

# A 'Pretty Normal' Life with Bronchiectasis. An Interpretive Description

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Doctor of Health Science

**Julie Blamires**

SCHOOL OF HEALTH CARE PRACTICE  
Primary Supervisor Dr Annette Dickinson

## Abstract

Bronchiectasis is a chronic respiratory disease in which recurrent infection and inflammation cause abnormal and permanent dilatation of the airways resulting in recurrent respiratory infections and a chronic wet cough. It is a significant health issue in New Zealand, particularly amongst Māori and Pacific children, young people and those from lower socioeconomic backgrounds. Using interpretive description methodology, this research explored the day-to-day life experience of a group of young people with bronchiectasis. Literature on bronchiectasis focuses largely on the improvements in diagnosis, treatment and management, with little known about the impact it has on people who live with the condition. The intention of this research is to bridge the gap and further the existing and emerging body of knowledge so that health professionals may understand the significance of bronchiectasis for the young person, come to know what is most important to them and then act and develop careplans to improve well-being and health outcomes.

Purposive sampling was used to recruit participants. The data were collected from 15 young people with bronchiectasis using semi-structured one on one interviews. Interviews were transcribed and data were managed by NVivo 9 software. Analysis of the participants' experience, using an interpretive description approach, resulted in a conceptual description of life with bronchiectasis as '*Pretty Normal*'. '*Pretty Normal*' life is made up of two co-existing views of life: '*Just normal*' and '*Normal to me*'. These views represent how the young people balance the ups and downs of normal adolescence while learning to accommodate and adapt to the challenge of living with bronchiectasis. '*Just normal*' represents a view of life where bronchiectasis is in the background and young people see themselves as being like their peers. '*Normal to me*' represents a different view, where the presence of bronchiectasis is more visible and three circling thematic elements are keenly felt: sick and tired, life interrupted and looking after self. '*Sick and tired*' describes the significant everyday symptom burden experienced by the young participants. '*Life interrupted*' illustrates how participants' lives are occupied with tolerable and intolerable interruptions that impact on school, social interactions, sport and family. '*Looking after self*' describes how participants were learning how to keep themselves well and safe and learning how to take control and make decisions. All three of these

thematic elements influenced and challenged participants' view of themselves and encouraged them to find ways of coping and integrating their experiences into a new view where they described their life experience as *'Pretty Normal'*.

## Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, not material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: 

Date: 19 June 2020

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## Ethics Approvals

Ethical approval was obtained from:

- Health and Disability Ethics Committees: (HDEC Ref 17/NTA/163). August 2017

Locality agreements were obtained from:

- Counties Manukau District Health Board: Reg number 445. October 2017
- Auckland District Health Board: Reg number 7736. September 2017

## Chapter 1. Introduction

This thesis presents an interpretive description study. The purpose of this research was to explore the day-to-day life experience of young people with bronchiectasis. This chapter provides an overview of the context of this doctoral work including background information about the topic, implications for the New Zealand context, rationale for the project and an overview of the methodology including theoretical underpinnings. In addition, I will position myself as researcher. The chapter concludes with an overview of the thesis structure.

### Background

Bronchiectasis is a progressive chronic lung disease that causes permanent dilation and changes to the function and structure of the airways (Dogru et al., 2005; Lesan & Lamle, 2019). It occurs most commonly as a result of previous lung disease or following an insufficiently treated lung infection (Lesan & Lamle, 2019). The resulting damage to the bronchi, from these previous insults, leaves the lungs vulnerable to further infections, damage and subsequent inflammation. This is known in the bronchiectasis literature as the vicious cycle or Coles cycle (Cole, 1997; Lesan & Lamle, 2019; Polverino et al., 2017). This cyclical process of infection and inflammation results in a clinical presentation that includes chronic cough, purulent sputum, reduced exercise tolerance, increased work of breathing, fatigue and recurrent respiratory exacerbations (O'Donnell, 2008; Twiss, Metcalfe, Edwards, & Byrnes, 2005). The most common clinical symptoms at presentation are a chronic productive cough accompanied by a previous history of recurrent chest infections (Chang, Redding, & Everard, 2008; Lesan & Lamle, 2019). Other significant clinical signs identified in the literature include wheeze (Singleton et al., 2014), dyspnoea (Karadag et al., 2005; Karakoc, Yilmaz, Altintas, & Kendirli, 2001), and signs of chronic lung disease such as chest wall deformity and finger clubbing (Chang, Masel, Boyce, Wheaton, & Torzillo, 2003; Edwards, Twiss, & Byrnes, 2004; C. Johnson & Haworth, 2016; Twiss, Metcalfe, Edwards, & Byrnes, 2005). Diagnostic criteria includes detailed history, clinical signs and symptoms and confirmation of disease with a high resolution computed tomography (HRCT) (Chang et al., 2010; Chang et al., 2015a; Chang, Byrnes, & Everard, 2011; Dogru et al., 2005; Hayes, Long, McCoy, & Sheikh,

2014). Bronchiectasis may occur at any age; however, often develops in childhood as result of recurrent respiratory infections, for example pneumonia and/or pertussis (Redding, 2009; Redding & Byrnes, 2009). It can only develop secondary to a wide range of clinical disorders including severe infections, rheumatological disorders, connective tissue disorders, cystic fibrosis, immune deficiencies and/or ciliary disorders (Chalmers & Elborn, 2015; Redondo, Keyt, Dhar, & Chalmers, 2016). Despite this long list of potential causes, often the underlying source is not found (with 30%-70% classified as idiopathic) (Edwards, Asher, & Byrnes, 2003; McCallum & Binks, 2017; Munro et al., 2011; Twiss, Metcalfe, Edwards, Byrnes, et al., 2005).

