a fun way of learning, kept her in the habit. (Parent 2)

Waiting Room

Parents viewed the waiting room visits as a positive distraction but did not discuss any educational or communication value:

Yes, it was a nice distraction in the waiting room potentially for a little bit, but there was nothing probably hugely educational.

(Parent 6)

Learning Online

No families had the opportunity to use WebEx with their own school and only 3 participated in sessions with HSSA, although most parents would have liked both opportunities. The 3 families that did have access to Learning Online reported that it was a useful option to flexibly continue schooling while at home:

...to actually have to do something at home when he was quite well but still couldn't go out, that was valuable, I thought. (Parent 9)

However, these parents also described some challenges such as the effort required to facilitate their child's engagement:

Most of the challenges with WebEx sessions were to do with his engagement, because if I didn't sit and do stuff with him, he wouldn't do it. (Parent 4)

School Visit

The school visit, with a School Liaison Nurse, was one of the most discussed components. It was viewed positively, as a much needed sharing of information from Hospital to School:

..there were definitely times when it was difficult for him to go, and I think the fact that his teacher had met with professionals helped her...it provided her with support. (Parent 8)

However, despite the fact that the program aims for universal school visits, not all families in this study received one. Those that didn't were unsure why it wasn't offered. Of those who did have a visit, many felt that they were not included enough:

I don't know what happened, that's my only feedback, I would have liked to be in on that meeting as I could have added information....
(Parent 5)

Most parents also expressed issues with the timing of the visit, and a need for the school visit to be repeated at key transition times, such a transitioning back to school and into new school years. This need was discussed at length, signifying a gap that had been challenging for parents:

I felt like we needed a visit at the start of each school year....That was a really hard transition time where I felt we were on our own....It would have validated a lot of what I was saying. (Parent 3)

It [the school visit] was soon after diagnosis, and [Child 4] wasn't back at school for a year..... schools need someone to go out and say here's how you support this child coming back to school... it was too early in [Child 4's] case...." (Parent 4)

Theme 2: The Bigger Picture of the Program

Parent Understanding

When asked to describe their understanding of the program, most parents reported some confusion. Only one parent seemed aware of the comprehensive nature of the program model, including the bigger picture of liaison and interdisciplinary support across systems, whilst the others tended to focus more narrowly upon the HSSA activities that their child was able to access:

Well I don't really have much understanding, I didn't really have that much information... I know that when we came in the teacher would sometimes come and see us..... I don't know anything really about their goals are or anything like that. (Parent 9)

The Message – Schooling is important

Despite some confusion with their understanding of the program model, and some issues with elements of program delivery, all families appeared to agree with and value the premise of the program, that schooling should be an important part of their child's cancer care. Support from the hospital system for the notion that schooling is important was perhaps the main benefit of the program related by parents.

I think the Women's and Children's, they did lead by the fact that they have set up an outreach service, it shows they value normality and education. (Parent 5).

One parent discussed that she felt that schooling was a consideration in her child's medical treatment plan:

I guess they let his schedule accommodate the need for school...(Parent 8)

The priority given to schooling fluctuated both between families and over time. Different benefits of maintaining schooling appeared to be important to different families, including academic, emotional, social, routine, normalising and life-affirming aspects:

It was important..... it was important to have routine and it was important that he.....didn't miss a whole lot of school. Routine.....is really good for you and the distraction of school was important, and also just him getting an education. (Parent 8)

One parent suggested that it would be beneficial for the program's message and expectations to be shared more explicitly with children themselves.

Theme 3: Communication - Not Proper Three-Way

Although parents clearly desired a high level of three-way communication between themselves, their school and the hospital, parents identified a number of gaps. In particular, parents discussed a lack of communication between the hospital and school, or a perceived lack of communication due to a lack of communication with the family.

