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**New Zealand Primary School Teachers' Preparedness to Teach
Children with Chronic Illnesses**

A thesis presented in partial fulfilment of the requirements for the degree of

Master
of
Educational Psychology

At Massey University, Albany, New Zealand

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2018

Abstract

All children are entitled to good quality education where they can learn alongside their peers from qualified, registered, and well supported teachers. However, previous research suggests that some teachers are underprepared and inadequately resourced to meet the needs of children living with chronic illnesses and that this can exacerbate the academic and social challenges these children may face in an educational context. Using a mixed-methods approach, this study examined New Zealand primary school teachers' preparation and experiences in teaching children with chronic illnesses. Fifty-five teachers responded to an online survey that gathered both quantitative and qualitative data. The results were further explored with a purposive nested sample ($N = 4$) using in-depth follow-up interviews. Seventy-eight percent of the survey respondents had not received any initial teacher education training with regards teaching children with chronic illnesses, and almost half (47%) had not undertaken any in-service professional learning and development. Information and supports available to teachers tended to have a specific focus on medical needs, with limited consideration for potential academic and social implications. Consistent with international findings, the results of this study indicate the need for improved teacher education, more readily accessible information and support, and further opportunities for interprofessional collaboration. The results extend on the international literature by highlighting a strength-based, family-centred approach to working with these learners. Teachers' self-efficacy beliefs are identified as an important area for further research on this topic.

Keywords: Childhood chronic illness, inclusive education, teacher education, primary school, mixed-methods, interprofessional collaboration, teacher self-efficacy

Acknowledgements

The completion of this thesis is thanks in large part to the wonderful people who have encouraged, challenged, and persevered with me along the way. I would like to extend my sincere thanks and appreciation to my supervisors, Associate Professor Roseanna Bourke and Terence Edwards. Thank you for allowing me to pursue a topic of great interest to me and for patiently guiding me through the research process. I am indebted to your on-going support, thoughtful critique, and professional expertise. Thank you also to Ceri John who was instrumental in the early stages of this research. It has been a pleasure and privilege to learn from all three of you. Thank you to two fantastic teachers and friends, Mr and Mrs W, along with colleagues who helped me to arrive at my research topic. I hope to draw attention to an important area of your professional practice for which you may not always get the support and recognition that is due. Many thanks to the teachers who contributed their time to this study - I was very motivated to do justice to the stories you kindly shared. Last, an enormous thanks to my family, friends, and colleagues for being so very patient and supportive throughout this endeavour. I am certainly looking forward to spending more time with you all.

Phase I of this study was reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 17/21 (see Appendix A). The second phase was evaluated by peer review and judged to be low risk. Consequently, it was not reviewed by one of the University's Human Ethics Committees (see Appendix B).

Dedication

I dedicate this thesis to my loving and patient husband. Thank you for your consistent support and encouragement through a challenging year, all the while quietly accomplishing your own career goals. I am immensely proud of you and so very thankful for all that you do.

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Chapter 1

Introduction

In New Zealand, the Ministry of Education (MoE, 2014, p.1) is committed to a fully inclusive education system in which all children and young people “are engaged and achieving through being present, participating and learning”. To realise this, we need to be proactive in identifying and removing any barriers to success (MoE, 2004). One group of children who may confront barriers along their learning journey are those living with chronic illnesses. Their educational experiences can be disrupted due to the symptoms of their illness, the side effects of treatments, and the need to be absent from the classroom for frequent or extended periods of time. This places these children at risk of social, emotional, and behavioural challenges and academic underachievement when compared with their healthy peers. It is thus imperative that our teaching workforce is professionally prepared and well supported so that teachers can help lessen these risks and contribute to positive educational experiences for these children.

The number of children and young people living with a chronic illness has increased dramatically in recent decades (Canter & Roberts, 2012). This is in part a consequence of advanced medical technologies, which have increased the survivorship of once fatal childhood diseases (Sawyer, Drew, Yeo, & Britto, 2007). It is also driven by the increased childhood incidence of chronic illnesses such as diabetes and asthma (Sawyer et al., 2007). Robust estimates of the burden of chronic illness are elusive since epidemiological studies tend to focus on one or a few diseases at a time, and this results in fragmented prevalence data (van der Lee, Mokkink, Grootenhuis, Heymans, &

Offringa, 2007). As an indication of the prevalence in New Zealand, Denny et al. (2014) reported that almost a fifth (18%) of New Zealand secondary school students had a chronic health condition¹. Importantly, the prevalence of chronic illness among children and adolescents is expected to continue to increase (Capurso & Dennis, 2017).

The increased prevalence of childhood chronic illness is of consequence to our education system. These children have the same right to education as their healthy peers (Education Act 1989; Human Rights Act 1993). However, previous research has identified a number of common consequences of chronic illness that can inhibit these youngsters from accessing the educational opportunities to which they are entitled (Crump et al., 2013; Lum et al., 2017). For example, children who are chronically ill are often absent from school and this can present challenges to academic continuity and social connectedness (Joe, Joe, & Rowley, 2009). Some illnesses, or their treatments, can directly impair emotional and cognitive functioning (Joe et al., 2009), and other illnesses have comorbid behavioural concerns (Kadan-Lottick et al., 2010). If the additional needs of children with chronic illnesses are not acknowledged and accommodated in an educational context, these children are at risk of significant social, emotional, and academic difficulties, which can have life-long consequences (Crump et al., 2013; Quach & Barnett, 2015).

To help mitigate these risks, research suggests that it is important for children with chronic illnesses to have knowledgeable and understanding teachers to support them on their learning journey (Lum et al., 2017). Teachers who are aware of a child's illness and are cognizant of the potential impact of the illness on school functioning can contribute positively to the child's sense of belonging, academic success, and social

¹ Denny et al.'s (2014) definition of *chronic health* included long-term disability.

integration (Hamon, 2015). On the other hand, young people with chronic illnesses have reported dissatisfaction with teachers who have inadequate knowledge of the potential educational impact of their medical conditions (P. Ferguson & Walker, 2014; Hamon, 2015; Wilkie, 2012). Concerns include that some teachers lower their academic and social expectations of these learners and focus only on supporting their medical needs. This can frustrate a chronically ill young person whose priorities are to keep up and fit in at school (Hamon, 2015). Other young people have shared concerns about teachers who assume that when they are present in the classroom with no acute signs of illness they are well enough to participate fully (Hamon, 2015). If teachers do not take account of the effects that sequelae such as fatigue and pain can have on learning, this can make youngsters with chronic illnesses feel unheard and belittled, and it can contribute to educational disengagement (Hamon, 2015; Lum et al., 2017).

It is therefore of significant concern that international research has found many teachers do not have sufficient knowledge of the implications of chronic illness in an educational context (Hinton & Kirk, 2015). Studies conducted in a range of countries including the United States (Nabors, Little, Akin-Little, & Iobst, 2008), the United Kingdom (Mukherjee, Lightfoot, & Sloper, 2000), and Australia (Shiu, 2004) have consistently reported that teachers receive little formal education with respect to chronic illness and that teachers would benefit from more knowledge to enable them to provide an equitable educational experience for these children. Further, research that has foregrounded the teacher experience has found that teachers' best efforts to support the complex needs of children with chronic illness can be curtailed by a lack of time, inadequate funding, and partial teacher supports (Cousins & DeLuca, 2016; Flanagan,

2015; St Leger, 2014). Within these contexts, teachers have described the experience of working with children who are chronically ill as a challenge for which they need more recognition and guidance at a policy level (Flanagan, 2015; St Leger, 2014).

To date, this issue has received limited research attention in a New Zealand context. There is a paucity of academic literature that has considered New Zealand teachers' role in meeting the complex needs of these children, particularly at a primary school level. For example, in the review of the literature in the next chapter, the majority of research is based on international work apart from two key exceptions involving recent New Zealand-based studies (Denny et al., 2014; Hamon, 2015). While the existing international literature can provide some guidance on how best to prepare and support teachers for this aspect of their role, there needs to be an exploration of this area of professional practice within a local context. Not attending to this issue is contrary to the National Education Goal of achieving equal educational opportunities for all learners through the identification and removal of barriers to success (MoE, 2004).

Thus, the purpose of the current study is to explore New Zealand primary school teachers' preparedness and experiences when working with children who have a chronic illness. It sets out to provide an overview of teachers' professional preparation in this area; to better understand the teacher experience; and, to gain practitioner-led recommendations on how teachers can best prepare for and work with these children. It is beyond the scope and purpose of this study to evaluate teachers' preparation through a review of existing teacher education programmes or through observing teachers' practice in working with children with chronic illnesses. Rather, the focus is on understanding teachers' subjective experiences.

The following research questions guide the study:

1. How well prepared do New Zealand primary school teachers feel to teach children with chronic illnesses?
2. What have been New Zealand primary school teachers' experiences of teaching children with chronic illnesses?
3. How have these experiences shaped teachers' understanding of how best to support the learning needs of children with chronic illnesses?

To answer these questions, a mixed-methods design is adopted, drawing on both quantitative and qualitative data and foregrounding teacher voice. The research design involves a nation-wide survey followed by in-depth interviews with a purposive sample of experienced teachers. This mixed-methods approach enables both the breadth and complexity of the issue to be explored, providing a useful starting point in the absence of an established local evidence-base. The specific focus on teachers of primary-school-age children enables the current study to build on the existing international literature in which the voice of secondary school teachers has so far taken precedence.

This thesis is organised into six chapters. Following this introduction, chapter two explores recent literature concerning teachers' role and readiness to support the diverse needs of young people with chronic illness. Chapter three outlines and provides justification for the two-phased, mixed-methods approach that was adopted in this study. In chapter four, the results of Phase I and Phase II are presented separately. Chapter five integrates and discusses the findings of both phases alongside the extant literature. The sixth and final chapter acknowledges the limitations of this study, provides recommendations for practice and policy, and makes suggestions for future research.

Chapter 2

Literature Review

All children have a right to education and to learn alongside their peers from knowledgeable, well supported teachers. However, for children who are chronically ill, their distinct health issues may adversely affect their participation and success in school. These children have unique special education needs and can face potential inequalities in their educational experience when compared with their healthy peers. To help mitigate this, it is important that teachers understand how best to support the academic, social, and emotional development of these children while also attending to their physical wellbeing. This chapter reviews the literature regarding the education of children with chronic illness, including research that has explored teachers' preparedness and experiences in supporting the learning journey of these children. With two exceptions (Denny et al., 2014; Hamon, 2015) the literature reviewed in this chapter reports on international findings. Recent New Zealand-based evidence with respect to the education of children with chronic illness is sparse, particularly at a primary school level.

An important first step is to identify the scope of chronic illness with regards the current study. Given there are numerous different definitions of chronic illness in the literature (Jackson, 2013), it is not surprising that there is no universally agreed-upon operationalisation of the term (Martinez, Carter, & Legato, 2011). Generally, though, it refers to medical conditions that persist or recur over a long period of time, impair daily functioning, and necessitate ongoing medical intervention (Martinez et al., 2011). This definition encompasses a diverse range of diseases, including diabetes, epilepsy, and

asthma. While their symptoms can be managed, most chronic illnesses are not currently curable (McKenna & Collins, 2010), and their disease-course tends to be unpredictable with erratic periods of remission and exacerbation (Dailey, 2010). Chronic illnesses are distinct from *acute illnesses*, such as influenza, which are intense but short-lived and tend not to have lasting implications for a person's health status and lifestyle (Shiu, 2001).

A subtler distinction exists between the term chronic illness and *chronic condition*. Although the two are often used interchangeably in the literature (Martinez et al., 2011), the latter is a broader term, which also covers long-term mental health concerns and physical disabilities (National Health Committee, 2007). These two terms are used intentionally throughout this chapter to distinguish the types of conditions included in any given study. The current research is concerned with the narrower of these two terms, focusing primarily on physical illnesses. Behavioural concerns (e.g., autism spectrum disorder), mental health concerns (e.g., depression), and physical or sensory disabilities (e.g., deafness) are not considered chronic illnesses in this study.

The current study takes a non-specific approach. It considers teachers' preparation and experience across a range of chronic illnesses, rather than looking at a specific illness in isolation. A non-specific approach, looking at trends across illnesses, is thought to have more practical relevance when considering the social and psychological implications of ill health (Stein & Jessop, 1989), and it is intended to support the transferability of findings to a wide range of teachers (Forrest, Bevans, Riley, Crespo, & Louis, 2011). Unless explicitly stated, the research reviewed in this chapter has also taken a non-specific approach. However, the systematic reviews or

meta-analyses that are referenced in this chapter have summarised findings from both illness-specific and non-specific literature.

Chronic Illness in an Educational Context

Prior research has established that children and young people with chronic illnesses can experience significant challenges within an educational context (Crump et al., 2013; Forrest et al., 2011; Lum et al., 2017). For a child, having a chronic illness does not preclude educational success, however, research has identified a number of common consequences of chronic illnesses that can compromise these children's academic success and social connectedness. This section provides a brief summary of findings from the extant literature.

A key educational issue for children with a chronic illness is their need to be away from the classroom for frequent or extended periods of time (Crump et al., 2013; Jackson, 2013; Lum et al., 2017). A recent meta-analysis (Lum et al., 2017) identified 12 literature reviews covering 88 original articles that had examined the relationship between chronic illness and school attendance. Eighty-two of the original articles reported lower attendance among young people with chronic illness when compared with healthy peers. Being absent from class can have significant implications for the academic performance of children with chronic illness (Flanagan, 2015; C. Kearney, 2008; Lum et al., 2017). These young people need to spend time catching up on schoolwork rather than keeping up with the rest of the class (Shiu, 2001). In turn, research suggests that this can cause anxiety, which may further inhibit academic work (Flanagan, 2015; Lum et al., 2017). In the longer-term, absenteeism is correlated with academic failure and increased rates of school dropout (C. Kearney, 2008).

Another issue for children and young people with chronic illness is that they can struggle to make and maintain constructive peer relationships (Lum et al., 2017; Martinez et al., 2011; Pinqart, 2017). There are accounts in the qualitative literature of young people with chronic illness being teased or bullied by their school peers (Lum et al., 2017), and this qualitative data has been substantiated with quantitative evidence. A recent systematic review reported that young people with chronic conditions were more likely than their healthy peers to be victims of physical, relational, verbal, or cyber-bullying, and illness-specific teasing (Pinqart, 2017). In a meta-analytic review of 57 quantitative studies, Martinez and colleagues (2011) reported decreased social competence² among children and adolescents with chronic illness when compared with healthy peers.

There is some New Zealand-based evidence with regards the association between chronic illness and negative peer interactions (Hamon, 2015). Four young men who participated in a recent qualitative study – which is discussed in more detail later in this chapter – recalled having been bullied in their primary school years. These boys were subject to name-calling and physical torment because their chronic condition meant that they looked different or learned differently to their peers. Hamon reported that this experience had had a negative impact on the boys’ learning and wellbeing. Another New Zealand-based study used self-report survey methodology to explore the association between chronic conditions and social-emotional functioning among 9,107 secondary school students (Denny et al., 2014). In this study, eight percent of adolescents with a chronic condition reported challenges socialising with peers (Denny

² Social competence is broadly defined as “the quality of social interactions with other children” (Martinez et al., 2011, p. 879).

et al., 2014). In turn, poor self-reported socialisation was significantly related to self-reported depressive symptoms (Denny et al., 2014).

Also of concern in an educational context is that some chronic illnesses or their treatments disrupt children's cognitive functions such as attention, concentration, and memory (Forrest et al., 2011; Jackson, 2013; Lum et al., 2017). For example, fatigue is a symptom that is common across many childhood chronic illnesses, and it can have subtle yet significant cognitive implications (Forrest et al., 2011; Jackson, 2013). Fatigue can impair students' attention and memory, which are both critically important to academic success (Commodari, 2012). If fatigue and other cognitive implications are not identified and managed in an educational context, they can contribute to academic disengagement and underachievement (Lum et al., 2017; Power, 2006).

Research has also found childhood chronic illness to be associated with children internalising and externalising behaviours that further compromise their school engagement and success (Lum et al., 2017). Although there exists disease-specific variation, chronic illness has been found to be associated with aggression (Lum et al., 2017; Pinquart, 2017), withdrawal behaviour (Lum et al., 2017), depressive symptoms (Denny et al., 2014; Pinquart & Shen, 2011), and disruptive behaviour (Forrest et al., 2011). When these maladaptive classroom behaviours co-occur with chronic illnesses, they can present barriers to participation and engagement and may exacerbate misunderstandings about the child with chronic illness, further compromising teaching and peer relationships (Wodrich & Cunningham, 2008).

Lastly, children with chronic illnesses are at risk of underachieving, academically (Lum et al., 2017). School attendance (Crump et al., 2013; C. Kearney,

2008), peer relationships (Moses & Villodas, 2017; Mundy et al., 2017), cognitive functioning (Power, 2006), and classroom behaviour (Forrest et al., 2011) can all have implications for academic engagement and success. It is therefore unsurprising that the literature has identified a risk of poor academic outcomes among young people with chronic illnesses (Lum et al., 2017). Lum et al.'s (2017) meta-review identified 17 literature reviews covering 63 original articles that had examined the relationship between chronic illness and academic outcomes (e.g., academic performance, repetition of a year level, and educational attainment). Thirty-one of the 63 original articles reported poorer academic outcomes among children who have a chronic illness when compared with healthy peers or population norms.

Importantly, the relationship between chronic illness and school functioning appears to be complex. Research has found that there is not a direct relationship between chronic illness and the aforementioned adverse educational outcomes (Lum et al., 2017). A range of illness-related, school-related, psychosocial, and socio-demographic factors are thought to mediate the relationship between chronic illness and poor school outcomes (Lum et al., 2017). This accounts for the fact that some studies have reported that children with chronic illness achieve the same or better academic and social outcomes when compared with their healthy peers (e.g., Dieluweit et al., 2011; Mackner, Bickmeier, & Crandall, 2012). As Lum et al. (2017, p. 43) argues, these positive findings are evidence that children living with chronic illness should be able to access the same educational experiences and outcomes as children without a chronic illness, as long as they are provided with adequate health, academic, and social support. To achieve this, we need to identify and address the factors that mediate the relationship between chronic illness and school outcomes (Lum et al., 2017).

Young People with Chronic Illness and Their Interactions with Teachers

Teachers' knowledge and attitudes toward children with chronic illness have been identified as an important mediating factor in the relationship between chronic illness and school outcomes (Hinton & Kirk, 2015; Lum et al., 2017). In fact, Lum et al.'s (2017) suggest teachers' knowledge and attitudes may be the most important modifiable factor in achieving academic and social success for these learners. To further explore the role of teachers, this section reviews recent research that has foregrounded the student experience, paying particular attention to the way in which these young people describe their interactions with teachers. The stories that have been shared in these studies demonstrate the importance of having teachers who are knowledgeable, not only of the health needs of children with chronic illness but also the broader implications for learning and peer relationships in an educational context.