The signs and symptoms of bronchiectasis are similar to other chronic lung diseases and can include chronic wet cough, chest wall deformity, finger clubbing, increased work of breathing, excess sputum production and recurrent lower respiratory tract infections (Edwards, Twiss, et al., 2004). All of these contribute to significant morbidity, lost school days, decreased exercise tolerance, parental absences from work and potentially other developmental, social and psychological effects for children and young people (Chang et al., 2010; Edwards, Twiss, et al., 2004). Treatment is aimed at limiting these effects through reduction of the worst symptoms, slowing progression of disease and reducing the impact of symptoms, exacerbations and hospitalisation. In addition, the focus of management is on improvement in both the *quantity* and *quality* of a patient's life (Polverino et al., 2017). Guidelines updated in 2015, provide the foundation for management and treatment, with the most common treatment involving exercise, chest physiotherapy for airway secretion clearance and antibiotics (Bibby, Milne, & Beasley, 2015; Butler et al., 2008; Chang et al., 2015b; McCallum & Binks, 2017). The symptoms of chronic cough, sputum production and chest infection require a commitment to regular chest physiotherapy and equate to considerable time burden for young people. Further, the symptoms of bronchiectasis potentially create disability, psychological stress and emotional and social challenges for the young person growing up with bronchiectasis. Studies in children and caregivers with bronchiectasis indicate that bronchiectasis impacts negatively on psychological status and quality of life (Bahali et al., 2014; Gokdemir et al., 2014; Hamzah et al., 2011).

## Bronchiectasis in New Zealand

In New Zealand, the rates of bronchiectasis are far higher than other countries that report on prevalence, such as Finland (Saynajakangas, Keistinen, Tuuponen, & Kivela, 1997) and the United States (Seitz et al., 2010). Recent NZ statistics suggest these numbers are continuing to increase with the most current population prevalence reported as 180 per 100,000 people (Telfar-Barnard & Zhang, 2019). Of particular importance, are the growing statistics relating to children and young people with bronchiectasis. The Asthma and Respiratory Foundation (2019) reported 123 new children under 15 were diagnosed with bronchiectasis in 2017. This figure is nearly 3½ times higher than reported in 2001/2002 (13.2 per 100, 000 in 2014 compared with 3.7 per 100,000 in 2001/2002). Those most affected by bronchiectasis in New Zealand are Māori and Pacifica children and young people (Munro et al., 2011; Twiss, Metcalfe, Edwards, Byrnes, et al., 2005). Young Pacifica people, under 15 years of age, are at higher risk of bronchiectasis and are more likely to be hospitalised because of it (11 times higher risk, for Pacific child). Similarly, Māori have high rates of both bronchiectasis and hospitalisation when compared to New Zealand European children and young people (Edwards, Asher, et al., 2003; Telfar-Barnard & Zhang, 2019). These ethnic inequalities and health disparities are well documented and have been identified in studies in Australia (Chang, Brown, Toombs, Marsh, & Redding, 2014) and the United States (Singleton et al., 2014), and are closely linked with issues relating to socioeconomic disadvantage including poverty, substandard housing, malnutrition, barriers to medical care and inadequate education (Edwards, Asher, et al., 2003; Kolbe & Wells, 1996)

In addition to having high rates of bronchiectasis, New Zealand has severe disease. It is not uncommon for children to have had a productive cough for some time prior to receiving their diagnosis of bronchiectasis (Eastham, Fall, Mitchell, & Spencer, 2004; Twiss, Metcalfe, Edwards, Byrnes, et al., 2005); subsequently resulting in signs of chronicity and significant impact of disease. Munro et al. (2011) found 34% of children had finger clubbing and chest wall deformity and almost half of the children and young people (45%) showed declining lung function over time despite follow-up in a tertiary respiratory clinic (Twiss, Stewart, & Byrnes, 2006). The severity of disease and level of lung involvement suggests prolonged insult to the lungs; and

illustrates how delay in diagnosis can result in long term affects beyond childhood into adolescence and young adulthood.

## Young people

According to the Youth Development Strategy Aotearoa, young people are defined as those “young women and young men moving between childhood and adulthood, aged 12 to 24 years” (Ministry of Youth Affairs, 2002, p. 11). Several terms such as ‘youth’, ‘teenager’, ‘adolescent’ and ‘young adult’ are used interchangeably to describe this significant time of change and development that occurs between childhood and when a person emerges into adulthood. In New Zealand, youth make up 19% of the total population and are an ethnically diverse group (Clark et al., 2013; Statistics New Zealand, 2013). According to the culture and ethnicity results from the Youth 2000 survey series 2012 report, where young people were allocated to one ethnic group only, 48% of students were categorised as European, 20% Māori, 14% Pacific, 12% Asian and 6% other (Clark et al., 2013).

A chronic illness is defined as a condition that persists for a long time (usually longer than three months), affects the young person’s normal daily activities and is rarely cured completely (Compas, Jaser, Dunn, & Rodriguez, 2012; Mokkink, van der Lee, Grootenhuys, Offringa, & Heymans, 2008). Young people living with any type of chronic illness face a number of challenges and must learn to cope with the symptoms and the self-management requirements over the course of their life (Lavery, O'Neill, Elborn, Reilly, & Bradley, 2007). In addition, they must deal with the usual physical, social and psychological changes associated with their developmental age while simultaneously facing ongoing demands of illness management (Holman & Lorig, 2000). As young people with chronic illness experience the same developmental stages as their healthy peers, such as struggling to gain independence and find their place in the world, they may also find themselves facing the reality that their lives and their futures might be quite different to those of their friends (Shearer, Rempel, Norris, & Magill-Evans, 2013). A number of studies suggest that young people with chronic disease are more vulnerable to adverse psychosocial outcomes, at greater risk of psychosocial stress and emotional disturbance, and have poorer quality of life (QOL) when compared to their healthy peers (Kourkoutas, Georgiadi, & Plexousakis, 2010; Samson et al., 2009; Santos et al., 2016; Sawyer, Drew, Yeo, &

Britto, 2007). Despite the ups and downs of chronic illness, young people strive for a sense of normalcy amidst the chaos and utilise various coping strategies to help them achieve this (Cartwright, Fraser, Edmunds, Wilkinson, & Jacobs, 2015; Ferguson & Walker, 2014; Heaton, Räisänen, & Salinas, 2016; Potì, Emiliani, & Palareti, 2018). There is a dearth of literature specifically surrounding the understanding of bronchiectasis from the young person's perspective; however, there are a number of papers that have explored other chronic lung conditions such as young people with cystic fibrosis (Badlan, 2006; Higham, Ahmed, & Ahmed, 2013; Jessup & Parkinson, 2010), primary ciliary dyskinesia (Behan, Rubbo, Lucas, & Galvin, 2017; Schofield & Horobin, 2014) and asthma (Mammen, Rhee, Norton, & Butz, 2017; H. Rhee, Wenzel, & Steeves, 2007). These papers are useful as we can glean some knowledge about how young people experience growing up with a lung disease. However, these papers do not adequately address the unique perspective of young people with bronchiectasis in New Zealand.