I just would've liked that to be proper three way.....sometimes I wasn't included in that hospital to school communication and it would've helped me to know what's going on.....It became tricky because I was either running it or excluded from it. (Parent 3)

Communication within the hospital and school systems was also seen as lacking, for example across hospital departments or school classes:

.... when [Child 4] had a relief teacher, they were not always aware of the situation, so as a parent I felt sometimes uneasy about leaving him..... Little things, for example the P.E [Physical Education] teacher wasn't told that [Child 4] had a port so I had to go and let the P.E teacher know.” (Parent 4)

Theme 4: A Burden of Responsibility for Parents

All parents, except one whose child missed little school, discussed feeling a significant burden of responsibility relating to their child's schooling. Parents reported they felt responsible for driving communication, providing educational support, monitoring progress and advocating for their child. Parents described this extra burden as exhausting and stressful:

I feel like I always had to drive it and I was exhausted. I'd had enough working out what meds she was on, which protocol she was on and

whether my son [sibling of Child 3] was alright and she [Child 3] was alright and who was looking after him, and who was doing what and then to add – you know – ‘Can you send us this work?’ Each week.”

(Parent 3)

It just became another thing I had to manage which was just too hard for me. (Parent 4)

Contributing to this often overwhelming sense of responsibility appeared to be 3 main factors; a lack of responsibility from their child’s school, a lack of three-way communication about the plan for their child, and a lack of resources and support once back at school.

The school takes a back seat

A common experience amongst families was a lack of knowledge and initiative from their schools. Most parents reported that their schools did not appear to know what to do when told about their child’s diagnosis.

They didn’t really know anything. They didn’t know what to do, how to deal with it. And neither did I. (Parent 1)

While some parents reported a general sense of supportiveness from their school, little practical help was offered. Some parents noted a lack of flexibility in the school system to accommodate a child with cancer. Some parents also felt responsible for providing the right information to the wider school community themselves:

[Child 1] and I sent out a letter to all the kids in the class.....we just explained, like, 'if your kids are sick can you stay away.'....And for the parents, if the parents don't know how to handle the questions from their children... they see that they can ask me....(Parent 1)

Most parents reported driving all academic-related communication with their school. While schools sometimes kept in contact on a social level, they did not initiate contact to assist schooling progress:

What I would have liked was a liaison appointed, someone who contacted us rather than me going in there all the time....To me it was hard to always be the one to have to go and contact them.
(Parent 4)

What's the Plan?

All parents expressed a persistent concern about their child's educational progress, both during treatment and when back at school. Most parents discussed worries about whether their child's learning progress was being planned or monitored by anyone, and whether it was 'enough':

It was much more that gap of when we were at home, what am I meant to be doing with him, how do I teach him?.....we did have to reach out for that information rather than here's your plan sort of thing, your kid's at home with you for three months. (Parent 7)

It was nonsense to compare her with the rest of the class, she needed to be compared to her own trajectory...they thought she was fine so what's the problem.....But is she on the same trajectory as she was before? I don't know. Does that matter? I don't know. (Parent 3)

A lack of resources and support for kids with cancer at school

A number of parents felt that their school had minimal resources to support their child, particularly during the transition back to school. Parents appeared to be the stopgap and would stay and support their child in the classroom, often for months:

It took us probably two terms to get him to where he was happy to go to school without someone. The first term he wanted someone there the whole time.....that's what these children need when they go back to school, access to an SSO [teaching assistant] to help them but there's not the funding for it. I think there's a gap with the funding for these kids. (Parent 4)

Theme 5: Other Sources of Academic and Social Support

Parents reported that their child's schooling adjustment was assisted by the wider community. Social contact during treatment was often arranged between parents. Sporting clubs provided another source of social contact and normality. More formal schooling support included tutoring organised by Childhood Cancer Association (CCA) and Ronald McDonald House, counselling from CCA, and classroom

presentations from Camp Quality. These extra supports were usually sought out and organised by parents themselves and were viewed very positively.