Of particular relevance to the current study are the findings of a recent New Zealand-based Interpretative Phenomenological study that was introduced earlier in this chapter (Hamon, 2015). Hamon's (2015) doctoral study used interviews ($N = 9$) and focus groups ($N = 20$) to explore the school experiences of adolescents (aged 12–19 years) with chronic conditions. Participants in Hamon's study spoke of physical, cognitive, and psychosocial challenges to their learning. These included pain, fatigue, and difficulties concentrating. Of concern, some of these young people found their classroom teachers to be unsupportive or even sceptical of their additional learning needs:

[S]tudents were in class suffering pain, fatigue, an inability to concentrate and found their learning was made more difficult

when teachers assumed they were well because they were in the class or did not appear ill. (Hamon, 2015, p. 173)

Hamon reported that these young people felt their teachers had dismissed their individual learning needs, and this had negatively impacted the students' self-esteem, trust in teachers, and engagement in learning. On the other hand, teachers who were knowledgeable and considerate of these students' illnesses and additional needs, contributed positively to the young people's sense of wellbeing and success in school. Based on her findings, Hamon asserted that teachers in New Zealand require further training with respect to meeting the school-based needs of learners who are chronically ill.

Similar findings have been reported in recent student voice literature from Australia (P. Ferguson & Walker, 2014; Wilkie, 2012). As an example, P. Ferguson and Walker (2014) present findings from the *Keeping Connected* study, a longitudinal research project in Australia that followed the educational journey of 31 adolescents (10–18 years old). The study drew on ethnographic and linked case study methodologies and followed these young people over the course of three years. Findings revealed a common dilemma among participants. On the one hand, these adolescents shared a strong desire to be perceived as 'normal' and not singled out within the school context. At the same time, participants in this study wanted their teachers to realise that they had additional learning needs that set them apart from their peers. Some of these students had received "haphazard or inappropriate" (P. Ferguson & Walker, 2014, p. 238) supports at school that created further barriers to academic success and social inclusion. Other students had teachers who understood the young person's need to be 'normal' yet

also treated differently. These more understanding teachers contributed to the youngsters' self-reported sense of connectedness and worth.

In another Australian study, Wilkie (2012) conducted a collective case study with 11 secondary school students with chronic illness and their mathematics teachers. The study explored how these young people and their teachers experienced their interactions with one another during the students' prolonged absence from school for medical treatment. Findings were that all of the young people prioritised *academic continuity*. This meant having contact with their own classroom teacher and continuing with the same schoolwork as their classmates. However, teachers were hesitant to initiate contact with these young people because they thought these students should be focusing on their health and not worrying about mathematics. In discussing these findings, Wilkie suggested teachers need to recognise that the needs of children with chronic illnesses are different to those who experience acute illnesses. When an individual has an acute illness, they typically assume the "sick role" (Wilkie, 2012, p. 10). It is socially acceptable for acutely unwell individuals to be exempt from their normal duties so that they can focus on their recovery (Wilkie, 2012). However, for individuals whose illness is long-term, the goal is often not recovery but learning to live well despite their illness (Wilkie, 2012). Therefore, taking time out from normal activities such as school may not be a priority for individuals with chronic illness (Wilkie, 2012). Wilkie concluded more needed to be done to build "teachers' knowledge, confidence and ability to support the increasing numbers of young people with chronic illness" (2012, p. 17).

A limitation of this student voice literature is that it has only captured the voice of older children and adolescents (i.e., children 10–19 years). The perspective of younger children is less evident in the literature on childhood chronic illness in general (Carter et al., 2017) and is particularly sparse in the literature exploring these youngsters' educational experience. As a proxy measure of the experience of younger children, parents of children with a chronic illness have been surveyed (Shiu, 2004) and interviewed (Hewitt-Taylor, 2009) with regards their children's schooling. Findings from these studies align with the student voice data already cited in this section, highlighting the importance of having knowledgeable and supportive teachers. For example, in the United Kingdom (UK), Hewitt-Taylor (2009) conducted semi-structured interviews with 14 parents of children with chronic conditions aged 18 months through 18 years. Participants reported challenges in accessing equal educational opportunities for their children. Perceived barriers included teachers' attitudes and confidence in working with these children and a lack of clarity over teachers' responsibilities. Hewitt-Taylor suggested there needs to be greater recognition among teachers that students with chronic illness may need – and are entitled to – special accommodations to help them achieve their academic and social potential.

Teachers' Preparedness to Teach Children with Chronic Illnesses

Recognising the important part that teachers play in supporting the needs of young people who are chronically ill, international researchers have measured the extent to which teachers are professionally prepared for this aspect of their role (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Nabors et al., 2008; West, Denzer, Wildman, & Anhalt, 2013). These studies tend to use cross-sectional, self-report surveys to examine teachers'

training, knowledge, attitudes, and confidence with respect to meeting the complex needs of these children. Such studies have consistently reported inadequacies in teachers' preparedness. This section details the methodological approach and relevant findings of studies in this area.

Although published 14 years ago, Clay and colleagues' (2004) study remains one of the more widely cited in the extant literature regarding teachers' preparedness to teach children who are chronically ill. Four hundred and eighty school staff from the United States (US) were surveyed with respect to their training and experience working with these children. The majority of participants (87.4%) were classroom teachers, however counsellors (4.6%), administration and support staff (2.9%), and other school personnel (2.1%) also comprised the sample. Fifty-nine percent of the participants reported having no academic training to prepare them to work with children who are chronically ill, and only 36.1 percent had undertaken formal workplace training on this matter. This lack of teacher training is consistent with earlier findings from the US (Johnson, Lubker, & Fowler, 1988), the UK (Mukherjee et al., 2000), and Israel (Brook & Galili, 2001).

Another study examined the relationship between teachers' knowledge and confidence in meeting the needs of children with chronic illness (Nabors et al., 2008). Nabors and colleagues (2008) surveyed 247 regular ($n = 193$) and special education ($n = 54$) teachers from elementary schools in the US. Participants rated their knowledge and confidence in meeting the academic and social needs of children with 13 relatively common chronic illnesses. Results found that self-reported knowledge was low overall, although, teachers rated their knowledge as higher for more common illnesses such as

asthma and diabetes when compared with less common conditions such as arthritis and renal failure. An unexpected finding was that teachers' confidence in meeting the academic and social needs of these children was not parallel to their self-reported knowledge. Teachers tended to rate their confidence as higher than their knowledge, although confidence was still low overall. Nabors et al. suggested that teachers' previous experience may have impacted upon their self-reported confidence levels, however, this relationship was not explored statistically.

More recently, in the US, West et al. (2013) used survey methodology to examine 140 elementary school teachers' knowledge and confidence in meeting the needs of children who have a chronic illness. Consistent with Nabors et al.'s (2008) earlier findings, teachers' self-reported knowledge was low overall, although it varied across the seven health conditions that were included in the study. Knowledge was again higher for more common illnesses, such as asthma and diabetes than for less common illnesses, such as heart disease and HIV/AIDS. West et al. also examined teachers' willingness to implement accommodations for these children. Teachers were less willing to implement accommodations if they perceived those accommodations to be burdensome. Examples of accommodations that were rated as burdensome included allowing missed class time for specialist services and informing children with chronic illnesses of missed assignments. West and colleagues suggested that teachers' perceptions of burden reflected both their knowledge and their prior experience.

Notably, the three studies reviewed thus far were all conducted in Midwestern states in the US (Clay et al., 2004; Nabors et al., 2008; West et al., 2013). While teachers' preparedness to work with young people with chronic illness has been

explored in other settings, these studies are either out-dated (e.g., Brook & Galili, 2001; Johnson et al., 1988) or have taken an illness-specific approach (e.g., Thacker, Verma, Ji, Thacker, & Mishra, 2008). A narrative review of the wider international literature has been conducted (Hinton & Kirk, 2015). Hinton and Kirk (2015) reviewed 58 studies published in English peer reviewed journals from 2003 to 2013. This included studies from Africa, North America, South America, Asia, Australia, and Europe. The review found three key areas in which teachers needed further preparation: (1) supporting the healthcare needs of children with chronic illness - that is, monitoring symptoms, providing treatment and responding to medical emergencies; (2) understanding the effect that a chronic illness, or its treatment, can have on learning; and, (3) knowing what accommodations children with chronic illnesses need in the classroom. Hinton and Kirk concluded that addressing the deficits in teachers' professional preparation is "crucial" to ensuring that children with chronic illnesses have access to appropriate support at school (2015, p. 108).

The Teacher Experience

Missing from the aforementioned literature on teacher preparedness is the voice of teachers. These studies have relied largely on closed-ended survey responses that limit the opportunity for teachers to share their experiences in working with children who have a chronic illness. This quantitative approach can oversimplify a complex issue of professional practice, and it can "drown out a sense of the participants as people with opinions that have relevance to what should happen next" (Yates, 2014, p. 287).

Teacher voice has been captured elsewhere in the literature. Several recent international studies have used case study methodology (Wilkie, 2012) and in-depth

interviews (Cousins & DeLuca, 2016; Flanagan, 2015; St Leger, 2014) to gain insight into the experience of teaching children and adolescents with chronic illness. By using methodological approaches that foreground the teacher experience, these studies present an authentic voice of teachers and enable the researcher to better understand the complexity of teaching children with chronic illness. These more nuanced insights into the experience of working with children with chronic illness are critical to designing professional development opportunities, resources, and supports for teachers that have contextual fit (Harn, Parisi, & Stoolmiller, 2013).

Taking an Interpretive Phenomenological approach, Flanagan's (2015) doctoral thesis explored the experience of six high school teachers in the US who were responsible for educating young people with chronic illnesses. Flanagan reported that the teachers were each attempting to address the needs of these young people as best they could with varying levels of training and experiential knowledge to draw upon. The six teachers had questions and concerns that were not being addressed, and they expressed frustrations that systematic and organisational factors prevented them from doing the best for these young people. Supporting these adolescents on their learning journey was at times "emotionally taxing" (Flanagan, 2015, p. 76) for these teachers, and Flanagan perceived a sense of helplessness in some of the interviews.

Wilkie's (2012) collective case study, which was summarised earlier in this chapter with regards student voice, also explored the experience of classroom teachers ($N = 11$). Wilkie (2012) wanted to know what concerns teachers had about the young people's learning and how teachers perceived their interactions with these students during absences. A key issue for teachers in Wilkie's study was uncertainty over their

role and responsibility in supporting these learners. Participants reported being unsure whether to “be the teacher” or to focus on providing social and emotional support (Wilkie, 2012, p. 14). All teachers in Wilkie’s study commented that their efforts to support their students’ academic continuity had been impeded by the fact that schools did not provide teachers with necessary supports such as additional release time. Because of ambiguity in their role, other workload pressures, and little guidance or infrastructure to support them, teachers in Wilkie’s study reflected that they might have underserved the needs of these learners.

In another Australian study, St Leger (2014) interviewed two teachers along with ten other school staff members (e.g., principals, student welfare staff, and management staff) who had been involved in supporting the learning of young people aged 10–19 years with a chronic illness. These educators reported a family-centred approach to their practice and a commitment to the full inclusion of these students. However, as with teachers in Wilkie (2012) and Flanagan’s (2015) studies, the educators that St Leger interviewed reported that their attempts to support their students’ inclusion were often hampered by a lack of organisational supports and resources. St Leger noted that, despite their best efforts, participants felt that their students had been let down by a service provision that is guided by medical and disability discourses which do not prioritise funding to support the young person’s educational needs.

Of note, the studies cited so far in this section have largely captured the perspectives of teachers of adolescent-aged students (>10 years). The literature search through to June 2017 returned only two studies published within the previous five years that used qualitative methodologies to explore primary school teachers’ experience of

educating a child with a chronic illness (Boden et al., 2012; Cousins & DeLuca, 2016). These studies had an exclusive focus on teachers of children with diabetes, and they were concerned primarily with teachers' knowledge and confidence in meeting the medical needs of these learners. Clearly, there is a need for specific qualitative research exploring teachers' experience in supporting the learning needs of primary school-age students with a chronic illness.

The Current Study

In summary, children living with chronic illness are entitled to participate, belong, and experience success in education alongside their peers. However, the extant literature has established that these children can encounter significant barriers along their learning journey. The literature further suggests that these challenges can be exacerbated when teachers are underprepared and inadequately resourced to meet the additional learning needs of these children.

Little is currently known about New Zealand teachers' preparedness in working with children who have a chronic illness, particularly at a primary school level. That this issue has received limited scholarly attention in a local context is at odds with the spirit and objectives of New Zealand's inclusive education system and it needs addressing if we are to achieve true inclusion for these learners. To contribute to this gap in the literature, the current study considers New Zealand primary school teachers' preparedness to teach children who are chronically ill. It looks at the nature and extent of the formal and informal training and supports that are available to teachers with regards these learners. The study also explores the teacher experience and it asks teachers who have practical knowledge in this area for their advice on how they and

their colleagues can best meet the needs of these learners (see Chapter 1, p. 5 for research questions).

Methodologically, the current study departs from trends in the extant literature. This topic has typically been explored from either a quantitative or a qualitative perspective. However, the current study adopts a mixed-methods approach. By drawing on the strengths of both research traditions, this study is able to explore both the breadth and depth of this issue within a local context. This provides a valuable starting point from which to leverage more focused research in the future. Further, by emphasising teacher voice, the current study ensures that teachers have a say in the way forward for this area of their professional practice. Finally, by capturing the voice of primary school teachers the current study contributes to the qualitative international literature in which the experience of secondary school teachers has so far taken precedence. The next chapter provides further detail with respect to the methodological approach to this study.

Chapter 3

Methodology

This chapter presents the mixed-methods approach that was employed to contribute to an understanding of New Zealand primary school teachers' preparation and experience in teaching children with chronic illnesses. In this chapter, the ontological, epistemological, and methodological assumptions that underpinned this study are made explicit. This is followed by a description and justification of the mixed-methods sequential explanatory design that was used. The target population is identified followed by details of the sampling procedures, data collection, and approach to data analysis employed in each phase. Consideration is given to the methodological quality of this study and selected ethical issues are discussed.

Research Paradigm

Ontological and epistemological perspective

I approached this study from an interpretivist perspective. As an educational psychology student, I am interested in how people make sense of the world within which they live, work, teach, and learn. I accept that there can be multiple contradictory yet equally valid accounts of the same social phenomenon (D. L. Ferguson, 1993), and I am interested in understanding how contextual factors contribute to diversity in our lived experiences. In this study, my intention is to understand, from teachers' own perspectives, the experience of teaching children with chronic illness. I also want to understand how teachers' access to training, information, and other resources have shaped their understanding of how best to support these learners. This approach

contrasts with a positivist paradigm which seeks to uncover universal truths about the social world (Punch, 2014).

Taking an interpretivist stance, I must reject the positivist notion that I can remain objective and dissociated from the social phenomenon that I am studying (Lincoln & Guba, 1986). Instead, I acknowledge, as an inevitable and valuable part of the research process, the reciprocal influence that the participants and I have on one another (Lincoln & Guba, 1986). I bring my own histories and perspectives to the research, and these impact on the types of questions that I set out to answer, how I ask these questions, and how I analyse responses to these questions (D. L. Ferguson, 1993). It follows that the findings derived from this study are provisional and context-bound. They are a co-construction of my and the participants' understanding of the joys, challenges, and opportunities for improvement with respect to this area of teaching practice. I do not claim the findings to be objective truths.

Methodological perspective

While interpretivist research is often associated with qualitative methodologies, the two are not synonymous. It has long been argued that interpretivism should not be considered anti-quantitative (Crotty, 1998; Lincoln & Guba, 1986; Schwandt, 1998). Guba and Lincoln (1981) said “there is no reason why both camps [positivism and interpretivism] should not exploit both quantitative and qualitative techniques” (as cited in Lincoln, 2010, p.7). While, our philosophical paradigm guides the types of questions that we might ask and the types of responses that we might judge sufficient to answer these questions (D. L. Ferguson, 1993), it is the research questions and not the paradigm per se, that should drive the choice of research method (Schwandt, 1998).

For this study, a mixed-methods approach is most appropriate as it enables researchers to engage with both quantitative data and qualitative data, integrates the two, and then draws inferences based on the combined data sets (Creswell, 2014). The underlying assumption of mixed-methods research is that both quantitative and qualitative approaches have their strengths and limitations, and that combining the two contributes to a better understanding of the research problem than can be achieved from either approach alone (Creswell, 2014; Venkatesh, Brown, & Bala, 2013). A mixed-methods approach was necessary for my study because there is a paucity of local literature on the topic, and I wanted to explore both the nature and extent of the issues in a New Zealand context. I want to identify general trends gathered from primary school teachers nationwide so that there is numerical weight to my findings. However, quantitative data is devoid of the type of contextual information that is invaluable for translating results into practical recommendations. To obtain this more nuanced information, I need to hear teachers' individual, context-rich stories. To achieve each of my objectives then, I need to draw on both the quantitative and qualitative research traditions, and so a mixed-methodology is required.

Research design

The design of mixed-methods studies is dependent on the research purpose. In this study, I employed a mixed-methods approach for both completeness and expansion (Venkatesh et al., 2013), and I achieved this by using a modified sequential explanatory design. A sequential explanatory design involves two phases. Typically, an initial quantitative phase is followed by a qualitative phase (see Figure 1). The quantitative results take precedence, and they are used to guide the selection of a subsample of

participants to follow-up with in an in-depth, qualitative investigation. The qualitative data is then used to explain or elaborate on the quantitative findings (Creswell, 2015).

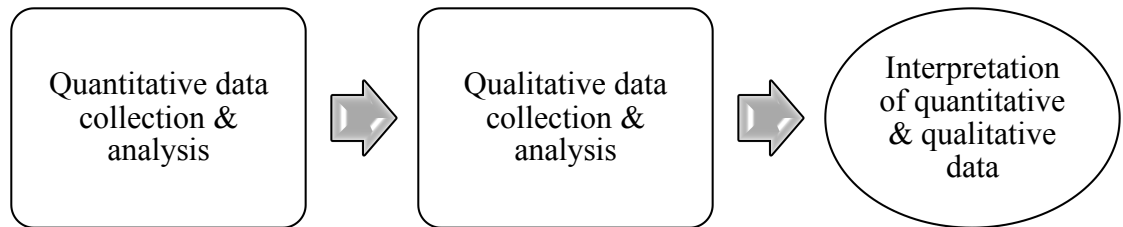


Figure 1. Typical mixed-methods sequential explanatory design (adapted from Creswell, 2015, p.39)

The specific research design used in this study differed from a typical sequential explanatory design because the first phase involved the collection of both quantitative and qualitative data (see Figure 2). This increased the opportunity for teachers to respond in their own words, providing a more complete picture of the teacher experience than can be gleaned from quantitative data alone. In this first phase, a national survey was used and this was supplemented with more in-depth qualitative data from semi-structured interviews with a subgroup of the survey participants.

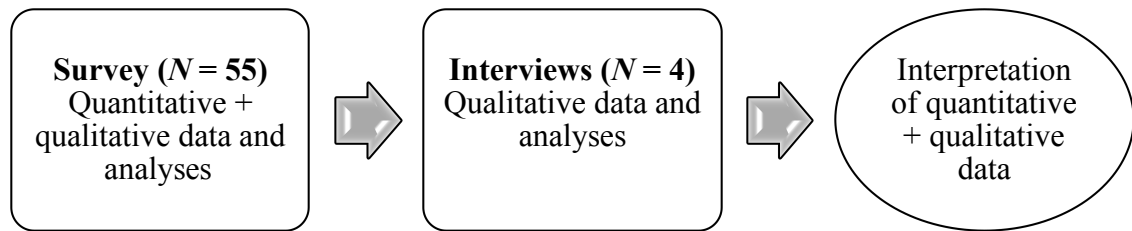


Figure 2. Specific mixed-methods design employed in this study

Target Population

The target population was New Zealand primary school teachers (i.e., teachers of Year 1 through to Year 6 students). My decision to limit the target population to primary school teachers was guided by several considerations. First, the literature suggests that the cognitive, social, and emotional challenges that are associated with chronic illness can vary depending on the developmental stage of the child (Sawyer et al., 2007). Limiting the inquiry to teachers of children in a specific age-bracket allowed deeper insight into the experience of teaching chronically ill children at that age. Second, the professional training and in-school resources that are available to teachers varies by sector, so limiting attention to teachers working within one sector allowed for a more focused exploration of the issues related to teacher preparedness within that context. Third, the extant qualitative literature has largely focused on secondary school teachers. Thus, I was able to extend on the international evidence-base by foregrounding the voice of primary school teachers.