### Rationale and purpose of the study

Bronchiectasis is a chronic lung disease that has a major impact on children and young people in New Zealand. In addition to having larger numbers affected (when compared to similar countries), the severity of disease in New Zealand is also significantly greater (Munro et al., 2011; Seitz et al., 2010; Twiss, Metcalfe, Edwards, Byrnes, et al., 2005). Māori and Pacific Island people, and those from a lower socioeconomic background, are disproportionately affected by bronchiectasis (Telfar-Barnard & Zhang, 2019). Given these facts about bronchiectasis and New Zealand, it is not surprising that local studies in children and young people have focused on incidence and prevalence rates, aetiology and severity of disease (Edwards, Asher, et al., 2003; Munro et al., 2011; Singleton et al., 2014; Twiss, Metcalfe, Edwards, Byrnes, et al., 2005); compared airway clearance techniques and adherence (Butler et al., 2008); and described the experiences of accessing care from the perspective of children and families (Jepsen, Charania, & Mooney, 2018). International and local studies in adults with bronchiectasis have drawn attention to the links between socioeconomic deprivation, ethnicity, readmission rates, mortality and exacerbations in bronchiectasis (de Boer, Fergusson, Ellyett, Lewis, & Wilsher, 2018; Roberts, Lowndes, Milne, & Wong, 2012); and described hospital admissions in order to



estimate burden of disease and financial cost (Bibby et al., 2015). The daily subjective experience of living with bronchiectasis has been explored primarily in the adult literature and highlights how the burden of symptoms impact on daily activities and quality of life (Dudgeon, Crichton, & Chalmers, 2018; McCullough, Tunney, Elborn, Bradley, & Hughes, 2015; Spinou et al., 2013), as well as describe how bronchiectasis is physically and psychosocially disruptive (Lavery et al., 2007; Wei-jie et al., 2019).

No literature—locally or from abroad—has focused exclusively on young people’s subjective experience of living with bronchiectasis. Given the significant burden of disease experienced by Pacific and Māori, this study provides an opportunity to shed light on the experiences of a high needs group. In addition, and importantly, this study will illuminate the experience from the unique perspective of a group of young people living in New Zealand. Understanding this experience is essential for improving patient outcomes and developing health care strategies that provide support and opportunities for healthy youth development that addresses the unique needs of young people growing up in New Zealand (Jardine, Glinianaia, McConachie, Embleton, & Rankin, 2014). Therefore, the purpose of this study is to discover how young people with bronchiectasis describe their everyday life experience and to understand what matters most to them. Ultimately, increased understanding of the issues will enable clinicians to act and plan care in a way that positively influences the lives of these young people and enable the young people, themselves, to be more actively engaged in management of their bronchiectasis.

## Research aim and question

The intent of the research question is to gain a deeper understanding of a complex experiential subjective clinical phenomenon; and to share this understanding with other health professionals. When developing the question it was deemed important to do it in a way that would enable participants flexibility to share their personal experiences and perceptions, while allowing for the application of inductive description and an interpretive lens (Thorne, 2016). The specific aim of this study is to understand the young people’s everyday life experience of living with bronchiectasis. The key objective is to find commonalities and differences between the experiences of young people with bronchiectasis and to understand the dynamics of this experience. Analysis of commonalities and differences will aim to determine

common themes and concepts that accurately reflect the experience of these young people living in New Zealand, while recognising the individual-ness of this experience. The following research question framed this qualitative study: How do young people with bronchiectasis describe their day to day life?

### Design of the study

Given the limited understanding of how young people experience bronchiectasis, and the purpose of the study being to further the existing and emerging body of knowledge through creating new knowledge relating to the experience of living with bronchiectasis, a qualitative approach was deemed to be the most fitting method for this study. The methodological design used for this research is interpretive description (ID). When I set out upon this doctoral journey, I explored several methodological texts including grounded theory, phenomenology and ethnography; and eventually, Sally Thorne's ID. As soon as I read about ID, I immediately felt a strong synergy and connection to its pragmatic, flexible and clinically applicable attributes. ID is a relatively new qualitative methodology that, epistemologically, stems from nursing while encompassing key components from the more traditional qualitative methodologies such as grounded theory and phenomenology (Thorne, 2016). ID is an analytical, inductive approach that arose out of the need to create a way of understanding human health and illness that is applicable to the clinical context (Hunt, 2009). It is aligned with a naturalistic and constructivist orientation and as such is well suited to studies that wish to create rich and detailed descriptions of a phenomena (Parente Pinheiro Teodoro et al., 2018). ID assumes the position that researchers are not satisfied with description alone; and, it is believed that exploration of meanings and explanations hold the potential to yield application in practice (Thorne, 2008).

The intention of this study is to contribute more in-depth knowledge to the overall understanding of the experiential perspectives of young people with bronchiectasis. The intention of this research is to bridge the gap in our knowledge so that health professionals may understand the significance of the bronchiectasis for the young person, come to know what is most important to them and then act and plan care to improve well-being and health outcomes. Through bringing this experience to the surface, the young person will potentially experience a more

collaborative healthcare approach and an increased ability to effectively self-manage their bronchiectasis. ID enabled me to position myself in such a way that participants could share their reality of the experience. This study offers insights into the impact that bronchiectasis has on to their day-to-day life.