....we sought out a psychologist at CCA and they met [Child 3] in January this year because I knew it was going to be hard...that made a big difference to her transition. (Parent 3)

...we were offered tutoring through CCA....and it alleviated that stress that he would fall behind the other children after having a year at home....we highly recommend that. (Parent 5)

Theme 6: Impacts of Cancer on Schooling

Parents discussed a wide range of impacts of cancer upon their child's schooling. These included prolonged absence, and physical, emotional, behavioural, social and academic impacts. While some concerns were on-going, they appeared to be greatest in amount and intensity during the period of transition back to school:

He also needed someone to break it down for him...The kids in the class had got used to the routine...he struggled to learn those routines.” (Parent 4)

The social ramifications of their child's diagnosis were especially important to parents. While most parents discussed some anxiety relating to changes in

appearance, many also remarked upon their child's resilience, and the fact that their class seemed well-prepared and accepting:

She handled it really well when kids would say things like "your face has changed", because the steroids would make her face puff up, and she would go "Oh, it's just my medicine." She had that inner confidence I suppose. (Parent 3)

Typically long absences of more than 6 months meant that parents often reported a sense of 'missing out' felt by both themselves and their child, relating to school experiences, milestones and time with friends:

So that was really heart-breaking. Because she didn't get to have her first day of school. (Parent 1)

Some parents also identified problematic changes in both their child's approach to learning and their teacher's approach to teaching them:

...it became that funny thing where [the child's teacher] sort of admired her too much, she's so brave, she's amazing, I was like well she still has to do her spelling!....it changed the relationship and changed the expectation, and her ability to follow instructions changed because she thought everything's optional. (Parent 3)

Few explicit links were made between the Oncology Education Program and schooling outcomes. As previously discussed, one parent attributed support from HSSA as key in preventing grade repetition. Another parent reported that the academic maintenance and social preparation provided by the program was generally valuable:

I think they did a great job, anything to do with prepping the school socially for her to come back was done really well.....the hospital academic side of things was fantastic, it was targeted, it was flexible, all those are huge ticks, and the school did a great job socially in that she could walk in there with no hair and no one commented.

(Parent 3)

Despite some challenges, no child in this study needed to repeat a grade, and all parents described their children as now relatively well-adjusted and enjoying school, or getting there:

He loves it [school], he absolutely loves it. (Parent 5)

When he went back to school he was so motivated and so excited to get backI think there's no lasting impact of him having those six terms [1½ Australian academic years] off school. (Parent 9)

DISCUSSION

While schooling with cancer poses a number of challenges for children and their families, the maintenance of schooling also brings with it a number of potential benefits. This study sought to explore the schooling experiences of families after a diagnosis of childhood cancer, in particular, parents' experiences of being involved in a hospital-based schooling intervention. Parents provided rich narratives of the experiences of their family, reflected in 6 themes and 11 subthemes (Table 5).

All parents in this study agreed with and valued the central message of the program, that schooling is important. This was fundamental to ascertain, as while parental support is key, parents' priorities and values cannot be assumed to align with those of health professionals (Woodend, Nair & Tang, 1997). Some literature suggests that schooling does not feature as a priority for parents in comparison to physical health, survival and wellbeing (Eiser, 1998; McLoone et al., 2011). However, this study found evidence to the contrary, with parents viewing schooling as an essential component of their child's wellbeing. Routine and normality were particularly significant benefits of the program noted by parents, consistent with the notion that school is one of the best ways to provide normality and hope for children with cancer (Bessel, 2001; Prevatt et al 2000; Moore et al., 2009). The parents of children with serious illness have a need for normality too (McLoone et al., 2013; Prevatt et al., 2000; McKeivitt et al., 2018), and while parents focused on the benefits for their children, it appears that a focus beyond their child's cancer was normalising and life-affirming for parents themselves. Schooling activities offered parents brief respites from the caring role and an opportunity to view their child as a student rather than a patient, participating

in developmentally normal, future-oriented activities.

From a systems perspective, this study suggests that the Family and Health systems have the same overall schooling-related goals, and this alignment is fundamental to the program. However, individual difference was found in terms of the reasons why parents viewed schooling as important, including academic, social, routine, normalising and life-affirming aspects. This may indicate differences in underlying values and motivations of parents, and may frame the way in which the Oncology Education Program is perceived. For example, those parents who view the academic aspect as important are likely to expect ongoing academic development, those who value routine may expect regularity and predictability, and those who value interpersonal aspects may place greater emphasis on opportunities for building relationships. Such variation may explain some diversity in how different components of the Oncology Education Program were appraised, and provides information as to variation in families' needs.