Phase I: The Survey

This section outlines Phase I of the current study. In this first phase, New Zealand primary school teachers were surveyed using a self-administered, online questionnaire.

Online questionnaires are becoming increasingly prevalent in research, and this is driven in large part by considerations of cost, efficiency, and participant experience (Fowler, 2014). These factors influenced my decision to use a questionnaire for the purpose of this study. It allowed me to gather data from a range of participants ($N = 55$) throughout New Zealand over a relatively short period of time. Since the questionnaire was web-based, the response data was available to me almost instantaneously, saving time, and avoiding the potential inaccuracies or biases that can occur when a researcher inputs paper-based questionnaire responses into data analysis software (Lefever, Dal, & Matthiasdottir, 2007). Another advantage of online questionnaires is that they allow participants to complete the questions when it is convenient to them (Fowler, 2014).

There are several disadvantages of online questionnaires. For example, they can impact on the sample quality since they limit participation to those with access to the internet, and since it is not possible to verify who is answering the questions (Fowler, 2014). Questionnaires are also restricted in terms of the depth of information that can be gathered, and the researcher is not able to probe for further information or clarity (Fowler, 2014). For this study, these potential disadvantages were minimal and were offset by the advantages that an online questionnaire offered in gaining insight from a broad range of teachers from across New Zealand. It was reasonable to expect that the target population would have access to the internet given its widespread use in New Zealand education settings (Ministry of Education [MoE], 2015a). The issue concerning the limited depth of information that can be gained from a questionnaire was addressed by having the second phase of the study.

Phase I data collection

The choice of software is an important consideration in the development of an online questionnaire. I explored SurveyMonkey, Qualtrics, and SoGoSurvey as possible online platforms for hosting the questionnaire because of positive feedback these platforms had received in recent comparative reviews (Capterra, 2017; PCMag, 2016). After reviewing all three, SurveyMonkey was chosen given my previous professional experience with this tool where I found it to be the most user-friendly of the three platforms, both for myself as the researcher and for participants.

The online questionnaire was developed specifically for the purpose of this research. This was necessary because existing questionnaires that have explored this research topic in other countries are not wholly relevant within a New Zealand context, nor do they address the exact research questions that this particular study set out to address. I developed the questionnaire in consultation with my research supervisors, and the content was informed by the extant literature on teachers' preparedness to teach children with chronic illnesses; a review of questionnaires and interview schedules used in related studies (Barracough & Machek, 2010; Clay et al., 2004; Flanagan, 2015; Shiu, 2004); and, discussions with colleagues in education. It was also informed by the national prevalence rates for childhood chronic illnesses.

A first iteration of the questionnaire was pilot-tested to check the functionality of the questionnaire and to ensure that the questions were valid and meaningful within a New Zealand context. The pilot testers were a convenience sample of four teachers and two non-teachers. Pilot participants were asked to provide feedback on the length of the questionnaire as well as the content and layout of the questions. One pilot participant

made specific comments about the clarity of some questions and these were adjusted for clarity.

The number of items in the questionnaire did not change between the pilot and the final version. In total, there were 28 questions that solicited a range of closed- and open-ended responses (see Appendix C). The first section gathered non-identifying demographic information about the respondents and the schools that they worked at. Other sections asked about respondents' training, knowledge, attitudes, experience, and approach to practice with respect to teaching children with chronic illnesses.

Phase I sampling procedure

Phase I used a non-probabilistic sample. In August 2017, 1,903 schools across New Zealand were sent an email inviting teachers of students in Year 1 through to Year 6 to participate in the survey (see Appendix D). These schools were identified using the Education Counts (2017a) school directory, which provided a list of 2,532 schools that had agreed to have their contact details publically advertised. Because of the target population for this study, only the following school-types were sent the invitation: Composite (Year 1-10), Composite (Year 1-15), Contributing, Correspondence, Full Primary, and Special School. The invitation email was addressed to school principals, and it provided a brief introduction to the research as well as a link to the Information Sheet (see Appendix E) and the questionnaire itself. The email invited principals to forward the invitation to their teaching staff. Teachers who received the email from their principals were able to self-select into the study.

Three weeks after the initial email, a reminder email was sent in order to solicit further responses. At this time, the research was also advertised in the Education Gazette

magazine, which is distributed to teachers nationwide, in print and online (see Appendix F). Since the number of teachers who read either the email or the advertisement is unknown, it is not possible to calculate a true response rate for Phase I.

Phase I data analysis

The survey data was exported from SurveyMonkey in two formats to facilitate data analysis. Response data from individual questions were exported into separated Portable Document Format (PDF) files, and all response data was exported into a single Excel file. No identifying data was included in the PDF files, however, if participants had provided an email address for the purpose of a follow-up interview, these personal identifiers were downloaded into the Excel file. These email addresses were removed and substituted for a unique code, so all survey data was anonymised during the analysis.

Quantitative data was converted to valid percentages by SurveyMonkey. This means that when there is missing data, or teachers have not responded to a particular item, the percent is based on only those responses received, and missing data are excluded from the calculations. SurveyMonkey provided percentages rounded to two decimal places. Since these percentages pertain to people, they were rounded to the nearest whole number. Decimal points of 0.50 and above were rounded up, and decimal points of 0.49 or below were rounded down. It is these rounded, valid percentages that have been reported in the results chapter. Where appropriate, percentages have been presented graphically to provide an accessible summary of the response data.

Qualitative survey data was analysed thematically. I first became familiar with the data through reading and re-reading the PDF documents, without making notes or highlighting. Next, I highlighted phrases, sentences, or whole sections of text and labelled

them with initial codes. These codes were later used to develop broader themes which were named and defined. Lastly, the data coded to each theme was reviewed to ensure it fit with the refined theme. Some pieces of text were coded to more than one theme and some participants made more than one comment that were coded separately to the same theme. The results chapter provides a frequency count for each theme, by question. Selected quotes have been included to maintain teachers' voice. The source of each quote has not been stated because this may inadvertently identify respondents.

The initial exploration of the qualitative data was conducted on paper and in Excel, using mind-mapping to help explore possible themes. I later uploaded the PDF files to NVivo for Mac version 11.4.2, which supported the final identification and refinement of themes. The qualitative analysis was first conducted separately for each question. However, recurrent themes were identified across questions and the entire data set was considered when naming and refining themes, and when selecting quotes for the final write-up.

Due to the timeframes of this project, the final refinement of the qualitative themes from Phase I occurred after the collection of Phase II data. In a typical sequential explanatory design, the analysis and write-up of the Phase I results would have been finalised prior to Phase II commencing (Creswell, 2015).

Phase II: The Interviews

This section outlines the sampling, data collection, and data analysis of Phase II. Phase II involved in-depth, semi-structured interviews. Interviews are the most common data collection strategy in qualitative research (Punch, 2014). They can give rich insights into a person's experiences and interpretation of reality and the researcher can seek clarity

or ask participants to elaborate on their responses (Punch, 2014). Therefore, interviews were an appropriate approach for expanding on the survey findings from Phase I.

Phase II sampling procedure

Phase II involved a purposive nested sample drawn from the survey participants ($N = 4$). In a sequential explanatory design, the participants in the second phase of the study are drawn from the first phase (Creswell, 2015). The purpose of this nested sample is to enable the researcher to seek further explanation and clarity of the responses given in the first phase of the study (Creswell, 2015). Twenty-five survey respondents indicated that they would like to be provided further information about participating in a possible follow-up interview. Of these 25 teachers, 12 were initially invited to participate in the interview. These teachers were selected because their responses to the questionnaire suggested they represented a diverse range of perspectives based on their gender, years of teaching experience, school-type, and the types of childhood chronic illnesses with which they had experience. Participants who were selected for Phase II were contacted, via email (see Appendix G), and invited to take part in a semi-structured interview to elaborate on their survey responses. Those teachers who were willing to participate completed a written consent form (see Appendix H), which was returned to me via email. Of the initial 12 teachers who were invited to the interview, only one chose to participate. For this reason, the timeframe was extended and another eight teachers were invited, again based on their recent experience as indicated in the survey. This resulted in a further three interview participants. Those teachers who did not have recent experience and therefore were not selected for Phase II were sent an email to explain this and to thank them for their contribution to the research (see Appendix I).

Phase II data collection

Unique interview schedules were developed for each interview participant based on their responses to the questionnaire (see Appendix J for template). The pre-prepared interview questions were used to guide the conversation, and participants were encouraged to share any thoughts that they had which were not directly related to the questions posed. I chose phone- and Skype-based interviews rather than face-to-face interviews so that there were no geographic barriers to participation.

Interviews were conducted in October and November 2017. Three interviews were conducted by phone and one was conducted over Skype, as per each participant's preference. The interviews ranged in length from 18 through to 48 minutes and, with written and verbal consent, they were audio recorded using an Endeavour 8Gb digital voice recorder. Following the interviews, participants were sent an email to thank them for their participation. Included with this email was a Teacher Resources sheet with a list of suggested resources for teachers of learners who are chronically ill (see Appendix K).

Following each interview, I transcribed the audio recordings smooth verbatim. Any identifying data was omitted from these transcripts, and participants were given pseudonyms. Next, I invited participants to review and edit their interview transcripts (see Appendix L). Only one word was changed as a result of this member-checking process.

Phase II data analysis

The interview data was analysed through a process of deductive thematic analysis, guided by themes identified in Phase I. I first read and re-read each transcript to familiarise myself with the participants' individual stories. Next, using printed PDF transcript files and highlighter pens, I highlighted sentences, or sections of text that

pertained to each of the themes identified in the survey data. Next, individual transcripts were uploaded in PDF format to NVivo for Mac version 11.4.2 and the process of deductive thematic analysis was repeated. The use of this software facilitated data management and interpretation. When presenting the interview data in the next chapter, narrative accounts have been provided. These accounts begin with a rich description of each participant. Then, I provide my own analysis of how the data from each interview served to clarify, extend on or provide an alternate perspective to the Phase I findings. This narrative analysis is supported by direct quotations from participants, as recommended by Braun and Clarke (2006).

Methodological Quality Criteria

This section outlines the strategies used to strengthen the methodological quality of the current study. There is no consensus with regard the most appropriate criteria for assessing the quality of mixed-methods studies (Fàbregues & Molina-Azorín, 2017). In a recent review of the literature, Fàbregues and Molina-Azorín (2017) reported that mixed-methods research should be evaluated against its own set of core quality criteria, but that there is no agreement on what exactly these criteria should be. Given the ambiguity in the mixed-methods literature, Lincoln and Guba's (1986) criteria for trustworthiness were relied upon to guide decisions of methodological quality in this study. *Trustworthiness* is a well-established measure of quality in qualitative research, and it is considered to parallel the concept of *rigor* in positivist methodologies (Lincoln & Guba, 1986). There are four criteria: credibility, transferability, dependability, and confirmability.

Credibility relates to the degree of confidence that readers can have in the research findings. It is comparable to the concept of *internal validity* in positivist research (Lincoln

& Guba, 1986). In the current study, I used two strategies to enhance the credibility of findings. The first was peer debriefing. Peer debriefing involves “exposing oneself to a disinterested professional peer to ‘keep the inquirer honest’, assist in developing working hypotheses, develop and test the emerging design, and obtain emotional catharsis” (Lincoln & Guba, 1986, p. 77). The research supervisors acted as peer debriefers in the current study. The second strategy used to enhance credibility was member-checking. Member-checking is the process of soliciting feedback from participants (Lincoln & Guba, 1986). As already mentioned, in Phase II, interview participants were asked to review and edit their transcripts to ensure that they were a fair representation of participants’ experiences. While it is also recommended that participants review the interpreted data (Birt, Scott, Cavers, Campbell, & Walter, 2016), this was not feasible within the timeframe of this study.

Transferability is the extent to which the findings of a study have applicability to other contexts. This is similar to the concept of *generalisability* in conventional scientific paradigms (Lincoln & Guba, 1986). In the current study, a broad cross-section of participants were recruited from across New Zealand and this contributes to the transferability of the survey findings. Further, when reporting the Phase II results, I have shared rich descriptive data about each participant. This allows readers to judge for themselves the degree to which participants’ stories have applicability to the readers’ own professional practice (Lincoln & Guba, 1986). Importantly, the current study is not intended to have transferability outside of a New Zealand context.

Dependability is the extent to which the findings of a study are consistent and could be repeated by another researcher. It is considered analogous to the criterion of

reliability in positivist research (Lincoln & Guba, 1986). Lincoln and Guba (1986) recommended that an external auditor examine the process of a research study to evaluate its dependability. Since the current study has been conducted as part of a masterate degree, the research procedures will be subject to evaluation as part of the examination process. As well, the two supervisors have acted as a sounding board for me to reflect on my research processes, thereby enhancing dependability.

Confirmability relates to the degree of neutrality in the research findings, and it is analogous to *objectivity* (Lincoln & Guba, 1986). Audit trails and reflexivity are two strategies that can increase the confirmability of qualitative research findings (Lincoln & Guba, 1986). In this research, regular supervision meetings have provided a forum for reflective thinking and I have kept minutes of these supervision conversations as a medium for documenting the methodological decisions that were made. Further, the data and analyses for the current study will be stored in electronic form for two years (before being disposed of as per the information provided to participants), and this provides an audit trail.

Ethical Considerations

This section outlines key ethical considerations. Procedurally, Phase I of this study was approved by Massey University's Human Ethics Committee Southern B (Application SOB 17/21) on 28/07/2017 (see Appendix A). A subsequent Low Risk Notification (4000018456) was submitted prior to data collection commencing for Phase II. The approval of this subsequent application on 19/09/2017 enabled Phase II to proceed (see Appendix B).

However, ethically sound research requires more than gaining ethical approval from a regulatory body at the outset of a research project (Hammersley & Traianou, 2012). Ethical practice remains the primary responsibility of the researcher, and it requires ongoing monitoring and reflection from the conception of a study through to the dissemination of its findings (Chamberlain, 2016). While an exhaustive account of the ethical considerations pertinent to the current study is beyond the scope of this section, three key considerations are outlined.

The first consideration relates to informed and voluntary consent. For a participant to provide informed and voluntary consent, they need to be given detailed information about the nature, purpose, and procedures of the study; understand the implications of their involvement; and, understand that they have the right to decline participation without reason or consequence (Chamberlain, 2016; Hammersley & Traianou, 2012; Massey University, 2015). However, research has shown that some participants may not fully understand the information provided to them and may not be aware of their right to decline or withdraw their participation (Anderson, Newman, & Matthews, 2017; Nishimura et al., 2013). Also, the emergent nature of qualitative research methods can be problematic for the informed consent process (Chamberlain, 2016; Hallinan, Forrest, Uhlenbrauck, Young, & McKinney, 2016). Qualitative researchers cannot always pre-empt the direction that data collection will take, and therefore cannot always provide complete information to participants at the outset of a study (Chamberlain, 2016). For these reasons, researchers are encouraged to see informed consent as an ongoing, collaborative process between themselves and participants; to ensure that information is clear and accessible; and, to consider

providing information to participants verbally (Anderson et al., 2017; Hallinan et al., 2016; Nishimura et al., 2013).

In this study, steps were taken to increase the likelihood that participation was informed and voluntary. In Phase I, prospective participants were given a detailed information sheet (see Appendix E), and then key information – including participants’ rights to decline or withdraw their participation – was reiterated at the start of the questionnaire (see Appendix C). Contact details were provided so that participants could seek clarity on the research aims and procedures. Before clicking ‘submit’ at the end of the questionnaire, participants were reminded they would not be able to withdraw their consent beyond that point. In Phase II, another detailed information sheet was provided (see Appendix G), and at the start of each interview, participants were reminded verbally that they did not have to answer any question, and that they could withdraw at any point. One teacher asked for comments to be disregarded during the interview, and these comments were omitted from the written transcript.

The second key consideration relates to confidentiality. During research, participants disclose information to researchers, generally on the basis that this information will be held in confidence (Hammersley & Traianou, 2012). However, it can be difficult to guarantee confidentiality, particularly in qualitative research where rich descriptions of the participants are provided to contextualise findings (Morse & Coulehan, 2015). Based on these rich descriptions, participants may be identifiable to themselves or those who know them (Morse & Coulehan, 2015). This was an important consideration in the current study, particularly because some participants provided information about children with rare illnesses. When combined with other demographic

information such as the participants' locations and position on staff, this could render a participant identifiable. Not only would this impact on the participants' rights to privacy, it could also breach the privacy of the children, families, and colleagues that participants spoke about. To guard against this, only information that is considered relevant to the analysis has been included in this thesis. It is for this reason that the names of certain illnesses have been omitted, as have the locations in which interview participants work.

The third key consideration relates to social and cultural sensitivity. In New Zealand, when research involves participants who identify as Māori or where research is of interest to Māori, careful consideration must be given to ensure the research protocol is appropriate and culturally sensitive (Chamberlain, 2016; Massey University, 2015). This is also a legal obligation under *te Tiriti o Waitangi* (Massey University, 2015). I acknowledge that an online questionnaire is incongruent with the way in which some Māori may choose to engage, *kanohi-ki-te-kanohi* (face-to-face). So, I sought cultural supervision to improve the accessibility of the study for teachers who identify as Māori and/or teachers who work in Māori-medium settings. Ethnicity data was not obtained in this study so it is not possible to ascertain whether teachers who identify as Māori participated. Only one survey participant identified that they worked in a kaupapa Māori kura (school), and this person did not participate in Phase II. As such, an important voice may be underrepresented in the research sample. In chapter six, this is acknowledged as an area for further research.

Summary

To investigate the complex phenomenon of teachers' preparedness and experiences in working with children who are chronically ill, this study employed a

mixed-methods sequential explanatory design. The research was approached from the theoretical perspective of interpretivism, taking account of individual differences in participants' lived experiences and acknowledging my role as an active contributor to the research process. Questionnaire data from the first phase of the research provided insight into the extent to which New Zealand primary school teachers are professionally prepared to teach children with chronic illnesses, and it identified broad trends in their experience in working with these children. These trends were further explored through in-depth qualitative interviews in the second phase of the research. In the next chapter, the participant demographics and results of the two sequential research phases are presented.

Chapter 4

Results

Using a mixed-methods approach, this study produced a rich data set combining both qualitative and quantitative data. The findings provide nuanced insights into the experience of teaching learners who are chronically ill and how primary school teachers prepare, and are prepared to meet the needs of these children. This chapter presents the results of this study in two separate sections. First, section A provides an analysis of the survey data from Phase I where a total of 55 teachers submitted responses to the online questionnaire. Second, section B provides a narrative account of the four semi-structured interviews that were conducted in Phase II to delve into the survey findings in some depth. When reporting on the data within this chapter the percentage of respondents has been rounded and valid percent has been used, as described in the previous chapter.