### Positionality of the researcher

ID accepts and expects that the researcher is positioned within the context of the study (Thorne, 2016). It is, therefore, important to acknowledge the role I play as instrument in this study—as a nurse and a novice researcher. From the onset of this doctoral journey I knew that I wanted to conduct a study that had potential to impact positively on the clinical care of young people with bronchiectasis. Over a period of 25 years I have been privileged to work alongside children, young people and their families, and have gained valuable insights into how they experience illness. I have spent a great deal of my career working with young people with chronic conditions and a significant amount of time caring for children, young people and families with chronic respiratory disease. My interest in bronchiectasis stems from my time as a respiratory nurse specialist where I cared for many young people with both bronchiectasis and cystic fibrosis. I could see many parallels between the two conditions; however, could see that those with bronchiectasis experienced their illness differently and had a need to have their voices heard. Later in my career, I co-conducted a qualitative study on young people with juvenile idiopathic arthritis exploring their transition experience. I enjoyed the opportunity to hear the view of these young people who openly shared the good and the bad of their transition to adult services. This cemented for me the value of conducting qualitative research and reaffirmed my specific interest in young people's health and well-being. My experience of being a children and young person's nurse underpins my ontological position and influences my theoretical position concerning qualitative research.

### Organisation of the thesis

The thesis structure consists of eight chapters.

- **Chapter One** presents the background underlying this research. A brief introduction to the study design and the aim are outlined. Also included is my positionality as the researcher.

- **Chapter Two** provides a comprehensive review of the literature that is divided into three sections. The first section provides information about what is known about bronchiectasis as a chronic condition, including how it is defined, common symptoms, treatment and significant issues relating to the New Zealand context. The second part describes the literature relating to the subjective personal patient experience of bronchiectasis. The third section summarises the literature about young people's experience of living with chronic illness.
- **Chapter Three** outlines the methodology underpinning of this study. This chapter is divided into three sections. First, the chapter outlines the origin, history and philosophical assumptions underpinning ID methodology explaining its purpose and utilisation for guiding this study. Next, the theoretical and personal assumptions that scaffold the study are explained, including consideration of the theoretical allegiances, disciplinary orientation and personal position of the researcher. In the third section, the study design will be discussed including sampling, data collection and analysis processes. The ethical considerations relevant to the research process are considered.
- **Chapter Four** introduces the study participants and includes an overview of demographic information and geographical distribution. In addition, this chapter introduces the findings and the overarching conceptual claim developed.
- **Chapter Five** reports on the first thematic element entitled 'Sore and Tired'.
- **Chapter Six** reports on the second thematic element entitled 'Life Interrupted'.
- **Chapter Seven** reports the third thematic element, 'Looking after Self'.
- **Chapter Eight** discusses the overarching conceptual claim that life with bronchiectasis is 'Pretty Normal'.
- **Chapter Nine** provides a brief overview of the findings and synthesises these in relation to what is currently known about the topic and what new knowledge this study brings. The implications of the research for clinical practice and potential future research are considered.

- **Appendices** are referred to throughout the thesis and are found following chapter nine and the references.

## Conclusion

This chapter has provided a brief description of the topic and rationale for this study. An overview of the research methodology and design has been presented and the content of the thesis chapters outlined. Chapter two will explore the literature surrounding bronchiectasis, the experience of living with bronchiectasis and the chronic illness experience in young people.

## Chapter 2. Literature Review

This chapter will review existing literature surrounding young people's experience of life with bronchiectasis. To provide the most comprehensive theoretical platform for this research, the literature is presented in three parts. The first part of the literature review will provide general information about bronchiectasis; how it is defined, aetiology, common symptoms and management, as well as key data about the New Zealand context. The second part will move beyond the condition itself to review the literature that explores the subjective experience of living with bronchiectasis. Part three will provide a summary of what is known about how young people experience chronic illness, of any kind, in daily life.

### Bronchiectasis

Bronchiectasis is a chronic suppurative lung disease characterised by a wet and/or productive cough, recurrent respiratory infections and radiological findings that include bronchial damage and abnormally dilated airways (Goyal, Grimwood, Marchant, Masters, & Chang, 2016; Pasteur et al., 2000; Polverino et al., 2017). Several mechanisms have been proposed to explain the pathogenesis of bronchiectasis; however, the most widely accepted is a cycle of inflammation and infection that starts with a primary insult causing bronchial damage and inflammation (King, 2009b). The damage caused by this insult impairs the natural drainage of bronchial secretions (mucociliary clearance) and causes chronic or recurrent infection, more bronchial wall damage, airflow obstruction and further inflammation that perpetuates a cycle, known as Cole's cycle (Cole, 1997; Pasteur et al., 2000). In the past, infectious diseases such as measles, tuberculosis and pertussis were common causes of bronchiectasis (Chang, 2011; A. T. Hill, Pasteur, Cornford, Welham, & Bilton, 2011). Improvements with childhood immunisations, nutrition, sanitation, living conditions and better access to healthcare and antibiotics have decreased the rates of these infectious conditions. Subsequently, the incidence of bronchiectasis has also declined in most resource rich western countries (Laverty, Jaffe, & Cunningham, 2008; McCallum & Binks, 2017; Saynajakangas et al., 1997). Despite this improvement, bronchiectasis continues to be a significant health issue for certain populations within Australia (Chang et al., 2003; O' Grady, Torzillo, & Chang, 2010),

Alaska (Singleton et al., 2000) and New Zealand (Edwards, Asher, et al., 2003; Twiss, Metcalfe, Edwards, & Byrnes, 2005).