Interestingly, parents perceived the School system to be the least supportive of the notion that schooling remains important after a cancer diagnosis. This is despite the fact that Australian law stipulates that education remains the responsibility of the child's enrolled school (Department for Education, Science & Training, 2005; Lum et al., 2017). Most parents in this study reported that while sympathetic, their school 'took a backseat' and did not tend to initiate contact to maintain, monitor or plan their child's schooling. The school stepping back after a cancer diagnosis has been noted previously (Marshall, 2017). Research suggests that teachers are not well informed about or trained in managing chronic illness, and may feel overwhelmed and

reluctant to intervene (Brown, 2002; Klibenstein & Broome 2000; Moore et al 2009; Prevatt 2000; Willkie, 2012). Also consistent with the literature, parents reported changes in teaching style such as lowered expectations and excessive admiration (Brown, 2002; Rynard et al 1998). Overall, the School system did not meet the expectations or needs of parents in this study, and therefore may require additional support to better understand their role and address challenges.

Across the meso-system, parents perceived a lack of individualized schooling-related planning and programming. Parents discussed feeling that no-one was monitoring their child's schooling progress and that no formal plan had been developed. There are two main possibilities for this perception. One is that there remains some confusion, across systems, as to who is responsible for producing such a plan, and what academic expectation should be placed upon the child. Such system-level confusion is reported in the literature (Moore et al., 2009). Another possibility is that children's schooling is being individually planned and monitored, but these details are not being communicated with parents. Regardless of which of these possibilities is most accurate, it remains the case that parents in this study were unaware that a formal learning plan had been developed and felt that this burden fell to them, despite also believing they were ill-equipped to assume this responsibility. The creation of an individualized learning plan, available to all school and hospital staff, is a key recommendation proposed by Lum et al (2017). This study adds that parents would also like to be included in this plan.

The concern driving parents to desire more rigorous academic planning and programming is particularly interesting to explore. Many parents in this study worried

about missing schoolwork, the standard of schoolwork, and that schoolwork was 'too optional'. It is noteworthy that concerns about 'keeping up' were so salient, given that the majority of children were in Reception during their intensive treatment phase. However, it seems that underlying schooling concerns were more complex worries: Will my child be able to return to a normal life post-cancer? Will they maintain the life trajectory they would have had if they had not had cancer? Parents linking current school progress to projected life outcomes may explain why worries about progress were prominent even when academic expectations were arguably relatively low. Parental need for control over addressing perceived schooling gaps was also evidenced by their discussion about using tutoring to accelerate the 'catch-up' process, consistent with findings of McLoone et al. (2011). Overall, while schools may feel that a child is managing at an acceptable level given the circumstances, this study suggests that parents are driven to minimize the impact of cancer and are attune to monitoring for gaps. Such increased parental involvement in education is likely to create parental needs that are more intense than schools are accustomed to.

A key finding of this study is that schooling is linked with significant perceived burden for parents. Little research has explored the role that schooling-related demands play in the overall caregiving burden experienced by parents, however the stress and exhaustion reported by parents in this study is consistent with findings by both Wakefield et al. (2011) and Bruce et al. (2012). After a diagnosis of cancer, parents become the managers of a number of aspects of their child's illness and treatment, and it appears that schooling maintenance is another perceived addition to the role. While it is possible that parents' perceptions of responsibility for schooling may be

influenced by a heightened need to protect, manage and advocate for their more vulnerable child, parents are nonetheless required to provide significant schooling support even in normative contexts (Anthony et al. 2003; Ratelle, Duschesne & Guay, 2017). Parental stress and exhaustion can have negative sequelae for both parent and child (Fedele et al., 2013; Wakefield et al., 2011; Immelt et al., 2006). This study suggests that in addition to supporting the child to maintain their schooling, health and education professionals must also be mindful of the support that parents need.