Section A: Phase I – The Survey

Demographics

A cross-section of primary school teachers from 14 regions across New Zealand participated in the survey ($N = 55$; see Table 1). The majority were female (87%), which is consistent with the current demographic profile of New Zealand's primary school teachers (Education Counts, 2017b). Fifty-eight percent of the respondents had been registered teachers for 16 years or more, and this aligns with available data about the experience level of New Zealand's teaching workforce (Ministry of Education, 2015b). While there was a large minority of Auckland-based respondents (35%), this was not

unexpected given that an estimated 35 percent of New Zealand’s population resides in Auckland (Statistics New Zealand, 2017).

Table 1
Phase I Demographics

Characteristic	Frequency (<i>n</i> = 55)	%
Gender		
Female	48	87
Male	7	13
Years of teaching experience		
1–2 (provisionally registered)	2	4
3–6	3	5
7–15	18	33
16+	32	58
Region		
Auckland	19	35
Waikato	7	13
Canterbury	6	11
Wellington	5	9
Northland	3	5
Bay of Plenty	3	5
Otago	2	4
West Coast	2	4
Manawatu-Wanganui	2	4
Hawkes Bay	2	4
Tasman	1	2
Nelson	1	2
Marlborough	1	2
Southland	1	2
Chatham Islands	0	0
Gisborne	0	0
Taranaki	0	0
Highest teaching qualification		
Not specified	1	2
Certificate/diploma	7	13
Bachelor	31	56
Higher degree	16	29

Table 2 presents demographic data relating to respondents’ roles and schools. Notably, 12 respondents indicated that they taught all six primary school year levels. Qualitative responses elsewhere in the survey revealed that at least some of these

respondents had non-teaching roles (e.g., Principal, special education needs coordinators [SENCO]). Since respondents were not asked to specify their role on staff, it was not possible to confirm how many of them held non-teaching positions. Most (78%) survey respondents indicated that they taught at state (not integrated) schools. While no respondent identified their school-type as *kura kaupapa Māori* or *bilingual*, one respondent selected *other* for this item and subsequently identified that they worked in a different Māori-medium setting. A fifth of respondents reported that their school had a formal policy with respect to assessing and monitoring the school-based needs of children with chronic illnesses.

Table 2
Survey Respondents' Roles and Schools

Characteristic	Frequency	%
Year level(s) taught [^] (<i>n</i> = 50)		
Year 1	21	42
Year 2	21	42
Year 3	25	50
Year 4	26	52
Year 5	23	46
Year 6	22	44
School-type (<i>n</i> = 55)		
State (not integrated)	43	78
State (integrated)	9	16
Private	2	4
Kura kaupapa Māori	0	0
Bilingual	0	0
Special education school (including Regional Health Schools)	0	0
Other	1	2
Formal policy (<i>n</i> = 54)		
I am uncertain	25	46
No	18	33
Yes	11	20

[^]Respondents could select more than one year level.

Teachers' preparedness to teach children with chronic illnesses

Formal preparation. Respondents had received limited formal preparation regarding learners who are chronically ill (see Table 3). The majority (78%) reported that their initial teacher education (ITE) had not included any training on this topic, and almost half (47%) had not undertaken any relevant professional learning and development (PLD).

Table 3
Teachers' ITE and PLD regarding Chronic Illness

Preparation	Frequency (n = 55)	%
ITE		
No training	43	78
Some reference but not a stand-alone topic	11	20
Stand-alone topic within a course/paper	0	0
Optional course/paper	0	0
Compulsory course/paper	0	0
I cannot recall	1	2
Formal PLD		
Yes	29	53
No	26	47

The 29 teachers who indicated that they had undertaken some formal PLD on teaching children with chronic illness were asked to provide a brief description of the PLD. Table 4 summarises responses according to illness(es), content, and mode of training. Of note, responses indicated that the content of this PLD tended to have a narrow focus on how to manage these children's medical needs. Examples included receiving training on how to monitor symptoms, administer treatments, and respond to medical emergencies. The data suggested that training with respect the broader educational and social implications of chronic illness was uncommon. Only one respondent identified that learning was a focus and noted that their PLD had provided "some information around the potential impact on their learning". Another respondent

reported that their PLD had helped them to prepare for the emotional implications of the child's illness for them as a teacher.

Table 4
Type and Content of PLD

Aspect of Training	Frequency (n = 29)
Illness [^]	
Diabetes	20
Epilepsy	9
Asthma	7
Allergies	4
Cancer	3
Other	6
Not stated	3
Mode	
Specialist-as-trainer	10
Formal training course (e.g., First Aid)	10
Parent-as-trainer	6
Collaborative planning	5
Not stated	8
Content	
Medical management	15
Learning implications	1
Social/emotional implications	1
Not stated	11

[^] Some teachers identified more than one illness.

In future, respondents indicated they would value interactive, multidisciplinary PLD opportunities. Teachers were asked what their preferred mode of training would be if they were to engage in further education with regards learners with chronic illness. The most popular response was full day workshops with presentations from both health and education personnel (33%).

Knowledge. Teachers' self-reported knowledge was variable across the nine chronic illnesses included in the questionnaire (see Figure 3). Most respondents reported having a *good or very good understanding* of asthma (80%), diabetes (71%), cancer (59%), and eczema (58%). Whereas fewer respondents reported having a *good or very*

good understanding of epilepsy (45%), arthritis (27%), heart disease (21%), inflammatory bowel disease (IBD; 19%), and kidney disease (15%).

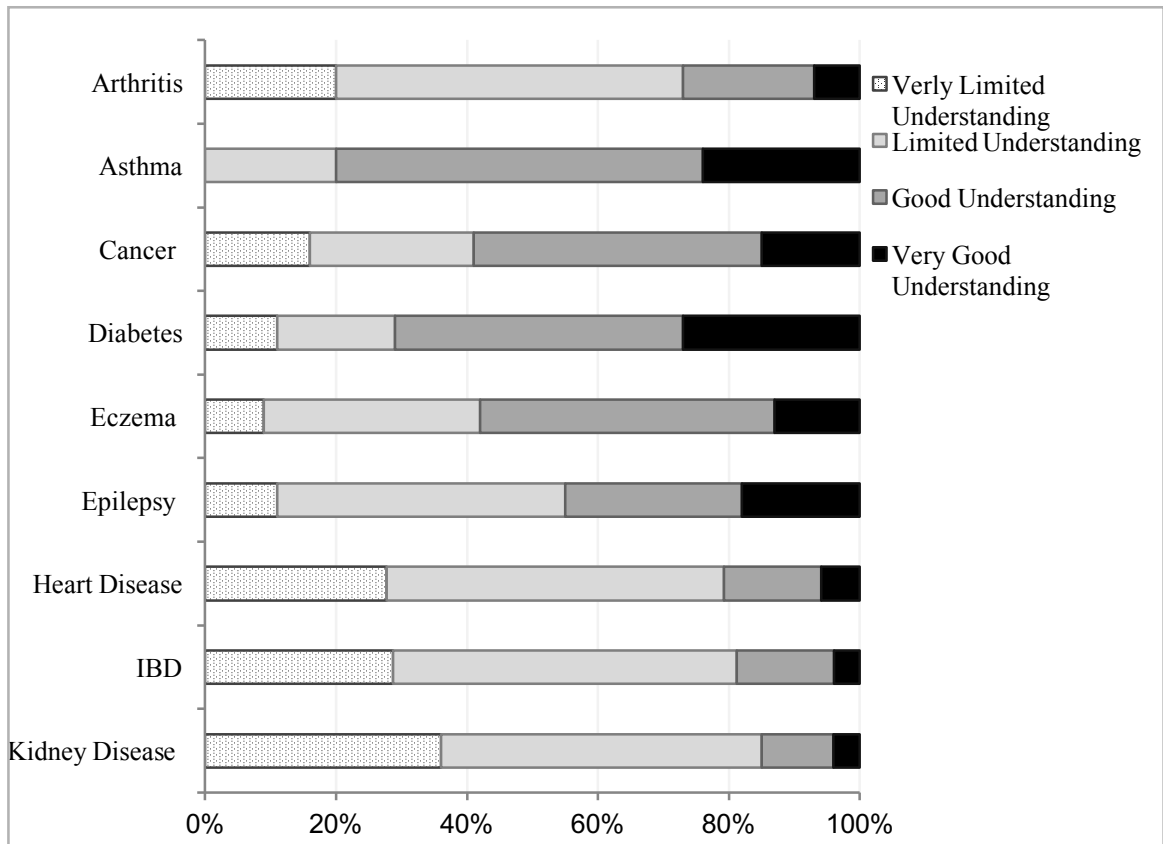


Figure 3. Respondents' self-reported knowledge of nine childhood chronic illnesses

Confidence. As shown in Figure 4, teachers generally demonstrated positive attitudes about working with children who are chronically ill. Of note, most respondents (73%) *somewhat agreed* or *completely agreed* that they were confident in their ability to meet the learning needs of a child who is chronically ill, even if they had a limited understanding of that child's particular illness.

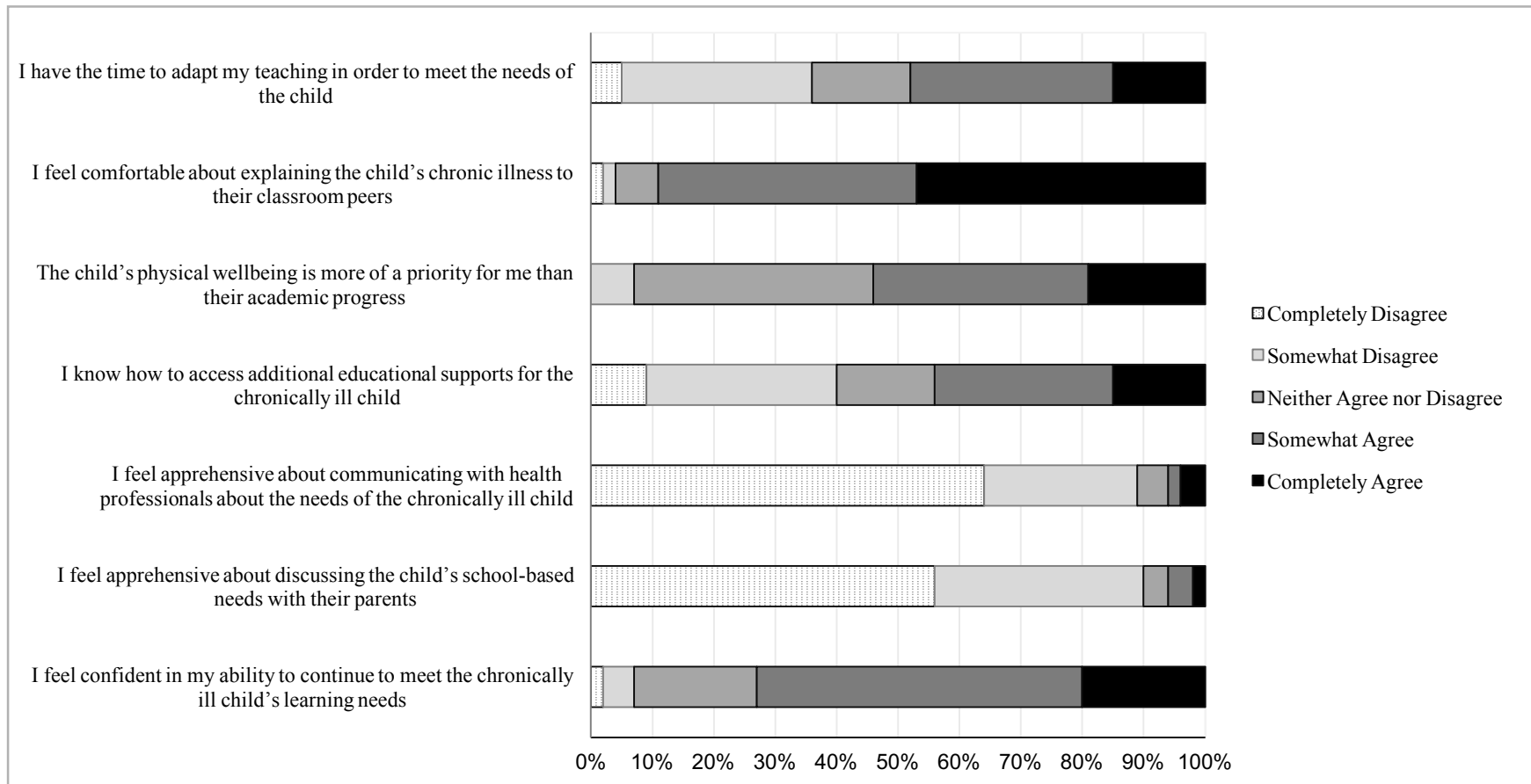


Figure 4. Teachers' self-reported attitudes toward a hypothetical child with chronic illness

Prioritising physical wellbeing over academics. Learners’ physical wellbeing was emphasised in the survey data. Over half (54%) of the respondents *completely* or *somewhat agreed* that the child’s physical wellbeing would be more of a priority for the teacher than the child’ academic progress (see Figure 4). Also, when teachers were asked what questions or concerns they might have about a child with a chronic illness joining their classroom, the most frequently raised questions were focused on what teachers need ‘to know and do’ to protect the child’s physical wellbeing (see Table 5).

Table 5
Teachers’ Questions About a Child with Chronic Illness

Questions	Frequency (n = 55)
What are the child’s... medical/physical needs?	21
learning needs?	19
strengths?	6
social needs?	2
How can I support the child’s... physical wellbeing?	47
learning?	18
social inclusion?	6
No concerns	2

The teacher experience

Experience in working with learners who are chronically ill was high among respondents. All 55 teachers had experience teaching at least one child with a chronic illness at some point in their teaching career and 76 percent of respondents had taught one or more child with a chronic illness within the 24 months prior to completing the survey. To better understand the experience of teaching children who have a chronic illness, the 42 respondents who had recent experience were asked to think about one child that they had taught in the past 24 months and to answer a series of questions

about working with that child. Respondents most frequently shared their experience working with children with diabetes (see Table 6).

Table 6
Chronic Illnesses with Which Teachers Shared Their Recent Experience

Illness	Frequency (n = 42)
Diabetes	17
Cancer	6
Eczema	5
Asthma	5
Heart conditions (including Rheumatic fever)	4
Neurological conditions (including epilepsy)	4
Kidney disease	2
Allergic conditions	2
Gastric conditions	1
Cystic fibrosis	1
Other [^]	2

Note. Some participants listed more than one illness.

[^] To protect respondent confidentiality, rare illnesses have not been specified.

Challenges to practice. Teachers had confronted a range of challenges when working with learners who were chronically ill (see Table 7). These challenges related most frequently to *disrupted learning and behaviour*. This included concerns about maintaining academic continuity during absences, managing expectations of the child’s learning, dealing with illness-related aggression and anxiety, and minimising disruption to the other children in the class.

Teachers also commented on the *risks and responsibilities* associated with meeting the medical needs of these children. There was a sense within this theme that teachers are not always well supported in this unfamiliar role, and teachers also shared concerns about their own culpability if they made a mistake when providing medications or responding to an emergency involving the child with chronic illness.

Table 7

Challenges Encountered by Teachers when Working with Children who are Chronically Ill

Theme	Q23 Frequency (n = 38)	Q27 Frequency (n = 43)	Examples
<p>Disrupted Learning and Behaviour</p> <p>Learning and behavioural challenges associated with the child's illness, medications, or absences. Includes concerns about disruption to peers' learning and behaviour.</p>	30	14	<p>"When the child uses the illness as a way to not participate, knowing when to push it to make him join in and when to let it go."</p> <p>"One eye on teaching, and the other seeing if that child is coming right"</p> <p>"I am trying to support the emotional well being of a settled class who have a friend who may or may not live to the end of the year."</p> <p>"Frequent absenteeism due to his illness, which made teaching continuity difficult"</p> <p>"The child can become very lethargic and unable to concentrate due to their levels crashing below 4."</p>
<p>Risks and Responsibilities</p> <p>Sense of responsibility in ensuring the child's medical needs are met while they are at school. Including concerns regarding the teachers' own emotional wellbeing and liability if mistakes are made.</p>	23	12	<p>"[I]t worries me that I could, one day, get it wrong [...] I would hate to be responsible for such a mistake however I am fully aware that it is possible."</p> <p>"It is a huge responsibility and can at times be quite scary."</p>
<p>Systemic Challenges</p> <p>Frustrations about the systems and processes for accessing information and resources.</p>	9	7	<p>"I was the one who had to keep pushing local DHB (paediatrician) for any updated information and communication regarding this child and how we could seek support."</p> <p>"Lack of apparent funding and paperwork/support seemed slow in coming."</p> <p>"The student also has academic needs and currently there is no funding for this."</p>

Table 8
Teachers' Approach to Working with Children with Chronic Illness

Theme	Q24 Frequency (n = 37)	Q26 Frequency (n = 40)	Q27 Frequency (n = 43)	Examples
<p>“Learn everything you can” Gather as much case-specific information from a range of informants including parents, previous teachers, and the medical professionals directly involved with the child. Includes knowing medical plan as well as knowing individual learner.</p>	17	40	14	<p>“Learn as much as you can about the condition and anything you can do to provide a positive learning experience. Watch the child. Get to know the child, not just the condition.”</p>
<p>“Work as a team” Build strong partnerships and work as part of a collaborative team to understand and support the child on their health and educational journey. Includes: parents, education specialists, medical professionals, teacher aides, classroom peers.</p>	39	60	22	<p>“Work as a Team-SENCO, Parents, Medical Professionals, TAs.” “The parents have a say in the care of the child, you are not the expert, you are there to listen and learn and respect the parents wishes for their child.”</p>
<p>“Don’t stress!” Embrace the opportunity, trust your expertise and those around you, you will be able to cope.</p>	0	11	7	<p>“Don’t panic!!!” “It is a reward to have a student facing these difficulties in your class. Watching how they grow and work and get on with their life is inspirational. The smile on my student's face makes me smile every day.”</p>

Respondents also identified *systemic challenges* that had affected their ability to provide a positive educational experience for these children. Comments within this theme highlighted challenges to communication between the health and education sectors, as well as funding arrangements that are difficult to navigate and that prioritise the medical needs of these children with less attention to the impact of chronic illness on academic and social development.

Approach to practice. Notwithstanding the challenges they had encountered, most teachers had identified useful strategies to help them work effectively with these learners. When asked what strategies and supports had helped them to overcome any challenges they had encountered, only one respondent indicated that they had not yet met the challenges. Data was missing for five respondents. Three key strategies were identified from the responses provided by the remaining 36 teachers: “*Learn everything you can*”, “*Work as a team*”, and “*Don’t stress!*” (see Table 8, Q24). These same themes were evident when respondents with recent experience were asked what advice they would give to another teacher who has just learned that a child with a chronic illness will be joining their classroom (see Table 8, Q26), and when all survey respondents were asked if they had any further reflections on this subject (see Table 8, Q27).