**Aetiology.** There is a variety of preceding disease processes that can cause bronchiectasis, and these vary among populations and age groups. Three systematic reviews focus on underlying aetiology in children and young people, and point to the strong relationship between social disadvantage and ethnicity (Brower, Del Vecchio, & Aronoff, 2014; Kapur & Karadag, 2011; McCallum & Binks, 2017). Post infection/pneumonia remains the most common cause (Eastham et al., 2004; Kapur & Karadag, 2011; Karadag et al., 2005; Kumar, Lodha, Kumar, & Kabra, 2015; Nathan, Muthusamy, Thavagnanam, Hashim, & de Bruyne, 2014; Singleton et al., 2000), followed by immune deficiency (Eastham et al., 2004; Karakoc et al., 2001; Li et al., 2005) and primary ciliary dyskinesia (Bahali et al., 2014; Gokdemir et al., 2014; Koh, Lee, Sun, Sung, & Chae, 1997; Santamaria et al., 2009). In addition to these underlying aetiologies, and despite improvements in diagnosis, all three systematic reviews support the assertion that a large proportion of bronchiectasis cases are idiopathic. In the most recent review by McCallum and Binks (2017) the numbers of cases with unknown aetiology ranged from 0-55% with three New Zealand studies contributing to the unknown aetiology numbers reported. These New Zealand studies reported idiopathic aetiology as the most common reason for bronchiectasis (45-54%); followed by post infection (23-25%) and immune deficiency (6-12%) (Edwards, Asher, et al., 2003; Munro et al., 2011; Twiss, Metcalfe, Edwards, Byrnes, et al., 2005).

**Clinical characteristics and diagnosis.** Cough is the most common presenting symptom of bronchiectasis. However, the presence of a chronic wet cough does not always lead to a timely diagnosis of bronchiectasis. In the past, there was confusion over the labelling of a prolonged moist cough, where clinicians would use labels such as bronchitis and chronic suppurative lung disease. However, Chang et al. (2008) have provided clarification in this regard where bronchiectasis is considered to be the end point along a clinical spectrum of chronic suppurative lung disease. Children and young people who have symptoms of bronchiectasis, but do not have confirmation of disease with a chest HRCT scan, are described as having chronic suppurative lung disease rather than bronchiectasis. The diagnosis of

bronchiectasis requires a chest HRCT scan showing the typical features of bronchial (airway) dilatation and bronchial wall thickening in one or more lobes of the lung (Chang, Grimwood, Mulholland, & Torzillo, 2002).

As mentioned previously, a recurrent wet or productive cough is the most commonly reported symptom in low and middle income countries such as India (Kumar et al., 2015) and Turkey (Karadag et al., 2005); and is also a highly reported clinical feature among indigenous populations in Alaska, Australia and New Zealand (Chang et al., 2003; Singleton et al., 2014). Despite its importance as a clinical feature of bronchiectasis, cough may be underreported and perhaps under-appreciated (2013). When investigating the burden of cough, Marchant et al. (2008) found that 80% of children in their study had presented for medical assessment or treatment more than five times before the cough resolved or a cause was found. In another New Zealand study, it was found that one third of newly identified cases of bronchiectasis reported a persistent cough for >3 years (Twiss, Metcalfe, Edwards, & Byrnes, 2005). Often children presenting with a wet cough are misdiagnosed with asthma, a potential reason for why diagnosis may be delayed in children (Al Subie & Fitzgerald, 2012). This 'delay in presentation', despite the presence of typical symptoms (chronic cough, recurrent respiratory infections) over prolonged periods of time, was a common theme in the literature, and resulted in delayed diagnosis and an increased severity of disease by time of diagnosis (Edwards, 2008; Johnston, Strachan, & Anderson, 1998; Weinberger & Fischer, 2014). This notion is supported in papers that report 39-82% of children with four or more lobes of the lung involved and 61-93% with bilateral lung disease at the time of diagnosis (Callahan & Redding, 2002; Eastham et al., 2004; Edwards, Metcalfe, Milne, Thompson, & Byrnes, 2003; Singleton et al., 2000). In New Zealand, a study by Munro et al. (2011) reported 34% of children with finger clubbing and chest wall deformity, and almost half of the children and young people (45%) showing declining lung function over time despite follow-up in a tertiary respiratory clinic. This level of lung involvement suggests prolonged insult to the bronchi (lower airways) and suggests that many of these children and young people have had recurrent symptoms for some time prior to diagnosis and intervention by health services. The themes of late presentation, delay in diagnosis and indigenous disparity was a common finding in both the New Zealand studies and



those from abroad (Chang et al., 2003; Edwards, Asher, et al., 2003; Kapur & Karadag, 2011; Karadag et al., 2005; Singleton et al., 2000; Twiss, Metcalfe, Edwards, & Byrnes, 2005).

Other significant clinical signs and symptoms in children and young people include wheeze (Banjar, 2007; Kim et al., 2011; Singleton et al., 2014); dyspnoea (Karadag et al., 2005; Karakoc et al., 2001), fever (Kim et al., 2011), failure to thrive (Singleton et al., 2014) and signs of chronic lung disease such as chest wall deformity and finger clubbing (Chang et al., 2003; Edwards, Twiss, et al., 2004; C. Johnson & Haworth, 2016; Twiss, Metcalfe, Edwards, & Byrnes, 2005). In adult patients, other important signs reported with bronchiectasis include fatigue, decreased exercise capacity, haemoptysis and chest pain (Hester et al., 2012; King, Holdsworth, Farmer, Freezer, & Holmes, 2012; King, Holdsworth, Freezer, Villanueva, & Holmes, 2006; Ozalp et al., 2012). These symptoms are not clearly reported in studies with children and young people although Kapur, Masters, Morris, et al. (2012) proposed chest pain as a minor criteria in their system for defining exacerbations in children with bronchiectasis.

Most of these papers describe signs and symptoms in relation to clinical findings rather than patient descriptions of what it is like to experience these symptoms. This is an important differentiation that is not well explored in the bronchiectasis literature. Understanding what these symptoms mean for children and young people is important because not only does it influence treatment plans and management, it also influences mood, quality of life, psychological status and informs health professionals about what matters most to patients in relation to living daily with bronchiectasis (Armstrong, 2003).

**Treatment and monitoring.** In 2002, a multidisciplinary workshop was held where a working group developed consensus recommendations for managing bronchiectasis in indigenous children and adults living in rural and remote regions in Australia. These recommendations were based on systematic reviews available at the time and expert opinion (Chang et al., 2002). Since the publication of these recommendations, there have been several updates and iterations with recommendations now including New Zealand (Chang et al., 2010; Chang et al., 2015a). The aim of bronchiectasis management is to optimise general well-being,

control symptoms, reduce the number of exacerbations and prevent further disease progression in order to prevent decline in lung function (Chang et al., 2015a).