It appears that underpinning a number of parental perceptions in this study is a lack of effective communication between systems. Effective three-way communication between the Family, Health and School systems is at the core of successful school support (Bessel, 2001; Georgiadi & Kourkoutas, 2010; Lum et al., 2017; Moore et al., 2009; Pini et al., 2012; Thompson et al., 2015), however parents in this study expressed a need for better communication. It is possible that communication gaps could account for, or mitigate, a number of program-related gaps and barriers for parents, such as a perceived lack of planning, perceived lack of support, poor understanding of the program and confusion regarding roles and responsibilities. This study suggests that while parent contact may be limited in an attempt not to over-burden them, this lack of involvement paradoxically increases the burden.

In line with research, the back-to-school transition and schooling at home were identified as phases associated with increased stress (Australian Research Alliance for Children & Youth, 2015; McLoone et al., 2011; Wakefield et al., 2011). The fact that many parents felt that they were the stopgap for within-classroom support, often for many weeks, is concerning. A lack of resources to meet the needs of children

with cancer within the school system has been reported within the literature (Bruce et al., 2012; Donnan et al., 2015; Lum et al., 2017). In addition to a lack of resources, challenges during transitions may reflect a lack of confidence of both the School and Family systems, and again suggests more support and communication is necessary.

A paediatric oncology team member acting as school liaison is a key component of proposed re-entry guidelines posited by Lum et al (2017). However, the school liaison role has varied widely in the literature (Bruce et al., 2012; McLoone et al 2011) and in this study, the role was defined as involving the provision of medical information at the school visit only, rather than an ongoing source of support.

Consistent with McLoone et al. (2011) and Bruce et al (2012), parents viewed the school liaison as a possible advocate, and felt that the role should be expanded to include ongoing support and advocacy. A school liaison model developed by Northman, Ross, Morris & Tarquini (2015) found that ongoing support throughout the child's schooling years was linked to high levels of satisfaction and perceived support, and attributed to better academic outcomes.

Parents in this study described a number of impacts of cancer on their child's schooling adjustment, including prolonged absence, fatigue, self-consciousness about physical differences, loss of contact with peers, poor concentration, falling behind in classroom skills, a sense of loss and a changed attitude to schooling. Impacts were perceived by parents to be greatest in both amount and intensity during the transition back to school. Overall, however, parents painted a positive picture of their child's re-adjustment to school. Consistent with findings of Rynard et al. (1998), parents reported few ongoing academic or social concerns and all children

now enjoyed school. In reference to the key study by Roberts et al. (2014), no students in this study repeated a grade. While the positive outcomes reported by parents cannot be attributed directly to the Oncology Education Program, this study nonetheless has found that the experience of schooling has been largely positive for this group of children who participated in the program.

Recruitment for this study was difficult. Due to ethics requirements, parents could not be approached directly by the researcher, which created considerable work for hospital staff. A number of strategies were employed to address this issue, such as the principal researcher remaining available on-site, regular meetings with staff, and a mail-out to reach all eligible families. However, it became necessary to reduce the scale and scope of the study due to low participation. While it is desirable for future research to triangulate data from a number of sources, including teachers, clinicians and children themselves, and include quantitative, objective and standardized data, this study highlights potential barriers to evaluating programs within a clinical setting, such as treatment and research fatigue (Clark, 2008; Pagano-Therrien & Sullivan-Bolyai, 2017). Families of children with chronic illness may be particularly susceptible to these barriers to participation.

It is recognised that the experiences of this small sample of parents may not be readily generalisable to all participants of the Oncology Education Program. For example, this group of parents were motivated to participate and may have placed greater focus upon their child's education. Experiences also pertain largely to the early schooling years. Nevertheless, this study provides new information about the experiences of parents with a comprehensive, Australian hospital-based schooling

intervention. Despite low participation, participation in this study falls within recommendations for a small-scale qualitative study (Braun & Clarke, 2013), and saturation of all key themes was reached, indicating that important commonalities of participating in the Oncology Education Program were able to be established.