The theme “*Learn everything you can*” captured the idea that teaching children with chronic illnesses is not something for which teachers can be adequately prepared through formal training alone. Rather, it is an on-going learning journey that needs to be very specific to the child and necessarily involves gathering information from a range of informants. This may include formal training, but it also includes information from

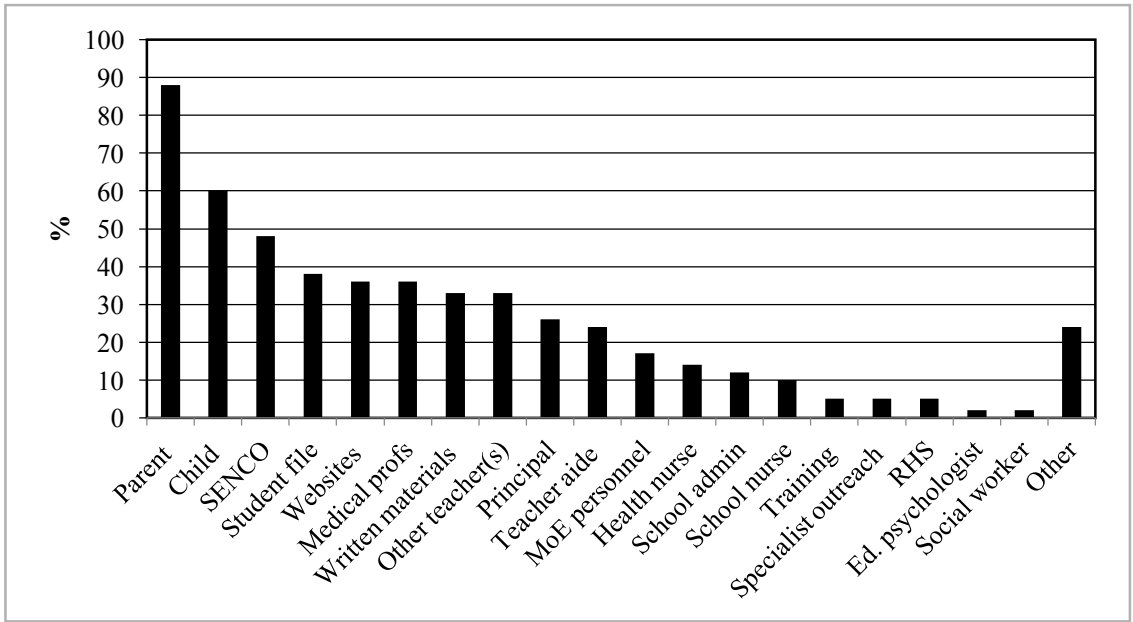


Figure 5. Resources teachers had consulted about the needs of a child with chronic illness (n = 42)

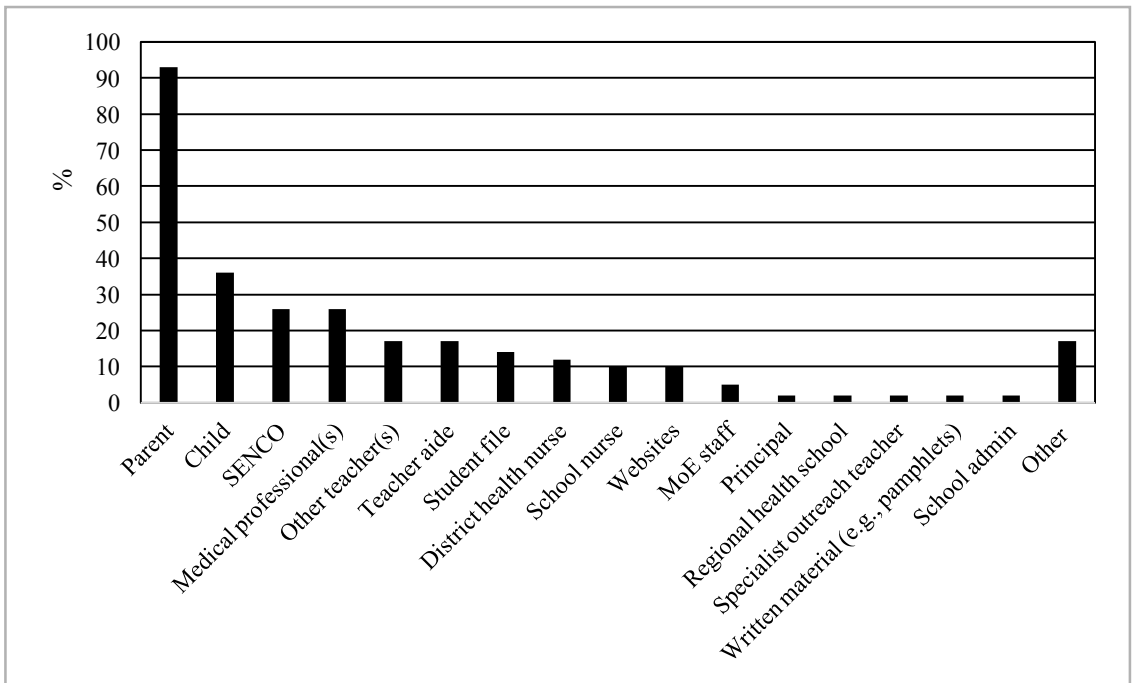


Figure 6. Resources perceived by teachers to be most valuable (n = 42)

parents, previous teachers, and the medical professionals directly involved with the child. Linked to this theme, quantitative data from the survey identified that parents were a particularly common (see Figure 5) and valued (see Figure 6) source of information for teachers.

Respondents' also shared that it was important to "*Work as a team*". This includes working closely with and supporting the child's parents, as well as collaborating with medical professionals, education specialists, and any other agencies involved with the child. Teacher aides were identified as particularly important team members. Teachers also noted the importance of building a good relationship with the child so that they "feel as if they can trust you and feel confident that their needs will be met".

While the theme "*Don't stress!*" occurred less frequently in the data set than others, teachers who shared this sentiment were emphatic in doing so and often used multiple exclamation marks. Comments within this theme suggested that teachers should trust their own expertise and know that they will be able to "cope and manage" despite any challenges. Teachers encouraged their colleagues to embrace the opportunity to learn alongside these inspirational children, and to teach the wider classroom about diversity and compassion.

Teachers' recommendations for change. Finally, respondents who had recent experience working with a child who was chronically ill were asked what additional information, resources, or supports (if any) they would have found beneficial in meeting the school-based needs of these children. The most common recommendation was for more readily accessible information, particularly from the health professionals directly involved with the child (see Table 9).

Table 9
Respondents' Recommendations for Change

Theme	Frequency (<i>n</i> = 36)	Examples
More information	17	“More information from the doctors and specialists that know his case”
More funding for in-class support	10	“Would be nice to have more teachers aide time perhaps to help him keep up with his work”
Improved systems and processes	8	“More support from ministry eg like we have RTLB for behaviour and learning - what support do we have for illnesses??”
None	3	

Summary

The 55 teachers who responded to the survey all had experience teaching at least one child with a chronic illness, yet, they reported having had scant formal preparation with respect to this aspect of their role. Any training they had received tended to have a narrow focus on supporting these children’s medical needs. However, respondents also had questions and concerns about how to effectively support the learning, behaviour, and social needs of these children. While teachers had confronted challenges in the course of working with children with chronic illness, they also identified positive strategies and supports. Teachers’ advice to their less experienced colleagues was: “*Learn everything you can*”, “*Work as a team*”, and “*Don’t stress!*” These findings were further explored in Phase II.

Section B: Phase II – The Interviews

To further explore how teachers prepare for and support children with chronic illnesses, Phase II involved semi-structured phone- or Skype-based interviews with four of the survey respondents. The four teachers had a range of experience as outlined in

Table 10. In this section, each participant’s story is shared separately, providing a descriptive insight into their experiences. Table 11 summarises the interview data with respect to themes from Phase I. All names have been changed to protect participant confidentiality

Table 10
Phase II Demographics

Pseudonym	Gender	Years of Experience	Current Role	School Decile	Experience
Kelly	Female	7 – 15	Deputy Principal	10	Allergies, diabetes, epilepsy, kidney disease, other.
Maria	Female	16+	Teacher (Year 2)	10	Asthma, cancer (remission), diabetes.
Abby	Female	16+	Teacher (Year 4,5,6)	-	Diabetes, epilepsy, other.
Tanya	Female	16+	SENCO	-	Diabetes, gastric conditions, cerebral palsy, life-limiting condition.

Note. Abby and Tanya did not specify the decile rating of their respective schools.

Table 11
Summary of Phase II Data According to Phase I Themes

Theme	Kelly	Maria	Abby	Tanya
Limited formal preparation	•	•	•	•
Challenges				
Disrupted learning and behaviour	•	•	•	
Risks and responsibilities	•	•	•	•
Systemic challenges	•	•	•	•
Approach to practice				
“Learn everything you can”	•	•		
“Work as a team”	•	•	•	•
“Don’t stress!”	•	•	•	•

Kelly

At the time of the interview, Kelly had between 7 and 15 years of experience as a registered teacher, and she was working as a Deputy Principal in a decile 10 state

school. She has had experience teaching children with a wide range of chronic illnesses including diabetes, epilepsy, allergic reactions, and conditions requiring intensive medical intervention such as tube feeding. Kelly, who spoke primarily about her experiences teaching children with diabetes, has diabetes herself and felt that she has a greater depth of understanding than other teachers with regards the potential implications of this illness on children's learning.

I think having someone who lives it and experiences it, it's completely different, to just reading in a textbook about it. Because I know what it is like when my blood sugar is low and I know that I can't learn. So I've got that understanding. I can hopefully pass on.

The interview with Kelly offered an opportunity to further explore some of the systemic challenges identified by survey respondents. Kelly had commented in the survey that "it is often difficult to access the specialist support and advice we need as teachers". When asked to elaborate on this comment during the interview, she shared her experience of trying to access specialist diabetes training that was only offered to educators at the time a child was diagnosed. Her anecdote highlighted a disconnect between the health and education systems. From the healthcare perspective, "the expectation was that once they have done the training, that's that". While Kelly understood that there was high demand on health professionals and that they need to prioritise newly diagnosed children, she thought there should be more regular training for educators since "things change".

She was diagnosed when she was four, and the specialist nurses went into kindy and trained the teachers and so when she started school they said that they wouldn't come in here because they have already done the training. So, there was no understanding that actually it's a completely different personnel working with her now.

In this situation, Kelly felt fortunate that the child had a proactive parent who:

is a nurse herself and will fight for what her child needs and went in and fought them on it, basically, and they came in. But if she hadn't I think it would have been extremely difficult for us to get any traction.

Kelly also spoke about the inflexibility of funding entitlements for children with chronic illness. The stories she shared indicated that existing funding arrangements do not adequately take account of the complex reality of supporting these children's needs in an educational context. She noted that the "funding is just for medical", and if the child has associated learning difficulties, schools may need "to be creative with funding".

In making recommendations for change, Kelly noted the need for better partnerships and shared understanding between the health and education systems, as well as more readily available information for teachers.

Like I said in that ideal world thing, to have someone from education involved in the training so that they had a good understanding of the impact in a busy classroom. Sometimes, the trainers who come in don't understand how classrooms work. Which is fair enough, they're not teachers.

There are so many different agencies that we deal with, so many different outside providers. Somewhere central we could go to have contacts for diabetes or epilepsy or whatever it is might be useful. Like a website or something.

Maria

Maria has 16 or more years' experience as a registered teacher and at the time of the interview she worked as a classroom teacher in a year 2 class at a decile 10 state school. Maria spoke primarily about her experience teaching children with type 1 diabetes, however, she has also had experience teaching children with asthma and cancer, among other illnesses.

Maria was one of the 20 percent of survey participants who reported that their school had a formal policy for assessing and monitoring the school-based needs of children with chronic illnesses. The content of her school's policy was further explored during Maria's interview. It was evident that the focus of this policy was on ensuring the child's medical needs are met. When asked whether the policy gave consideration to the child's learning needs, Maria commented that this was not part of the policy because they "do that within [the school's] normal programme anyway".

Like Kelly, Maria noted that existing funding arrangements for these children are focused primarily on medical needs and do not allow for additional learning or behavioural support. Maria commented "it would be wonderful. I mean, if you could [...] get the teacher aide to fill in to catch them up sometimes".

Maria's interview also provided further insight into the theme *Don't stress!* While she acknowledged that these learners have diverse needs to accommodate, she did not see this as different to any other child.

[W]e cater for it nowadays, we're trained as to set high expectations for them to reach, and support them in doing that.

Maria also saw it as a valuable opportunity to foster an inclusive mind-set among students.

And I think it helps with the other children as well to be tolerant. You know, and that we're all different and we have different needs and we have to make those allowances, and how altogether, we can work together and solve most of our problems – not all – but most.

In general, Maria shared the perspective of other survey respondents that teachers should trust their own expertise and make good use of the supports

available to them. That said, she acknowledged that she was “fortunate” to work in a decile 10 school, where the needs of these children are prioritised and where extra funding is available for teacher aide time. She recognised that this may not be the experience of all teachers.

When I was doing country teaching, it was a little isolated at times. You know, I feel that the opportunity for them to have supports would be quite important.

Abby

Abby has 16 or more years of teaching experience and at the time of the interview was teaching a Year 4–6 class in a state-integrated school. Abby spoke primarily about her experience of teaching children with diabetes, however, she also had experience teaching children with epilepsy, and other less common chronic illnesses.

Abby was one of the few survey participants who reported having had some reference made to chronic illness during her ITE. When asked about the content of this training during the interview, she said that the topic was covered “very briefly” and it was not something that was routinely included in the curriculum. Rather, it had come up because some of her fellow trainee teachers had found themselves on teaching placements where children with chronic illnesses were in the class and they felt unprepared to meet these learners’ needs.

[T]hey were like, “woah, I’m in a class with a child who’s got this and I actually don’t know what to do. What do we do there?”

Like most of the survey participants, Abby has found it valuable to seek information directly from the child’s parents. In the interview, she explained that this information was “more valuable [than formal training] because it’s so

specific to the child”. She commented that every child with a chronic illness is different, and it is their parents who are able to provide the most up-to-date and relevant information.

Like other interview and survey participants, Abby valued the support she had from teacher aides. She found that this allowed her to focus on teaching rather than being “a health professional”.

[F]or me as a teacher, that sort of stuff is really, that’s really putting on added pressure that we just don’t need. Yea. So, you’re just juggling so many balls in the air as it is. So I think we’re a bit lucky, I guess, that we are in a small school and we’ve got some discretionary sort of people that [...] take care of those quirky things that actually would be really easy for us to miss.

Tanya

Tanya is a registered teacher with 16 or more years of experience. At the time of the interview she was employed as a SENCO in a state school. The types of illnesses she has had experience with include diabetes, gastric conditions, and cerebral palsy. Tanya also had experience working with children with life-limiting conditions.

For Tanya, a lack of formal preparation for supporting children with chronic illnesses meant that she felt as though she was “in the deep end learning” at times. However, she did not think it would be feasible to have it any other way. As she said, it is about:

responding to the need at the time, which is probably what has to happen, because there’s no point in doing it and then not having anyone that you needed to worry about for five or 10 years.

In lieu of formal training, Tanya agreed that parents are an important source of information, but she had also found it valuable to get information from the medical

professionals involved in the child's care. She shared her experience of attending a specialist appointment with a child with chronic illness and their family. For Tanya, this served two purposes. It enabled her to offer support to the family, but it also allowed Tanya to ask questions of the paediatrician that the family may not otherwise have had reason to ask.

And they said it was really good, because I could ask questions and they said like, what questions have I got? And then, the whole context, they didn't have to repeat it, and if they hadn't understood it or really didn't understand, or there was something that made an impact for us at school, but they might not have realised it had an impact. You could sort of share that information a lot easier, and, get it from the horse's mouth basically, rather than having to have it relayed and something missed, or misinterpreted.

Tanya recognised that, as a full-time SENCO she was in an advantageous position that other teachers or schools might not benefit from.

[T]he classroom teacher doesn't always have access or know who to contact. And, a lot of SENCOs don't know either, I've just happened to because I've, you know, got stuck into that role because I know in a lot of schools, the SENCO "oh, it's your turn this year" or "your turn for two or three years".

Summary

All four interview participants concurred that they had had little formal preparation to work with learners with chronic illness, and they all reinforced the importance of working in close partnership with the child, their parents, other educators, and medical specialists to ensure a safe and positive learning experience for these children. Systemic challenges, including insufficient teacher aide funding and difficulties in accessing information, were further explored in the interviews, as were the professional joys of working with these resilient youngsters. In the next chapter, the results of both phases are discussed together alongside the extant literature.

Chapter 5

Discussion

Children living with chronic illness have the right to access a positive educational experience, and their teachers need to be well prepared to meet these children's individualised health and learning needs. The current study explores New Zealand primary school teachers' preparation and experiences in working with children who have chronic illnesses. The research was undertaken using a two-phased mixed-methods approach. Phase I involved an online nationwide survey of 55 New Zealand primary school teachers. In Phase II, key findings from the survey were further explored through four in-depth follow-up interviews. The results are consistent with international findings and highlight issues around teachers' preparedness to work with these learners. In exploring teachers' experiences, this study identified both professional joys and challenges. In this chapter, the results of both phases are discussed together alongside empirical and theoretical literature. Teachers' professional preparation is explored, and then key findings with regards teachers' experiences and approach to practice are discussed.

Teachers' Preparedness to Teach Children with Chronic Illnesses

Knowledge and formal preparation

The first aim of this study was to examine New Zealand primary school teachers' preparedness to work with children living with a chronic illness. In this respect, the results of the current study are consistent with international findings indicating that teachers need more information and training with regards these learners (Hinton & Kirk, 2015). As has been observed elsewhere (Nabors et al., 2008; West et

al., 2013), teachers' self-reported knowledge varied by illness. However, there were knowledge gaps for all of the illnesses included in this study, with few teachers reporting to have a very good understanding of the educational impact of any of the nine illnesses. Also consistent with international trends (Hinton & Kirk, 2015), teachers had received limited formal training with respect to teaching children with chronic illnesses. When participants had engaged in relevant initial teacher education (ITE) or professional learning and development (PLD), qualitative data from both phases of this study revealed that the content of this training had only partially met teachers' needs. The training tended to have a specific focus on medical needs with little attention to learning, social, or emotional considerations.

These findings are important since research has found a lack of knowledge and training can contribute to unacceptable consequences for both learners and teachers (Hinton & Kirk, 2015; Lum et al., 2017). When teachers have insufficient knowledge of the complex needs of learners who are chronically ill, research suggests this can compromise these students' academic success, social integration, and emotional wellbeing (P. Ferguson & Walker, 2014; Hamon, 2015; Hewitt-Taylor, 2009; Wilkie, 2012) as well as risking undue physical harm to these children (Hinton & Kirk, 2015). Research has also shown that a lack of appropriate preparation with regards the needs of these learners can contribute to stress among teachers (Boden et al., 2012; Cousins & DeLuca, 2016; Wilkie, 2012) and there was some evidence of this within the current study. Represented by the theme *Risks and responsibilities*, teachers shared a sense of being ill-prepared and apprehensive about meeting these children's medical needs. As an example, one teacher in this study, who had recent experience working with a

chronically ill child, but had not had any formal preparation for this role, noted that the experience had been “quite scary” (survey). It is unacceptable for any child to be placed in a position where they feel either unsafe or unable to learn, and no teacher should have to feel underprepared or stressed in their role. As has been argued in the literature for at least three decades (Johnson et al., 1988), there needs to be more teacher education about the educational, social, and medical needs of chronically ill children.