Hospitalisations, medications and airway clearance techniques (ACTs) are the primary treatment strategies discussed in the literature (Bibby et al., 2015; Butler et al., 2008; McCallum & Binks, 2017). ACTs are prescribed to “facilitate mucociliary clearance, optimize sputum expectoration, relieve symptoms, and improve well-being” (Lee, Burge, & Holland, 2015, p. 1). There are various different types of ACTs available and the technique selection and recommendations are individualised to the patient’s age, maturity and developmental stage (Lee et al., 2015).

In terms of monitoring disease progression and measuring success of treatment, bronchiectasis management plans mirror that of cystic fibrosis with chest HRCT scans and pulmonary function tests considered the most suitable measures (Chang et al., 2003; Edwards, Metcalfe, et al., 2003; McCallum & Binks, 2017). In particular, HRCT enables clinicians to quantify the progression of structural lung changes (Edwards, Narang, et al., 2004). In children and young people with bronchiectasis, this is important given there is some evidence that following intensive treatment children can show, on repeat HRCT, improvement in both airway wall thickening and bronchial dilation (Gaillard, Carty, Heaf, & Smyth, 2003).

**Bronchiectasis in the New Zealand context.** My research project takes place in New Zealand and, therefore, it is important to understand the context in relation to bronchiectasis. In New Zealand, the national incidence of bronchiectasis is high. The first review of paediatric bronchiectasis was based in Auckland and described an alarmingly high estimated prevalence of paediatric bronchiectasis at 1 in 6000 (Edwards, Asher, et al., 2003). In addition to having high rates of bronchiectasis, Edwards et al. (2003) also drew attention to the severity of disease present in children and young people, with 93% having bilateral widespread disease and 64% having more than four lobes of their lungs involved.

In another New Zealand study, Twiss, Metcalfe, Edwards, Byrnes, et al. (2005) reported an overall incidence rate of 3.7 per 100,000 for those under 15 years of age. Although both studies were published over 15 years ago, it seems that the rates of bronchiectasis in New Zealand still pose a reason for concern. The most recent report on the national impact of respiratory disease in New Zealand 2000-2017 provides

important information about the impact of respiratory disease, including bronchiectasis. In 2017, 123 new cases of bronchiectasis in children aged under 15 years were found, compared to 104 in 2016 and 103 in 2015, indicating a significant increased incidence. Hospitalisation rates for children and adults with bronchiectasis also increased by 45%, over the study period, and mortality rates increased by 88% (Telfar-Barnard & Zhang, 2019). These findings show a marked increase since those measured in 2001/2002 by Twiss et al. and indicate that bronchiectasis continues to represent a significant issue in New Zealand.

Twiss, Metcalfe, Edwards, Byrnes, et al. (2005) found the highest incidence rates for bronchiectasis to be among Pacific children and young people (17.8 per 100,000) and Māori children and young people (4.8 per 100,000) compared to 1.5 per 100,000 for New Zealand European. Similarly, Munro et al. (2011) study focused on a group of children in Auckland with bronchiectasis and found a predominance of Māori and Pacific children with over half (67%) residing in the most deprived areas. The most recent statistics continue to support the relationship between ethnicity and bronchiectasis, and point to a significant increase in these numbers over time, with the report on the national impact of respiratory disease indicating rates for Pacific now at 28.0 per 100,000 and 17.7 for Māori (Telfar-Barnard & Zhang, 2019).

As a group, Māori children and young people have worse health than non-Māori across a wide range of health status indicators, including higher rates of hospitalisation and mortality related to respiratory and infectious diseases (Duncanson et al., 2019; Ministry of Health, 2013). These health disparities between Māori and non-Māori are largely a result of socio-economic factors (e.g., income, employment, housing, and education) where Māori continue to live in the most deprived areas and are at significant disadvantage (Ministry of Health, 2015). Pasifika peoples are similarly disproportionately represented in low socio-economic areas and have low incomes and high levels of unemployment. Pacific young people are more likely to experience overcrowding and live in lower decile areas and, consequently, have poorer health status in key areas such as infectious and respiratory disease (Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). There is no doubt that social and economic circumstances contribute to New Zealand's high rates of bronchiectasis among young Māori and Pacific people.

## Summary of the literature on bronchiectasis

Bronchiectasis is a chronic lung disease characterised by irreversible bronchial dilation and chronic inflammation, resulting in chronic wet cough (bpac<sup>nz</sup>, 2012). It results from a variety of underlying conditions; however, commonly aetiology is unknown (although likely to often be post-infectious). The most common symptom is a chronic productive cough and recurrent chest infections. Bronchiectasis disproportionately affects Māori and Pacific young peoples and people from lower socioeconomic communities. New Zealand has high rates and high severity of disease in young people compared to other countries.

This first part of the literature review has provided important background information on bronchiectasis as a chronic illness, with a focus on statistics, symptoms and treatment. Useful as background information for this research, it has not covered extrapulmonary features and/or emotional and psychosocial issues a young person might face living day to day with bronchiectasis. In the second section, findings related to the subjective experience of living with bronchiectasis will be reviewed.

## Children and young people's experience of bronchiectasis

This section reviews current understanding related to the experience of children and young people with bronchiectasis. The intention was to discover what is known about how bronchiectasis impacts other non-clinical, psychological and social aspects of life. As the literature related to young people with bronchiectasis was limited, two different search strategies were utilised: the first focused specifically on literature relating to children and young people with bronchiectasis; and the second on qualitative studies related to bronchiectasis in children and adults.