IMPLICATIONS FOR PSYCHOSOCIAL ONCOLOGY

This study has a number of implications for practice. To our knowledge, it is the first Australian, hospital-based schooling intervention reported in the literature. A theoretically-based intervention model is presented, which addresses over half of the Australian recommendations proposed by Lum et al. (2017) (see Table 6). The study also responds to the criticism that the separate components of school interventions have not been well described (Lum et al., 2017; Helms et al., 2016; Thompson et al., 2015). As recommended by Lum et al. (2017) schooling-related needs of parents have been identified. Parents valued the program's focus on schooling and were satisfied with their child's eventual school adjustment. However, findings highlight a number of areas for practice improvement, based on feedback from families, including more frequent and structured communication, collaborative development of an individualised schooling plan, expansion of the school liaison role, additional support for families and schools during transition periods and beyond, and greater support for parents.

Table 6: Recommendations addressed by the Oncology Education Program (OEP)

(adapted from Lum et al., 2017)

Health and education professionals caring for children with cancer need to...	
<input checked="" type="checkbox"/>	Provide a continuing, flexible education program in hospital or home
<input checked="" type="checkbox"/>	Assign a paediatric oncology team member as the hospital-based liaison officer
<input type="radio"/>	Assign a school team member as the school-based liaison officer
<input checked="" type="checkbox"/>	Establish a collaborative learning support team to regularly meet, involving family, school and hospital personnel
<input type="radio"/>	Develop an individualised education plan that is available to all school and hospital staff
<input checked="" type="checkbox"/>	Develop an individualised health plan that is available to all school and hospital staff
<input checked="" type="checkbox"/>	Transition the child to school as soon as possible
<input checked="" type="checkbox"/>	Maintain communication between school, family and hospital
<input checked="" type="checkbox"/>	Provide resources for teachers to understand the illness, its educational implications and how they can be managed at school
<input checked="" type="checkbox"/>	Educate classmates about cancer and its implications
<input checked="" type="checkbox"/>	Monitor academic functioning annually throughout school enrolment
<input checked="" type="checkbox"/>	Monitor psychosocial well-being annually throughout school enrolment
<input checked="" type="checkbox"/>	Identify and monitor high-risk students (e.g. CNS treatment)
<input type="radio"/>	Give special consideration to transition periods (e.g. progressing from primary to high school)
<input checked="" type="checkbox"/>	Provide information regarding legally bound educational support
<input checked="" type="checkbox"/>	Have in place, if necessary, a special palliative care plan for the student, their peers and teachers

Addressed by the OEP Partially addressed by the OEP Not addressed by the OEP

CONCLUSION

Limited research exists that explores the experiences of schooling intervention for families who have a child with cancer, especially within an Australian context.

Despite its limitations, this study has made a number of contributions to our knowledge about schooling with cancer, and in particular, the experience of participating in a hospital-based schooling intervention. A theoretical framework was developed to examine the effect of system-level schooling intervention after a diagnosis of cancer. Findings suggest that there are modifiable, system-level influences that moderate schooling experiences and outcomes for families of children with a chronic illness that can be addressed by a hospital-based schooling intervention. Parents in this study described significant stress involved in navigating their child's schooling, and their experiences inform several recommendations for practice including clearer and more frequent three-way communication and greater ongoing practical and psychological support for parents. Overall however, parents in this study valued the support they received from the hospital system in maintaining their child's schooling and perceived minimal impacts of cancer upon their child's schooling trajectory. Although further research is necessary to objectively evaluate its effectiveness, the views of parents in this study provide preliminary support for this hospital-based model of schooling intervention. In particular, findings suggest that in addition to school being an important developmental context for children, parents believe that the maintenance of schooling provides additional benefit for children with cancer and their families.

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APPENDIX 2

NOTE OF EXPLANATION REGARDING LOWER WORD LIMIT:

I am aware that a lower word is limit stipulated by the *Journal of Psychosocial Oncology* and propose that I would meet this lower limit by substantially condensing the report, primarily the amount of detail given in the Introduction and Discussion sections. This reduction of the Introduction and Discussion would also reduce the number of references to 45.