Prioritising physical wellbeing over academics

Over half (54%) of participants in the current study indicated that they would prioritise the physical wellbeing of children with chronic illnesses over their academic performance. This finding is consistent with previous research (Flanagan, 2015), and it is a concern in light of evidence that young people with chronic illnesses place a high priority on keeping up-to-date academically, and that they want their teachers to recognise and support this goal (e.g., Hamon, 2015; Wilkie, 2012). There may be a need to increase general awareness among teachers that the additional needs of these children are complex and extend well beyond their specific healthcare requirements (Hewitt-Taylor, 2009). This finding further supports the argument that teachers should receive more routine training about the impact of chronic illness in an educational context.

Confidence and self-efficacy

Interestingly, despite a lack of formal training and limited self-reported knowledge with regards the educational needs of children with chronic illness, teachers in this study were generally confident with being able to meet the learning needs of these children. This finding is inconsistent with international trends. In the current study, the majority of teachers (73%) rated themselves as confident in meeting the learning

needs of a child with chronic illness. In contrast, other studies have reported low levels of confidence among teachers with respect to meeting the needs of these learners (Nabors et al., 2008; West et al., 2013). It has been hypothesised that teachers' previous experience may be a better predictor of their confidence than their self-reported knowledge of the illness (Flanagan, 2015; Nabors et al., 2008; St Leger, 2014), and this is consistent with previous research with regard teacher self-efficacy (Malinen et al., 2013; Zee & Koomen, 2016).

Self-efficacy is a person's belief in their ability to perform a task (Bandura, 1982). A person's judgement of self-efficacy has important implications for the amount of effort that they exert in the face of new or challenging tasks (Bandura, 1982; Stajkovic & Luthans, 1998). Someone who has a high sense of self-efficacy to achieve a certain task is more likely to persevere despite adversity than a person who has a low sense of self-efficacy for that same task (Bandura, 1982). There is a significant body of literature that specifically considers the implications of teachers' self-efficacy beliefs for teaching and learning (Zee & Koomen, 2016). This evidence-base has found that teachers' previous experience plays a key part in teachers' perceived self-efficacy to overcome challenges to professional practice (Malinen et al., 2013; Zee & Koomen, 2016). For example, Malinen et al. (2013) conducted a quantitative, cross-national study in China, Finland, and South Africa exploring teachers' self-efficacy beliefs in regards teaching in inclusive settings. This study found teachers' previous mastery experiences in teaching children with additional needs was the strongest predictor of teacher self-efficacy in all three nations. The implication of Malinen et al.'s finding for the current study is that teachers' self-efficacy beliefs in working with children who have a chronic

illness is likely to build overtime, with each positive experience that a teacher has with these learners. It also follows that if inexperienced teachers are not provided with the training, information, and support that they need in order to have a positive mastery experience, and if instead they have a negative experience, then this will likely have adverse implications for their future self-efficacy beliefs (Malinen et al., 2013). Again, this supports the argument that there needs to be more routine training and support provided to teachers regarding learners who are chronically ill, particularly for those teachers who have not worked with these learners previously.

The Teacher Experience

The second and third aims of this study were to explore the teacher experience and to understand how teachers' experiences had shaped their understanding of how best to work with learners with chronic illness. Taking a strength-based approach, this section foregrounds the positive strategies that teachers had identified in working with these learners and so it is organised around the following three themes: *“Don't stress!”*, *“Learn everything you can”*, and *“Work as a team”*. The section concludes with a discussion of the importance of ensuring children living with chronic illnesses are visible within inclusive education policy.

“Don't stress!” – A focus on professional joys and rewards

Teachers in this study reflected on the professional joys and rewards of working with children with chronic illness. This is an important finding because teachers' perceptions of learners have significant implications for inclusive practice (A. Kearney, 2011; Lum et al., 2017). Teachers need to have positive, accepting attitudes toward learners with additional needs and must be committed to meeting the academic and

social needs of all children (A. Kearney, 2011). Captured within the theme “*Don’t stress!*”, experienced teachers shared a sense of professional fulfilment in supporting these children on their health and learning journeys. These teachers described the children with chronic illnesses that they had taught as diligent and ambitious, and these teachers demonstrated genuine admiration and compassion for these youngsters. Teachers also shared that they had embraced the opportunity to foster an ethos of acceptance and caring among classroom peers.

It is essential that these strength-based stories are not lost from the academic and professional discourse with regards learners who are chronically ill. In the extant literature, children with chronic illnesses have been described as “inherently ‘risky’ pupils whose healthcare needs place additional responsibilities and demands on teaching staff” (Hinton & Kirk, 2015, p. 112). While this may get the attention that is needed for this issue to find its place on the education agenda, such deficit-discourse problematises the learner and is in direct conflict with the spirit of inclusive education. Moving forward our discussions of these learners need to be strength-based and constructive, celebrating these children, while also shedding light on contextual barriers that need shifting to enable success for teaching and learning (A. Kearney, 2011).

“Learn everything you can” – A case-specific approach

Critically, in this study, teachers who had recent experience working with chronically ill children were aware that the ‘same illness’ for children, did not mean the ‘same learning needs’ for each of them, and teachers described the need for case-specific approaches to learning about and working with these children and their families. This finding is unsurprising if childhood chronic illness is viewed from a social-

ecological perspective (Kazak, 1989). Drawing on Bronfenbrenner's (1979) bio-ecological approach, Kazak (1989) proposed a social-ecological model of challenge and adaptation in children with chronic illnesses, and this model has shown validity in research and practice with these children (Cushing, Brannon, Suorsa, & Wilson, 2014; Kazak, Alderfer, & Reader, 2017). From this perspective, the child – who is unique in terms of their personal dispositions and illness-specific characteristic (e.g., severity, visibility, onset) – is in the centre of a series of overlapping social systems that have reciprocal effects on one another, and on the developing child. The systems closest to the child represent the child's immediate environments and are considered to have the most influence on the child's development. For children with chronic illness, salient social systems include home, school, and medical settings (Power, 2006). Outside of these proximal environments are the wider social and political contexts that have indirect influences on the child's development. From a social-ecological perspective, it is not possible to understand or support a child's academic, social, or behavioural competence without taking account of the unique characteristics of the child, their family, the school, and the dynamic relationships between these systems (Power, 2006).

It follows from a social-ecological perspective that no two children with chronic illness will have the same school-based needs, and that no two families will interact with the school system in the same way (Power, 2006). Further, it is likely that the needs of children, and their families, will change overtime, both in response to developmental changes in children's illnesses, changes in the school environment, or in response to other external stressors (Power, 2006). This complexity was certainly evident in the stories that were shared by teachers in the current study. Teachers reflected that their

experience had been different for every child, and there was considerable diversity between the stories that different teachers shared. Data captured within the theme *“Learn everything you can”* suggested that teachers’ approaches to learning about and working with these children are dynamic, ongoing, and very much case-specific. Across responses, however, one source of information was identified as particularly valuable and that was these children’s parents. Teachers recognise that parents remain the experts on their child. They have the nuanced, up-to-date information about the child’s individual strengths, needs, and behaviours, and it is this information that is critically important to working successfully with these learners.

These findings imply that it is too simplistic to suggest that teachers’ practice with chronically ill children will be optimised through providing one-off, generic training and information alone. To support teachers in providing the best possible educational experience for these learners, we must have flexible systems in place to ensure that teachers have the necessary time and resources to engage in this case-specific learning (Flanagan, 2015; St Leger, 2014; Wilkie, 2012). For example, teachers could be provided additional release time (Wilkie, 2012), or allowed to miss staff-meetings (St Leger, 2014) to meet regularly with these children and their families.

“Work as a team” – Key partnerships in supporting children with chronic illnesses

Represented in the theme *“Work as a team”*, teachers emphasised the importance of working in close partnership with others to achieve the best possible outcomes for learners with chronic illnesses. Key team members identified by teachers included whānau (family), the child, teacher aides, and medical professionals. Each of these key partnerships are discussed in this section.

Partnering with whānau. In New Zealand, the Education Review Office (ERO) recognises working in close partnership with parents and whānau as a cornerstone of inclusive practice (ERO, 2015). It is expected that teachers and schools will build constructive partnerships with every child's parents and whānau (Ministry of Education [MoE], 2014). This requires that teachers take the time to talk to parents and understand their wishes for their children; that families and schools work together to achieve shared outcomes for children; and, that schools listen to and act upon family concerns (ERO, 2015).

This commitment to parent- and whānau-oriented practice was reflected in the current study. As already mentioned, teachers preferred to gather information about these learners from parents, which is inconsistent with data from the international literature where teachers have shown a preference for information from medical professionals (Hinton & Kirk, 2015; Shiu, 2004). Teachers had sought information from parents not only about the children's needs, but also their strengths and interests, as well as the parents' aspirations for their children. Critically, the qualitative data demonstrated that teachers' interactions with parents went beyond information gathering and were described as partnerships. Teachers recognised that childhood chronic illnesses can have significant implications for family wellbeing, and that the extent to which parents and families are coping with a child's illness has reciprocal implications for that child's own coping (Morawska, Calam, & Fraser, 2015). As such, experienced teachers perceive that a key part of their role is to act as an advocate and support for the family. St Leger (2014) observed similar findings and encouraged school leaders and policy makers to

ensure that teachers are provided with sufficient time and support so that they can foster genuine partnerships with these families.

Partnering with the child. In inclusive practice, it is also important to listen to student voice (MacArthur, Berman, & Carroll-Lind, 2018). It is every child's right to be heard and to have their opinions taken into consideration on matters that affect them (United Nations, 1989), including their education (Lundy, 2007). Upholding this right and taking the time to listen to children's ideas and aspirations for their learning can contribute positively to students' sense of belonging in school (MacArthur et al., 2018). If children are not invited to share their views on their own learning, or if students' views are dismissed, this works against the spirit and objectives of inclusive education (Hamon, 2015; MacArthur et al., 2018). The detrimental impact of not inviting student voice was evidenced in Hamon's (2015) qualitative study with secondary school students with chronic conditions. As outlined in the literature review, Hamon shared accounts from these young people of teachers who had been unsupportive or even sceptical of these students' additional learning needs. In turn, Hamon reported that these young people felt their concerns had been dismissed and this impacted negatively on their trust in teachers and their sense of belonging at school.

It is therefore encouraging that teachers in the current study talked about involving children with chronic illness in decisions about these children's learning, social, or physical wellbeing. The majority (60%) of teachers who had recent experience working with a child who was chronically ill indicated that they had sought information directly from the child to learn about their school-based needs. There were also clear accounts in the qualitative data of teachers taking the lead of these children when it

came to things such as deciding how to share details of the children's illnesses with their classroom peers. Critically, any such engagement with student voice must not be superficial (Lundy, 2007). Among the teachers in this study, there was an awareness that children's authentic voice will only be heard if teachers build a strong and trusting relationship with these learners where they feel that their views are listened to and given due weight in decision-making (Lundy, 2007; MacArthur, 2009). As MacArthur (2009) observed, this requires systematic supports for teachers. Teachers need to have time and resources made available to them so that they are able to listen to and act upon students' wishes (MacArthur, 2009).

Partnering with teacher aides. Teachers in this study valued the support they had received from teacher aides, and they felt that the role of teacher aides in supporting learners with chronic illness should be extended. In New Zealand, some children who have ongoing health needs are eligible for School High Health Needs Funding (SHHNF; MoE, 2018). This provides funding for teacher aides to assist these children with their medical needs and personal care while they are at school (MoE, 2018). Teachers in the current study who had experience working with teacher aides described these support staff as an indispensable resource for ensuring the safety of these children. However, teachers also expressed frustrations with the inflexibility of the teacher aide provision. In particular, teachers lamented that teacher aide support was "only for medical" (survey) and that schools have to "be creative" (Kelly³) with funding if these children also require academic support. Teachers suggested a revised approach to funding that takes better account of the complex and varied needs of these children. For example, one survey respondent commented:

The student also has academic needs and currently there is no funding for this [...] Surely in circumstances like this the Ministry of Education should automatically provide learning support funding without the incredibly lengthy process of applying for ORS⁴ funding. The child in my opinion should be assessed prior to commencing school so supports can be in place for the student starting school. (Survey)

There is little guidance in the literature as to the most effective and socially valid role of teacher aides in supporting the school-based needs of children with chronic illnesses (Hinton & Kirk, 2015). Hinton and Kirk (2015) observed that, internationally, teacher aides play an increasing part in supporting these learners, but that there is a dearth of empirical evidence to guide and validate teacher aides' role. In reviewing the empirical literature on the role of teacher aides in inclusive education more generally, Rutherford (2012) noted conflicting findings. On the one hand, research has shown the positive contribution that teacher aides can make to supporting "students' presence, participation and achievement in school life" (Rutherford, 2012, p. 770). On the other hand, there is evidence that teacher aides can inadvertently interfere with teaching and learning; that they can contribute to learners' feelings of social isolation; and, that teacher aides' presence can stigmatise learners (Rutherford, 2012). Taken together, the results of the current study and the ambiguity in the literature suggest that the role of teacher aides in supporting learners with a chronic illness in a New Zealand context warrants further critical consideration.

Partnering with medical professionals. The findings emphasised both the importance of and challenges to adopting an interprofessional approach when working with learners who are chronically ill. An interprofessional approach is integral to

³ Pseudonym

⁴ Ongoing Resourcing Scheme (MoE, 2017).

success in inclusive classrooms (Mentis, Kearney, & Bevan-Brown, 2012). It involves professionals with diverse expertise coming together to learn from one another and to work together toward achieving the best possible outcomes for children with additional learning needs (Mentis et al., 2012). For children with chronic illnesses, it has long been argued that there needs to be close partnerships, information-sharing, and problem-solving between health and education providers to maximise these children's learning, health, and social-emotional outcomes (Johnson et al., 1988).

However, prior research has identified significant challenges to interprofessional collaboration between health and education professionals (Ekornes, 2015; St Leger, 2014). Organisational and contextual factors such as scant time, ill-defined roles and responsibilities, and challenges to communication due to differences in professional terminology and concepts of confidentiality can present significant barriers to collaboration (Ekornes, 2015). Findings from the current study suggest that systemic challenges compromised teachers' ability to engage meaningfully with health professionals. Consistent with international findings (Clay et al., 2004; Hinton & Kirk, 2015), teachers in the current study identified that it would be desirable to have contact with the medical professionals directly involved with a child, but that this was uncommon and often difficult to achieve in practice. There is no simple answer to strengthening partnerships between sectors, and there needs to be further intersectorial conversations to find a shared way forward (Hinton & Kirk, 2015; Moss, 2014).

Visibility in policy

All of the results discussed thus far underscore the need for greater visibility of learners with chronic illness in inclusive education policy. In the current study, only a

fifth of the survey respondents reported that their school had a formal policy to guide them in assessing and monitoring the school-based needs of learners with a chronic illness. Qualitative data from both phases revealed that when these school-level policies do exist, they tend to focus on these children's medical needs. There was little evidence of intentional planning on the part of schools to proactively address these children's academic, social, and emotional wellbeing. That there appears to be few school-based policies with regards the academic and social-emotional needs of learners with chronic illness is consistent with international findings (Flanagan, 2015; St Leger, 2014; White, 2014), and the current study indicates further guidance from government would be beneficial for teachers.

Currently, there is a paucity of specific attention to the academic and social-emotional needs of learners with chronic illnesses at a policy level in New Zealand. The MoE (e.g., 2014, 2016a) does provide direction to school leaders and teachers with regards providing an educational environment in which all learners can participate, belong, and experience success. In addition, the MoE (2018) provides SHHNF for some learners with chronic illness, as discussed above. There is also the Regional Health School (RHS; MoE, 2016b)⁵ service, which is available to support the learning of children who are unable to attend school for a significant period of time due to ill health. However, there is little specific guidance as to what local schools and classroom teachers need to do to achieve academic and social success for learners who are chronically ill.

⁵The RHS service was not a focus within the data in this study. Only two survey respondents indicated that they had engaged with this service. Therefore, the RHS has not been discussed in this study. Targeted research with teachers and learners who have engaged with the RHS would make a worthwhile contribution to the literature.

For schools to respond proactively to the academic and social wellbeing of learners who are chronically ill, more targeted policy is required. As Yates (2014) has argued, generic rhetoric to provide an inclusive education for all learners has minimal power to guide pedagogic action and it can lead to the needs of certain groups of learners, including those with chronic illness, being overlooked. Specific attention needs to be paid to the different ways in which children can experience exclusion so that schools are better placed to notice and remove any barriers to success (White, 2014; Yates, 2014). For learners with chronic illness, there needs to be explicit acknowledgement at a national level of the educational and social vulnerability of these children, and of schools' obligations to ensure that these learners' entitlement to academic and social success is not overshadowed by attention to their medical needs. It is only through this national policy that the necessary changes to teacher education, PLD, and resourcing that have been identified throughout this chapter, will be validated and supported (Ainscow, 2008; MacArthur, 2009).

Summary

Drawing on both quantitative and qualitative data sets, the results from this study identify inadequacies in the training and supports that are available to teachers regarding learners with chronic illness. Where there is information and support available to teachers, there appears to be a focus on these children's medical needs with scant attention paid to learning and social-emotional wellbeing. The findings also highlight positive strategies that teachers have drawn on to support these children to achieve their academic and social potential. Experienced teachers valued a case-specific, whānau-oriented approach to practice drawing on parent and student voice, and working in close

partnership with teaching colleagues, teacher aides, and, where possible, medical professionals. Recommendations to enhance teaching and learning are presented in the next chapter, along with the limitations of this study and opportunities for further research.

Chapter 6

Conclusion

Teachers' preparedness to teach children with chronic illnesses is an important factor in ensuring that these young people have access to a successful learning experience. This study considered the nature and extent of the formal training and informal support that teachers receive in regard to learners who are chronically ill; gave voice to teachers so that they could share their experiences, joys, and concerns in working with these children; and, sought practice-led advice on how teachers can best work with these learners. Both quantitative and qualitative data were solicited through a nationwide online survey of New Zealand primary school teachers ($N = 55$), followed by an in-depth account of four teachers' experiences using semi-structured follow-up interviews. The findings identify clear implications for practice and these are outlined in this chapter along with suggestions for future research. Three research questions were addressed through this study (see Chapter 1, p. 5) exploring three specific areas: (1) the preparedness of New Zealand primary school teachers to teach children with chronic illness, (2) these teachers' experiences of teaching children with chronic illness, and (3) how these teachers' experiences influence their understanding of how best to support the learning needs of these students.

The results of this study were consistent with international findings indicating that teachers receive limited formal preparation to teach children with chronic illnesses. Instead, teachers learn about the needs of these children 'on the job', in the course of working with them and their families. The suggestion has been made that teachers' self-efficacy to work with these learners develops over time with each positive mastery

experience they have. Further empirical exploration of the predictors and outcomes of teachers' self-efficacy beliefs in working with these learners is an important next step.

When sharing their experiences of working with children who are chronically ill, teachers described both professional rewards and challenges. Teachers drew satisfaction from supporting these inspirational children on their health and learning journey and watching them participate and achieve alongside their peers. At the same time, teachers noted difficulties in managing disrupted learning and behaviour, alongside concerns about meeting the medical needs of these learners. Teachers cited systemic challenges including a lack of access to information and barriers to interprofessional practice that hindered teachers' ability to achieve the best possible outcomes for these children.

Teachers in this study had clear advice for their less experienced colleagues. They emphasised the need to seek out as much case-specific information as possible, drawing on the expertise of the child, their families, and medical professionals. This included information about the child's strengths and aspirations, accommodations to support their learning and social inclusion, and necessary information about medical needs and treatments. A collaborative, whānau-centred approach was emphasised by teachers in this study, drawing on the support of teacher aides. Lastly, teachers in this study encouraged their colleagues to embrace the opportunity, to trust in their own expertise, and not to stress.