**Experience of bronchiectasis for children and young people.** The first search strategy used the following key search words: 'adoles\*/child/young person\*' AND bronchiectasis\* plus combinations of the following terms; 'impact on'; 'living with'; 'experience of'; or 'challenge of' or 'quality of life'. The following databases were searched: CINAHL, EBSCO, SAGE and Google Scholar. The search was limited to English and the years 2000-2019. Even given this substantial time frame, and the inclusion of children, the results of this search yielded only 41 studies. Following exclusion of observational studies, randomised controlled trials, genetic and

microbiological studies, non–primary research articles (letters, commentaries, and reviews), the number reduced to eight (Bahali et al., 2014; Gokdemir et al., 2014; Hamzah et al., 2011; Jepsen et al., 2018; Kapur, Masters, Newcombe, & Chang, 2012; Lovie-Toon et al., 2019; Nathan et al., 2014; Pifferi et al., 2010). Apart from the Jepson et al. (2018) qualitative study, which focused on the experience of mothers of children with bronchiectasis, the remaining papers focused on children and young people and the impact of bronchiectasis on health related quality of life (HRQoL). Table 1 provides an overview of these studies.

These studies offer some information about the experience of bronchiectasis from the patient’s perspective and provide a more holistic view of the patient experience moving beyond the disease itself. Most of the papers reviewed focused on health-related quality of life as the primary means of describing children and young people’s life with bronchiectasis. HRQoL is a multidimensional concept which includes the physical, psychological and social domains of health that impact and influences a person’s subjective evaluation of well-being. It is influenced by experiences, beliefs and perceptions (Solans et al., 2008; World Health Organization, 1995). Within the HRQoL research, a person’s quality of life is usually described in terms of how he/she copes in relation to his/her disease, and is an ‘individual’s evaluation’ of the QoL in relation to one’s own *personal* expectations (Asadi-Lari, Tamburini, & Gray, 2004). The standard and most common approach to researching HRQoL is with quantitative measurement tools in the form of patient questionnaires (either generic or disease specific). These questionnaires ask a series of questions about a variety of experiences (physical, mental, emotional and social) associated with the person’s illness and then often compare these to other measurable clinical symptoms. The intention is to assess the functional and subjective impact of the chronic illness and its treatment on the person (Cella & Nowinski, 2002, p. 10). HRQoL measurement tools can serve as a screening mechanism for identifying the physical and psychosocial health concerns of the child/ young person and parent that may otherwise have been overlooked (Varni, Seid, Knight, Uzark, & Szer, 2002).

Table 1 Children and young people and the impact of bronchiectasis on HRQoL

Authors	Research Question/Purpose	Methodology/Methods/Tools	Participants	Key Findings
(Bahali et al., 2014)	To evaluate the relationship between psychological symptoms and quality of life (QoL) and clinical variables in a cohort of children and adolescents with non-cystic fibrosis (non-CF) bronchiectasis.	Case control study PedsQL Child Depression Inventory (CDI)	N=76 Aged 8-17 years	Bronchiectasis associated with poorer QoL in childhood. Exacerbations, hospitalisations, severity, and frequency of symptoms (including dyspnoea) were found to negatively influence QoL. Anxiety, stress and depression may increase with age (i.e., the psychological burden worsens with age).
(Gokdemir et al., 2014)	To evaluate the health-related quality of life (HRQoL) in non-CF bronchiectasis children and also to assess the risk factors associated with HRQoL	Prospective study HRQoL and assess risk factors Short form 36(SF-36) St George's Respiratory Questionnaire (SGRQ) Form on socioeconomic status (SES) Lung function tests	N=42 Aged 9-18 years	Early diagnosis and regular follow-up important for improving QoL. As expected, the severity and frequency of symptoms are inversely related to the pulmonary function and the QoL scores. Patients with lower SES were diagnosed later.
(Hamzah et al., 2011)	To evaluate the HRQoL and associated factors in children with non-CF bronchiectasis.	Measurement in a clinic cohort: age of onset, age of diagnosis, frequency of symptoms Physical exam findings, LFT HRCT St George's Respiratory Questionnaire (SGRQ) and the Medical Outcomes Study Short Form-36	Numbers not reported Aged 5-14 years	Conference presentation. Minimal data presented. Worse pulmonary functions = lower QoL. Early diagnosis and treatment may increase QoL and survival.
(Jepsen et al., 2018)	To explore the health care experiences of mothers of children with bronchiectasis in the Counties Manukau District Health Board area of Auckland, New Zealand	Qualitative study Semi- structured interviews Thematic analysis	N=10 Mothers	Health provider parent relationship crucial for fostering positive health care experiences. Mothers' acquisition of knowledge facilitated empowerment. Mothers' perceptions of the quality and benefit of health services motivated to overcome access barriers.

Authors	Research Question/Purpose	Methodology/Methods/Tools	Participants	Key Findings
(Kapur, Masters, Newcombe, et al., 2012)	The burden of disease in paediatric non-CF bronchiectasis.	Cross sectional PC-QOL DASS-21	N=69 Children and parents Children aged <18 years	Parents of young children were more likely to report an impaired QoL. Pulmonary exacerbation significantly worsened QoL scores. Radiological extent, baseline lung function, underlying aetiology, and chronic upper airway disease did not influence the burden of disease scores. In any given month, approximately 1/4 of children within the cohort missed some period of school or childcare due to their bronchiectasis.
(Lovie-Toon et al., 2019)	To estimate healthcare resource use over a 12month period for children aged <18-years with bronchiectasis receiving ongoing care in paediatric respiratory medical centres.  To measure and correlate the health related QoL of parents/carers and children with bronchiectasis.	Prospective cohort Frequency of health care attendance Medication use, work/school absences Parent and child QOL and cough severity	N=85 <18 years	Health resource use in this cohort of children is high, reflecting their severe disease burden.
(Nathan et al., 2014)	To investigate the impact of chronic suppurative lung disease (CSLD) on growth and lung function in the child as well as QoL of the child and parent.	Cross-sectional Interviews PCQOL (parent cough QoL) DASS-21 (Depression, anxiety, stress)	N=60 Children>19years Included CSLD, bronchiectasis, CF, bronchiolitis obliterans	CSLD had a negative impact on growth, lung function and QoL. Children with CF had a better outcome in growth as well as better parental mental health compared to children with other aetiologies.
(Pifferi et al., 2010)	To determine the health impact of primary ciliary dyskinesia as well as the unmet needs in a group of patients.		N=78	Progressive worsening of the disease was observed and adherence to physiotherapy was found to be poor, particularly in adolescents. Patients with the highest treatment burden had worse QoL. Positive correlation between time since diagnosis and improvement in perceived QoL. No correlation between scores with age or age at diagnosis.