Implications

Taking account of the findings of this study and earlier research in this area, several recommendations can be considered. Foremost is the need for improved teacher education about the influence of chronic illness on young people's learning. Non-

specific information about the potential academic and social ramifications of chronic illness should be included as part of the curriculum during initial teacher education, and case-specific professional learning and development should be provided for all teachers working directly with a child with a chronic illness (Flanagan, 2015; Hinton & Kirk, 2015). Any formal education that teachers undertake should cover the full scope of potential implications of the child's illness, and how to access timely support when needed. Teacher education should be multidisciplinary in nature, having input from both health and education professionals.

A second recommendation is for information to be made more readily accessible to teachers. Teachers in this study encountered challenges when accessing relevant information about the educational needs of children with chronic illnesses. To address this, a recommendation made by two teachers in this study was for there to be a centralised website with high quality information and links to support services for teachers. The Ministry of Education's *Te Kete Ipurangi* webpage would be an apt place for this information to be stored, and there are already a number of informative, locally developed resources that could be uploaded to this website (e.g., Child Cancer Foundation, n.d.; Kedzlie & Crosbie, n.d.; Kids with Arthritis New Zealand, 2016).

A third recommendation is for interprofessional practice to be further enhanced. School leaders need to facilitate opportunities for teachers to engage collaboratively with parents and medical professional so that teachers are able to proactively support these children's academic and social success. Individual education plans (IEP) are one means of facilitating collaborative practices between home, health professionals, and schools. These plans are developed with the child's team (e.g. teacher, teacher aide,

parent, child, and medical specialists) to provide clear guidance on the child's physical, psychological, and social needs, as well as appropriate curricular accommodations (Lum et al., 2017). In this way, IEPs can help to enable students' strengths and needs in all domains of school life to be proactively assessed and routinely monitored.

For the above recommendations to be prioritised at a local level, they will need to be validated and supported through national policy. There needs to be greater recognition from government that maximising the academic and social outcomes of young people who are chronically ill is an equity issue and that it is the shared priority of education and health. Identifying and providing ways to foster communication, knowledge-sharing, and the coordination of supports across and within sectors is an important consideration. Until the educational and social needs of children with chronic illness are afforded more specific attention in policy, these children, their parents, and their teachers are likely to continue to encounter challenges.

Suggestions for Research

Recognising that this is a shared challenge for health and education, interdisciplinary research should be prioritised. The current knowledge-base has largely been built on studies that have been conducted from either an educational or a medical perspective. Such an approach can “yield naïve assumptions and work against deepening our knowledge across human service sectors” (Moss, 2014, p. 220). Instead, collaborative research projects should be conducted, capturing the perspective of both health professionals and educators. It would also be valuable to include the perspective of psychologists in this research given their expertise in preventative and remedial strategies for managing social, emotional, and behavioural challenges (Barracough &

Machek, 2010; Nabors et al., 2008). An interdisciplinary approach will be integral to finding a shared way forward and increasing the likelihood of achieving the best possible outcomes for these young people.

A second suggestion is for kaupapa Māori research to be conducted. In New Zealand, Māori are disproportionately represented among children with chronic illnesses (e.g., B. Jones, Ingham, Cram, Dean, & Davies, 2013; Ministry of Health, 2013) and evidence suggests that their experience can be hampered by euro-centric service provisions that do not take adequate account of *hauora Māori* (Māori philosophy of health and wellness; R. Jones et al., 2010). Māori are also disproportionately represented within the lower socioeconomic portion of New Zealand's population (Fahy, Lee, & Milne, 2017) and this social position has the potential to further disadvantage Māori who are living and learning with chronic illness (Lum et al., 2017; White, 2014). Thus, it is a concern that there is a paucity of research exploring the educational experiences of chronically ill Māori children. Hamon (2015) made a timely recommendation that such research should be prioritised.

A third suggestion is to conduct specific research with regard teachers' self-efficacy to work with learners who are chronically ill. While the current study did not specifically research teacher self-efficacy, it has been briefly discussed as it emerged as an important and complex issue that requires further in-depth inquiry. Since research has identified country-specific variations in factors affecting teacher self-efficacy (Malinen et al., 2013), a systematic, New Zealand-based enquiry into teachers' self-efficacy beliefs in working with children who have a chronic illness would make an important contribution to the evidence-base.

Limitations

While this study highlights important aspects with regards teachers' experiences of supporting children with chronic illness and ensuring these children's learning is not compromised, there are some limitations to note. The results cannot be generalised because the survey in Phase I used non-probability sampling, with a response rate of 55 teachers. However, these teachers had experience working with children with chronic illness and therefore the data is valid and may serve to highlight issues to explore in more depth. It is also possible that there was a response bias with only teachers who have strong opinions on this topic having responded. That said, the issues raised are nonetheless real for these teachers, and they provide a useful backdrop to understand the challenges and joys of teaching children with chronic illness. It is important to note that because survey respondents' role on staff was not identified, it is not possible to discern the extent to which findings represent the voice of classroom teachers or registered teachers in non-teaching positions.

Similarly, the stories shared by the four participants in Phase II are their experiences and should not be considered the experiences of New Zealand primary school teachers in general. Three of the four interview participants spoke primarily about their experiences with children with diabetes. The transferability of these findings to teachers of children with other chronic illnesses is therefore only speculative. Two interview participants shared that they worked in decile 10 schools, which they indicated was a factor that was advantageous to their experiences (i.e., they were generally well-resourced and had the support of active, involved parents and communities). It is not clear whether teachers working in less affluent schools share in this experience, and this

is something worth further investigation.

As with much qualitative research, it is also important to acknowledge the possibility of researcher bias in the collection and analysis of qualitative data. While I endeavoured to remain neutral in conducting the interviews, it is not possible to remove all researcher bias in this process. My own biases may also have influenced the analysis and interpretation of the qualitative data. The themes that were identified were founded on direct quotations from participants, however, they were constructed from my own perspective and the possibility of bias in this interpretative process cannot be eliminated. However, these threats to trustworthiness were lessened through member-checking and triangulation of data through a mixed-methods approach.

Conclusion

This mixed-methods study explored New Zealand primary school teachers' preparation and experiences in working with children who have a chronic illness. The findings are consistent with international trends indicating that teachers receive limited specific training or supports to work with these learners. When teaching children with chronic illnesses, teachers place a high priority on case-specific, whānau-oriented, and collaborative approaches. The results suggest teachers' practice could be further enhanced through improved opportunities for teacher education, more ready access to information, explicit policies and provisions with respect to the learning and social needs of these children, and better interprofessional collaboration. The current study builds on previous New Zealand-based research (Hamon, 2015) that highlighted the central role teachers play in facilitating positive educational experiences for young people who have a chronic illness. For all children to have successful learning

experiences, they need teachers who understand the implications of their individual lives, and this is especially important when these children are living with chronic illness. As educators, we can play a pivotal role in ensuring any barriers to academic success and social inclusion are made visible and addressed so that these children can access the same educational opportunities as their healthy peers.

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Appendix A

Phase I Ethical Approval



Date: 28 July 2017

Dear Nicola Adams

Re: Ethics Notification - **SOB 17/21 - New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern B Committee** at their meeting held on **Friday, 28 July, 2017**.

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

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

Yours sincerely

Dr Brian Finch
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Appendix B

Phase II Low Risk Ethics Notification



Date: 19 September 2017

Dear Nicola Adams

Re: Ethics Notification - **4000018456** - **New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses (Phase II)**

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our system which is reported in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please go to <http://rims.massey.ac.nz> and register the changes in order that they be assessed as safe to proceed.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

A reminder to include the following statement on all public documents:

"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research."

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 3569099 ext 86015, email humanethics@massey.ac.nz.

Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

Research Ethics Office, Research and Enterprise

Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 350 5573; 06 350 5575 F 06 355 7973
E humanethics@massey.ac.nz W <http://humanethics.massey.ac.nz>

Appendix C

Questionnaire

Introduction

Kia ora koutou ngā kaiako | Dear teachers,

This questionnaire explores New Zealand primary school teachers' experiences and perceived preparedness with respect to teaching children with chronic illnesses. It is open to all New Zealand registered and provisionally registered teachers who teach in the primary school sector (i.e., teachers of Year 1 to 6 students).

Please ensure that you have read and understood the [Information Sheet](#) prior to completing this questionnaire.

You will not be asked to provide information that could identify any student(s).

You are under no obligation to complete this questionnaire. If you do choose to participate, you have the right to refuse to answer any question. You may also withdraw, before submitting your responses, by exiting out of the questionnaire. Submission of your responses at the end of the questionnaire will imply consent.

1. I have read and understood the [Information Sheet](#) for this study, and I give my informed consent to participate.

- Yes
- No

Demographic Information

This section of the questionnaire asks you to provide non-identifying information about you, your role, and the school that you work at. Your responses to these questions will help the researcher to know how representative their research sample is.

2. Please specify your gender:

- Male
- Female
- Transgender
- Prefer not to disclose

3. In which region of New Zealand do you currently work?

- Northland
- Auckland
- Waikato
- Bay of Plenty
- Gisborne
- Hawkes Bay
- Taranaki
- Manawatu-Wanganui
- Wellington

- Tasman
- Nelson
- Marlborough
- West Coast
- Canterbury
- Otago
- Southland
- Chatham Islands

4. What year level(s) do you currently teach? (Select all that apply)

- Year 1
- Year 2
- Year 3
- Year 4
- Year 5
- Year 6

5. Which of the following best characterises the school that you currently work in?

- State School (not integrated)
- State Integrated School
- Private School
- Kura Kaupapa Māori
- Bilingual School
- Special Education School (includes Regional Health Schools)
- Other (please specify):

6. How many years of experience do you have as a registered teacher?

- 1 - 2 years (Provisionally Registered Teacher)
- 3 - 6 years
- 7 - 15 years
- 16+ years

7. Does your school have a formal policy for you to follow with respect to assessing and monitoring the school-based needs of chronically ill children?

- I am uncertain
- No
- Yes

Definition of Chronic Illness

As you read through this questionnaire, please keep the following definition in mind:

For the purpose of this study, a chronic illness is defined as *any medical condition that persists or recurs over a long period of time, disrupts daily functioning, and necessitates ongoing medical intervention*. Examples include asthma, cancer, and diabetes.

The following are **NOT** considered chronic illnesses for the purpose of this study:

- Behavioural concerns (e.g., attention-deficit-hyperactivity disorder, autism spectrum disorder)
- Mental health concerns (e.g., depression, obsessive compulsive disorder)
- Physical disabilities (e.g., blindness, deafness)
- Intellectual disabilities.

8. Please list your tertiary qualification(s):

9. How did your tertiary education prepare you to teach children with chronic illnesses?

- No training
- Some reference** was made to the potential educational implications of chronic illness, but it was not addressed as a stand-alone topic
- Chronic illness was included as **a stand-alone topic** within one of my courses/papers
- Chronic illness was included as **an optional course/paper** within my training programme
- Chronic illness was included as **a compulsory course/paper** within my training programme
- I cannot recall

10. Have you had any formal workplace training that specifically addressed the educational implications of chronic illnesses?

- No
- Yes (please provide a brief description including the illness[es] that the training related to):

11. If you were to engage in professional development to increase your knowledge about the potential educational implications of chronic illnesses, what mode of training would you MOST prefer?

- Live presentation
- Recorded presentation
- Full day workshop with presentations from education and health professionals
- Face-to-face training course (over several days)
- Online training course (over several days)
- Other (please specify):

12. Please rate your understanding of the following relatively common chronic illnesses and their potential implications for children and young people's learning:

	Very Limited Understanding	Limited Understanding	Good Understanding	Very Good Understanding
Arthritis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eczema	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart Disease (including Rheumatic Heart Disease)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inflammatory Bowel Disease (including Crohn's Disease)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kidney Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. From Question 12 above, which illness would you say that you know the LEAST about?

- Arthritis
- Asthma
- Cancer
- Diabetes
- Eczema
- Epilepsy
- Heart Disease (including Rheumatic Heart Disease)
- Inflammatory Bowel Disease (including Crohn's Disease)
- Kidney Disease

Please think about the illness that you identified in Question 13 above (the one that you know the least about). If a child with this illness was to join your class tomorrow:

14. What (if any) questions or concerns might you have with respect to teaching this child?

15. What would be your approach to learning about this child and their school-based needs? (Comment on the processes, strategies, people, and/or resources that you would draw on).

16. Thinking about this hypothetical child joining your classroom, please rate the extent to which you would agree or disagree with the following:

	Completely disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Completely agree
I feel confident in my ability to continue to meet the chronically ill child's learning needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel apprehensive about discussing the child's school-based needs with their parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel apprehensive about communicating with health professionals about the needs of the chronically ill child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how to access additional educational supports for the chronically ill child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The child's physical well-being is more of a priority for me than their academic progress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel comfortable about explaining the child's chronic illness to their classroom peers (with child and parental permission)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have the time to adapt my teaching in order to meet the needs of the child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. During your teaching career, and to the best of your knowledge, have you taught one or more child with:

	Yes	No
Arthritis	<input type="radio"/>	<input type="radio"/>
Asthma	<input type="radio"/>	<input type="radio"/>
Cancer	<input type="radio"/>	<input type="radio"/>
Diabetes	<input type="radio"/>	<input type="radio"/>
Eczema	<input type="radio"/>	<input type="radio"/>
Epilepsy	<input type="radio"/>	<input type="radio"/>
Heart Disease (including Rheumatic Heart Disease)	<input type="radio"/>	<input type="radio"/>
Inflammatory Bowel Disease (including Crohn's Disease)	<input type="radio"/>	<input type="radio"/>
Kidney Disease	<input type="radio"/>	<input type="radio"/>

18. At your current school and in the past 24 months, have you taught a child with ANY chronic illness?

- Yes
- No

Please think of ONE chronically ill child that you have taught at your current school in the past 24 months and answer the following questions with respect to that child:

Reminder: For the purpose of this study, a chronic illness is defined as *any medical condition that persists or recurs over a long period of time, disrupts daily functioning, and necessitates ongoing medical intervention*. Examples include asthma, cancer, and diabetes.

The following are **NOT** considered chronic illnesses for the purpose of this study:

- Behavioural concerns (e.g., attention-deficit-hyperactivity disorder, autism spectrum disorder)
- Mental health concerns (e.g., depression, obsessive compulsive disorder)
- Physical disabilities (e.g., blindness, deafness)
- Intellectual disabilities.

Note: Some children with chronic illnesses have co-occurring conditions. For example, a child with epilepsy might also have a diagnosis of ADHD. If the child that you are thinking of has a co-occurring condition, please think primarily about the chronic illness (e.g., epilepsy) when responding to the following questions.

19. What chronic illness(es) does this child have?

20. How did you FIRST learn that this child had a chronic illness?

- The parent of the chronically ill child
- The chronically ill child themselves
- Principal
- Student file
- School nurse
- Another teacher
- Special education needs coordinator (SENCO)

- I cannot recall
- Other (please specify):

21. What resources did you rely on for information about the needs of this child? (Select all that apply)

- Parent of the chronically ill child
- The chronically ill child
- Principal
- Student file
- School nurse
- Special education needs coordinator (SENCO)
- Social worker
- Other teacher(s)
- Medical professional(s)
- Ministry of Education personnel
- Regional health school
- Specialist outreach teacher
- District health nurse
- Educational psychologist
- Published empirical research
- Websites about the illness
- Written materials (e.g., pamphlets about the illness)
- Training workshops
- Counsellor
- Teacher aide
- School administrator
- Other (please specify):

22. Of the resources that you identified in Question 21, above, which would you rate as the THREE most valuable sources of information? (Select only 3)

- Parent of the chronically ill child
- The chronically ill child
- Principal
- Student file
- School nurse
- Special education needs coordinator (SENCO)
- Social worker
- Other teacher(s)
- Medical professional(s)
- Ministry of Education personnel
- Regional health school
- Specialist outreach teacher
- District health nurse
- Educational psychologist
- Published empirical research
- Websites about the illness
- Written material (e.g., pamphlets) about the illness
- Training workshops
- Counsellor
- Teacher aide
- School administrator

- Other (please specify)

23. Please outline any challenges that you encountered when teaching this child (if any):

24. If you encountered challenges in the course of teaching this child, what strategies and supports helped you to overcome them?

25. What additional information, resources, or supports (if any) would you have found beneficial in order to meet this child's school-based needs?

26. What advice would you give to a teacher who has just learned that a child with this chronic illness will be joining their classroom?

27. General Reflections

Thinking about your own practices and experiences, do you have any further reflections with respect to teaching chronically ill children?

28. Follow-Up Interview

Would you be willing to be contacted with regard to a possible follow-up interview? If so, please provide your email address below. Please note: by providing your email address, your questionnaire responses will be identifiable to the researcher and research supervisor. You will not be identified in research reports or publications. Follow-up interviews will be conducted via phone and are anticipated to take between 30 and 45 minutes.

- I do not wish to receive further information about a possible follow-up interview
- Please contact me with further information regarding a follow-up interview, my email address is:

Thank you, you have reached the end of the questionnaire. Please click DONE to submit your responses.

You will not be able to change or withdraw your responses after you submit.

If you would like to receive a summary of the research findings at the conclusion of this project, please email the researcher [REDACTED] with the subject line:

Request for Summary of Findings.

Tēnā rawa atu koe | All the best to you

Appendix D

Information for Principals



Institute of Education | Massey University
Private Bag 102 904 | North Shore Mail Centre
Auckland 0745 | New Zealand

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

QUESTIONNAIRE INFORMATION SHEET FOR PRINCIPALS

Tena koe ngā Tumuaki | Dear Principal,

My name is Nicola Adams and I am a student at Massey University studying toward a Master of Educational Psychology. I am conducting research investigating New Zealand primary school teachers' experiences and perceived preparedness with respect to teaching children with chronic illnesses such as asthma, cancer, diabetes, eczema, epilepsy, heart disease, inflammatory bowel disease, and kidney disease. It is intended that this study will provide an understanding of how best to prepare and support teachers who have a chronically ill child in their classroom.

This is a nationwide survey and your school's email address was obtained from the Education Counts school directory. I would like to invite you to share this study with your Year 1 to 6 teachers. Their frontline insights and recommendations would be invaluable.

Clicking on the link at the bottom of this email will take staff to the Information Sheet and the questionnaire. I have also attached the full Information Sheet for your reference.

What does this study involve?

This study will be conducted in two phases.

1. Online Questionnaire

Phase one involves an online questionnaire that is expected to take about 20 minutes to complete. There are 28 questions, which are a range of multiple choice, rating scale, ranking, and open-ended questions. The questionnaire will be accessible online, via SurveyMonkey. At the end of the questionnaire, participants will be asked to indicate whether they would be willing to be contacted about the second phase of the study.

2. Phone-Interview

The second phase of the study will involve semi-structured phone interviews with a small number of the questionnaire participants. The intention of these interviews will be to follow up on general trends or ambiguities in the questionnaire data and to gain a more in-depth understanding of teachers' experiences and recommendations with regard to teaching chronically ill children.

Who are the participants of this study?

The invitation to participate is extended to all New Zealand registered or provisionally registered teachers working in primary schools nationwide (i.e., teachers of Year 1 to 6 students).

Project contacts

If you have any questions regarding this research project please feel free to contact me. Alternatively, you can contact one of my research supervisors Associate Professor Roseanna Bourke (r.bourke@massey.ac.nz) or Mr Terence Edwards (t.edwards@massey.ac.nz).

If you would like to receive a summary of the research findings at the completion of this project, please email me ([REDACTED]) with the subject line: *Request for Summary of Findings*.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 17/21. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz

Survey link

Submission of the questionnaire signals a teacher's informed consent to be part of the project. The questionnaire will be open from today **until Thursday 31st August 2017**.

Link to questionnaire: <https://www.surveymonkey.com/r/2KZBD6F>

With best regards,

Nicola Adams - Primary Researcher
Massey University Student

[REDACTED]

Appendix E

Information for Teachers



Institute of Education | Massey University
Private Bag 102 904 | North Shore Mail Centre
Auckland 0745 | New Zealand

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

QUESTIONNAIRE INFORMATION SHEET FOR TEACHERS

Kia ora koutou ngā kaiako | Dear teachers,

My name is Nicola Adams and I am a student at Massey University studying toward a Master of Educational Psychology. I am conducting research investigating New Zealand primary school teachers' experiences and perceived preparedness with respect to teaching children with chronic illnesses. I would like to invite you to share your insights and experiences.

About the research

In Aotearoa New Zealand, a significant proportion of the school-aged population suffers from a chronic illness. Advanced medicines and assistive technologies enable most children with chronic illnesses to participate in mainstream schooling. However, their medical conditions can disrupt their learning journey, and they may be at risk of social, emotional, and behavioural maladjustment and academic underachievement. It is important to understand what training and support you need, as teachers, to ensure a positive school experience for chronically ill children.

What is a chronic illness?

For the purpose of this study, a chronic illness is defined as any medical condition that persists or recurs over a long period of time, disrupts daily functioning, and necessitates ongoing medical intervention. Examples of childhood chronic illnesses include arthritis, asthma, cancer, diabetes, eczema, epilepsy, heart disease, inflammatory bowel disease, and kidney disease.

Given the specific focus of this study, the following are not considered chronic illnesses:

- Behavioural concerns (e.g., attention-deficit-hyperactivity disorder, autism spectrum disorder);
- Mental health concerns (e.g., depression, obsessive compulsive disorder);
- Physical disabilities (e.g., blindness, deafness);
- Intellectual disabilities.

Why am I receiving this invitation?

This is a nationwide survey and your school's email address was obtained from the Education Counts directory. The invitation to participate is extended to all New Zealand registered or provisionally registered teachers working in the primary school sector (i.e., teachers of Year 1 to 6 students).

Why should I participate?

It is intended that the results of this study will highlight pre- and in-service training priorities for our teaching workforce and will provide insight into how best to prepare teachers to support the learning needs of these children. It is also hoped that this study will stimulate further local and international inquiry into the educational impact of chronic illness and how to ensure chronically ill children have access to a positive educational experience. Your frontline insights would be invaluable.

What does this study involve?

This study will be conducted in two phases:

1. Online Questionnaire

Phase one involves an online questionnaire that is expected to take about 20 minutes to complete. There are 28 questions, which are a range of multiple choice, rating scale, ranking, and open-ended questions. The questionnaire will be accessible online, via Survey Monkey, from Wednesday 16th August 2017 to Thursday 31st August 2017. At the end of the questionnaire, participants will be asked to indicate whether they would be willing to be contacted about the second phase of the study.

2. Phone-Interview

The second phase of the study will involve semi-structured phone interviews with a small number of the questionnaire participants. The intention of these interviews will be to follow up on general trends or ambiguities in the questionnaire data and to gain a more in-depth understanding of teachers' experiences and recommendations with regard to teaching chronically ill children.

Will questionnaire responses be anonymous?

Unless a participant indicates that they are willing to be contacted for a follow-up interview, they will not be asked to provide information that could identify them, their school, or their student(s). Any such information that is provided inadvertently, will be removed from the data. The risk of unwittingly identifying a participant or their school will be minimised by including a wide range of participants and schools.

Participants who indicate that they are willing to be contacted about the second phase of the study will be asked to provide an email address. This will mean that their questionnaire responses are identifiable to the researcher and the research supervisors. All reasonable measures will be taken to ensure that their responses remain confidential, and their email addresses will be removed from the data prior to data analysis. No participant will be identifiable in the report. At no point in the study will a participant be asked to provide information that could identify any student.

What will happen to questionnaire responses?

Responses to this questionnaire will be stored on SurveyMonkey and will only be accessible by the researcher and her supervisors. The research findings will be presented in a written thesis and may be published in journals or conference proceedings. The data will be stored for two

years before being disposed of by the first supervisor. If you would like to receive a summary of the research findings at the completion of this project, please contact the primary researcher ([REDACTED]) with the subject line: *Request for Summary of Findings*.

Participant's rights

You are under no obligation to accept this invitation. If you choose to participate, you have the right to decline to answer any particular question and to withdraw from the questionnaire up until the point of submission. Submitting your responses at the end of the questionnaire will imply consent.

Participant care

Given the subject matter, completing this questionnaire may cause you to view your teaching practices from a new perspective and you may find it valuable to debrief with a colleague. You are encouraged to seek professional advice and support in the event that your participation in this questionnaire evokes feelings of discomfort, stress, or grief.

Ethics

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 17/21. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz

Project contacts

If you have any questions regarding your participation in this questionnaire then please feel free to contact the researcher or one of the research supervisors:

- **Nicola Adams - Primary Researcher**
Massey University Student
[REDACTED]
- **Roseanna Bourke - First Supervisor**
Associate Professor in Learning and Assessment Massey University
r.bourke@massey.ac.nz
- **Terence Edwards - Second Supervisor**
Senior Professional Clinician Massey University
t.edwards@massey.ac.nz

Appendix F

Education Gazette Advertising

Online Content

Kia ora koutou ngā kaiako | Dear teachers,

You are invited to share your insights and recommendations as part of a Massey University student's research project. The study explores New Zealand primary school teachers' training and experiences with respect to teaching children with chronic illnesses such as asthma, diabetes, epilepsy, and cancer.

The first phase of this study involves an online questionnaire, which is open to all New Zealand registered or provisionally registered teachers working in the primary school sector (i.e., teachers of Year 1 to 6 students).

Chronic medical conditions can disrupt a child's learning journey, and these students may be at risk of social, emotional, and behavioural maladjustment and academic under-achievement. It is intended that the results of this study will contribute to an understanding of the training, strategies, and supports that can help teachers to ensure a positive learning experience for chronically ill children.

If you are interested in participating, please follow the link below to access a detailed information sheet and the questionnaire itself: <https://www.surveymonkey.com/r/2KZBD6F>

This research is being conducted under the supervision of Associate Professor Roseanna Bourke (r.bourke@massey.ac.nz) and Mr Terence Edwards (t.edwards@massey.ac.nz) as part of the requirements of a Master of Educational Psychology with Massey University. If you have questions about this project, please do not hesitate to contact me or one of the research supervisors.

Nāku noa atu | Yours sincerely,
Nicola Adams – Primary Researcher

Print Content

Childhood chronic illnesses can present challenges for teaching and learning and it is important to ensure that teachers are well prepared and supported to work with these children. NZ registered and provisionally registered primary school teachers are invited to share their insights and recommendations on this topic as part of a Massey University student's research project. If you are interested in participating, an information sheet and the questionnaire itself can be accessed from www.surveymonkey.com/r/2KZBD6F

Project contacts: ([REDACTED]); Associate Professor Roseanna Bourke (r.bourke@massey.ac.nz).

Appendix G

Interview Information Sheet



Institute of Education | Massey University
Private Bag 102 904 | North Shore Mail Centre
Auckland 0745 | New Zealand

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

PHASE II: INTERVIEW INFORMATION SHEET

Kia ora | Greetings

Thank you for your recent participation and completion of the online questionnaire '*New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses*'. I am following up on your indication that you were willing to receive further information about a follow-up phone interview. I would welcome your participation in this next phase and have provided further information below.

About the Interview

I am conducting research exploring New Zealand primary school teachers' training and experiences with respect to teaching children with chronic medical conditions such as diabetes, epilepsy, and cancer. Following on from the questionnaire you have completed, I would like to conduct individual interviews with up to 12 registered (or provisionally registered) primary school teachers. While the questionnaire responses provided rich data covering a broad understanding of the experience of teaching chronically ill children, these follow-up interviews will add specific insight and depth. This will allow me to further explore and understand the issues and joys for teachers and any perceived training or support needs you think important.

Interview Procedures

Interviews will be conducted between now and the **3rd November 2017** at a time convenient to you. These interviews will be conducted via phone (or Skype) so that it does not limit the choice of geographic areas for teachers to participate. Each interview will take between 30 and 45 minutes. If you provide informed consent to tape the interview, it will be audio recorded using a digital recorder. I will then transcribe the recording and provide a copy of the transcript to you to review and approve before the information is analysed. However, if you would rather not be taped, I will take notes and send you a summary statement for you to check.

Data Management

All audio files and transcripts will be stored without personal identifiers, and participants will not be identified in the written thesis or any subsequent publication of this research. Extracts

from the edited transcripts may be used in the dissemination of the research. The interview data will be stored for two years before being disposed of by the first supervisor.

Participant's Rights

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

- decline to answer any particular question;
- withdraw at any time, without providing a reason;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

Project Contacts

This study is being conducted in partial fulfillment of a Master of Educational Psychology at Massey University and is supervised by Associate Professor Roseanna Bourke (r.bourke@massey.ac.nz) and Mr Terence Edwards (t.edwards@massey.ac.nz). If you have questions about this research, please do not hesitate to contact me ([REDACTED]) or one of the above-named supervisors.

Low Risk Notification

This phase of the project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 356 9099 ext 86015, email humanethics@massey.ac.nz.

Participant Care

Participation in this interview may cause you to view your teaching practices from a new perspective and you may find it valuable to debrief with a colleague. As a participant in this research, you are encouraged to seek professional advice and support in the event that your participation in the interview evokes feelings of discomfort, stress, or grief.

How do I take part?

If you would like to take part in an interview, please complete and return the attached *Consent Form* to me via email by Wednesday 4th October 2017. On the consent form, please indicate a convenient day and time(s) for an interview (between 9th and 27th October 2017).

Nāku noa atu | Yours sincerely,

Nicola Adams

Massey University, MEdPsych student
[REDACTED]

Appendix H

Interview Consent Form



Institute of Education | Massey University
Private Bag 102 904 | North Shore Mail Centre
Auckland 0745 | New Zealand

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

PHASE II: INTERVIEW CONSENT FORM

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

I agree to this interview being sound recorded (please indicate). YES NO

I wish to have my recordings returned to me (please indicate). YES NO

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

Signature: _____ Date: _____

Full Name (printed): _____

Email address: _____

Interviews will be conducted between the **9th October and 27th of October 2017**. Please indicate a suitable day and time below.

- Convenient Date(s):
- Convenient Time(s):
- Phone:
- (or) Skype:

Please tick this box if you would like to receive a *Summary of Findings* at the completion of this project.

Please scan and return the completed form to [REDACTED] by 4th October 2017.

If you are unable to scan the form, please complete and attach as a word document to [REDACTED]

Appendix I

Thank You Email for Teachers not Selected for Phase II



Institute of Education | Massey University
Private Bag 102 904 | North Shore Mail Centre
Auckland 0745 | New Zealand

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

Thank You

Kia ora | Greetings

Thank you for your participation and completion of the online questionnaire '*New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses*' last term. At the end of the questionnaire, you kindly indicated that you would be willing to receive further information with regard to a possible follow-up interview. I am touching base to let you know that, given the nature of the follow-up questions and the timeframes associated with this project, I have only interviewed a select few participants based on their recent experiences working with children with chronic illnesses. While I will not be conducting any further interviews, I wanted to make contact and thank you for your contribution to this project, it is sincerely appreciated.

If you have any questions or comments, please do not hesitate to contact me, and if you would like to receive a copy of the *Summary of Findings* when it is available, do let me know.

With thanks and best wishes for the end of the year.

Nicola Adams

Massey University MEdPsych Student
[REDACTED]

This phase of the project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 356 9099 ext 86015, email humanethics@massey.ac.nz.

Appendix J

Template Interview Schedule

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

TEMPLATE INTERVIEW SCHEDULE

Introduction	<p>[Greeting, introduction, ask about their day]</p> <p>Thank you again for your participation in the earlier survey and for your willingness to take part in this interview.</p> <p>The purpose of the interview is to gain further insight into your experiences with regard to teaching children with chronic illnesses. I have prepared some questions, but I want you to feel free to direct the conversation if there is anything that you want to share in particular.</p> <p>I have not started recording, but if you agree I will shortly start taping the interview using a digital recorder. After our call, I will transcribe the interview and return the transcript to you for your approval before I use any of the data in my research.</p> <p>You do not have to answer any of the questions that I put to you, and you can withdraw at any time, without giving a reason.</p> <p>Do you have any questions for me before we get started?</p> <p>Is it OK for me to start recording and begin the interview?</p> <p>[Start recording]</p> <p>I have now started recording.</p>
Experience	<p>Recap their questionnaire responses: In the questionnaire, you shared your experience teaching a child with [illness].</p> <p><i>Have you had experience teaching other chronically ill children in the past 24 months? [If yes]: What illnesses did this/these child/ren have? And how has your experience of teaching this/these child/ren been similar or different to the child with [illness from questionnaire]?</i></p>





<p>Training</p>	<p>Recap their questionnaire response: In the questionnaire you indicated that you had [<i>some/no</i>] tertiary training specifically related to chronic illnesses, and [brief outline of in service training] - ask clarifying questions if necessary [e.g., mode of training?].</p> <p>[If had some training] <i>What did you find most valuable about this training and was there anything that the training did not cover which you might have found valuable?</i></p> <p>Probes:</p> <ul style="list-style-type: none"> ● Coverage of <u>learning and social</u> implications versus medical management. ● Any advice you would put forward to trainers/educators? <p>OR [if they have not had any training] <i>Do you think that training would have been beneficial? If yes why? If not, why not?</i></p> <p>Probes:</p> <ul style="list-style-type: none"> ● [If yes] What type of training, by who, what content? ● How has your general teacher training contributed to understanding of how to support the learning needs of these children?
<p>Communication/Relationships</p>	<p>Summarise questionnaire finding: One of the central themes to emerge from the questionnaire data is the importance of working collaboratively and having strong relationships and open communication with the child and everyone involved in their care. <i>Would you agree? Why/why not?</i></p> <p><i>In your experience what have been the facilitators and barriers to communication/collaboration?</i></p>
<p>Child Voice</p>	<p>[Recap what they shared about taking the lead of students and ask to elaborate] OR</p> <p><i>Thinking about the chronically ill child/ren you have worked with recently, what role have they played in planning/management of their educational supports?</i></p>
<p>Access to supports/funding</p>	<p>Recap their questionnaire response: [If concerns were raised in the questionnaire data, recap and ask to elaborate where appropriate].</p> <p>[If they did not comment on this in the questionnaire]: <i>What has been your experience of accessing additional funding or supports/resources for the chronically ill child/ren that you have taught?</i></p> <p>Probes:</p>

	<ul style="list-style-type: none"> ● Thoughts on the process including timeliness ● Adequacy of funding/supports/resources ● Particularly valuable supports/resources ● Comparison between illnesses (if applicable) ● Comparison with accessing funding/support for other support needs (e.g., ESOL)
<p>Social Implications</p>	<p>Recap their questionnaire response: [Recap any comments they made in the questionnaire about the impact on peers or strategies for including peers - ask any clarifying questions]</p> <p><i>In your experience, how have other children in the classroom reacted to their peers' illness(es)?</i></p> <ul style="list-style-type: none"> ● Has there been any clear implications for their classroom relationships? ● [If negative implications for relationship] how have these been managed? ● What information have you shared with peers and how? ● Have you involved peers in supporting child?
<p>Closing</p>	<p>That brings me to the end of my pre-prepared questions. Is there anything more that you would like to share?</p> <p>Thank you again for taking the time to participate in this interview. I will transcribe our conversation and send through a copy of the transcript for your review and approval. I will not make use of the interview data unless you approve the transcript.</p> <p>You noted on the consent form that you do/do not wish for the recording to be returned to you. Is this still the case? (If they do want recording - explain how this will be delivered to them)</p> <p>Do you have any questions for me?</p> <p>Thank you, I wish you and your students all the very best.</p>

Appendix K

Resources for Teachers

<u>RESOURCES FOR TEACHERS</u>	
<p>Even Kids Get Arthritis Kids with Arthritis New Zealand (KWANZ) have developed this video to support parents in educating teachers about Juvenile Idiopathic Arthritis. http://www.kidswitharthritis.org.nz</p> <p>Back to School for Children with Cancer A guide for teachers developed by the Child Cancer Foundation. https://www.childcancer.org.nz/assets/Uploads/1731-B2SBrochOCT11.pdf</p> <p>Diabetes in Schools Guidelines for schools and early childhood centres. https://www.starship.org.nz/for-health-professionals/new-zealand-child-and-youth-clinical-networks/clinical-network-for-children-and-young-people-with-diabetes/diabetes-in-schools/</p> <p>Eczema in Schools Eleven top tips for schools. http://www.healthshare.health.nz/docs/default-source/skin-resources/eczema-at-school-top-tips.pdf?sfvrsn=2</p> <p>Children and Asthma An information booklet on symptoms, inhaler use, medicines, physical activity, and asthma-friendly schools. https://www.asthmafoundation.org.nz/resources/children-and-asthma</p>	<p>Epilepsy and Teaching Epilepsy information and support services for teachers. http://epilepsy.org.nz/epilepsy_and_teaching.cfm</p> <p>Educating Children with Cardiac Conditions Authored by Teresa Kedzlie, a past-teacher at the Paediatric Cardiac Unit and Mary Crosbie, a heart parent, this booklet provides useful information for teachers of children with cardiac conditions. http://www.heartkids.org.nz/others/book/hcbookindex.htm</p> <p>School, Sports, and Inflammatory Bowel Disease A guide for teachers of children with IBD. https://crohnsandcolitis.org.nz/Schools%2C+Sport+and+IBD</p> <p>Kidney Kids Kidney Kids NZ is a parent-driven organisation set up to meet the needs of children who have kidney disorders. http://www.kidneykids.org.nz/</p> <p>Kids Health Kids Health provides information and links to support services for a wide range of illnesses. https://www.kidshealth.org.nz/</p>

<u>PARTICIPANT CARE</u>
<p>In the event that participation in this research has prompted feelings of stress, grief, or loss, you are encouraged to seek professional support. The following are suggested resources only.</p> <p>Skylight Skylight is a national not-for-profit trust that provides education, training, and support for professionals, agencies, and individuals who assist those dealing with trauma, loss, and grief.  0800 299 100  skylight@paradise.net.nz  https://skylight.org.nz</p> <p>Talking Works Talking Works is a nationwide directory of professional counsellors, psychotherapists, and psychologists.  https://www.talkingworks.co.nz</p>

Appendix L

Authority for Release of Transcript



Institute of Education | Massey University
Private Bag 102 904 | North Shore Mail Centre
Auckland 0745 | New Zealand

New Zealand Primary School Teachers' Preparedness to Teach Children with Chronic Illnesses

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview between myself and Nicola Adams.

I agree that extracts from the edited transcript may be used in the disseminations of the research.

Signature: _____

Full Name (printed): _____

Date: _____

**Please scan and return the completed form to the researcher
[REDACTED] by 3rd November 2**