The papers in this review used several validated tools including: the Pediatric Quality of Life Inventory Child Version (PedsQL-C), The Child Depression Inventory (CDI), STAI-C, State-Trait Anxiety Inventories for Children, the Parent Cough-Specific Quality of life Questionnaire (PC-QOL), and the St George's Respiratory Questionnaire (SGRQ) (Newcombe et al., 2010; Nilsson, Buchholz, & Thunberg, 2012; Varni, Seid, & Rode, 1999; Wilson, 1997). These tools provide useful information about the psychological, physical and social impact of bronchiectasis; however, they have several limitations. For example, none of these tools are bronchiectasis specific, most rely on parent and child responses rather than focusing on young people's perspective, and all of these tools were designed in the context of European or North American setting so therefore, do not relate well to the unique ethnic and cultural context of New Zealand.

Despite the limitation of these tools, the papers did provide evidence that supports the notion that bronchiectasis impacts negatively on QoL and results in significant burden to children and their families. Bahali et al. (2014) compared HRQoL and psychological symptoms (such as depression and stress) in children and young people with bronchiectasis with a healthy control group. They evaluated and compared psychological symptoms and QoL in the two groups. In addition, they looked at the relationship between QoL, psychological symptoms-defined clinical variables within the bronchiectasis group alone. Overall, the results of this study indicated that having bronchiectasis results in poorer QoL in childhood and showed a relationship between decreased QoL and frequency of symptoms such as dyspnoea (Bahali et al., 2014). Although this study focused on frequency of symptoms rather than intensity or distress, it did highlight the importance of understanding the symptom experience from the patient's perspective. Gokdemir et al. (2014) and Hamzah et al. (2011) also found that exacerbations, hospitalisations, severity of disease and worse pulmonary functions tests, negatively influenced QoL in children with bronchiectasis. These studies tell us that while there is limited data on the relationship between bronchiectasis, psychological status and QoL in children and young people, there is certainly evidence that bronchiectasis does have an impact.

When compared to children with cystic fibrosis, children with bronchiectasis seem to fair worse in terms of QoL and morbidity. Studies assessing QoL in children



with chronic illness frequently make comparisons between children and young people with different disease clusters and/or comparisons with healthy children (Varni, Limbers, & Burwinkle, 2007). These comparisons often attempt to draw conclusions between groups of patients that have similar physical symptoms such as cough. As an example, children/young people with cystic fibrosis and congestive heart failure are frequently grouped and compared, and comparisons are often drawn between cystic fibrosis and bronchiectasis. In New Zealand, cystic fibrosis and bronchiectasis patients are cared for under the same model of care and tertiary service. Yet, the bronchiectasis cohort have missed more outpatient reviews, have greater decline in lung function over time and significant morbidity and mortality (Bibby et al., 2015; Edwards, Asher, et al., 2003; Munro et al., 2011).

In a Malaysian cross-sectional study by Nathan et al. (2014), comparisons were made between chronic supportive lung disease, including bronchiectasis, and cystic fibrosis and found that as a group, cystic fibrosis children fared better in relation to physical and parental mental health aspects than the chronic suppurative lung disease group participants. The children and young people with cystic fibrosis also had physical improvements with weight, body mass index and better mental health compared to the non-cystic fibrosis group. The explanation given for this was that cystic fibrosis patients had more intensive follow up and increased frequency of interaction with healthcare providers (Nathan et al., 2014). This correlation between regular clinic attendance and improved health related QoL was also found by Gokdemir et al. (2014). These studies that compare cystic fibrosis and non-cystic fibrosis bronchiectasis are useful, especially given the dearth of literature surrounding bronchiectasis as on its own; however, drawing conclusions should be done with caution. It is likely there are some similarities between how children and young people with bronchiectasis and those with cystic fibrosis experience symptoms and treatment. However, it is also likely there are unrecognised differences that potentially impact how these two groups live day-to-day with their illness. It is, therefore, pertinent to assess how young people with bronchiectasis experience their daily lives rather than translating what is known about cystic fibrosis and presume that this is the same experience for both groups.

Frequency of exacerbations and hospitalisations, that occurs with bronchiectasis, impact negatively on the normal activities of life such as attending school and work. Lovie-Toon et al. (2019) provided important information about the various ways that bronchiectasis impacts on day-to-day life for children and their families. They found that, on average, children experienced 3.3 exacerbations of bronchiectasis per year (defined as the child being unwell for  $\geq 3$ -days with at least one of the following symptoms: an increased cough, change in cough quality, or increased sputum volume or purulence); and in any given month 1/3 of children in the cohort missed some period of school or childcare due to bronchiectasis (Lovie-Toon et al., 2019).

The experience of frequent exacerbations and missing out on school undoubtedly impacts on the young person's normal day-to-day life, and this impact is felt by their family and caregivers. Two studies focused on the parents of children with bronchiectasis rather than the children themselves (Jepsen et al., 2018; Kapur, Masters, Newcombe, et al., 2012). A New Zealand qualitative bronchiectasis study and an Australian QoL study both identified the significance of exacerbations on parents' mental health and on parents' rated QoL in their young children, both indicating a significant burden during times of disease exacerbation (Kapur, Masters, Newcombe, et al., 2012). Understanding the caregiver/family experience of bronchiectasis is important as parents and families play a role in how children and young people themselves experience and manage their disease. Jepsen et al. (2018) found that the impact on the family was substantial where participants (mothers) described how keeping up with medications, physiotherapy and other health needs was challenging.

In summary, this section of the review revealed the following key insights relating to children and young people's experience with bronchiectasis:

- Children and young people suffer significant burden of disease
- Bronchiectasis negatively impacts QoL in childhood
- Exacerbations, hospitalisations, worsening lung function, plus severity and frequency of symptoms negatively impact on QoL
- Patients with cystic fibrosis and bronchiectasis experience chronic illness differently

- Health resource use in children with bronchiectasis is high

Although these studies have provided important insights into children, young people and their families' experience with bronchiectasis, the number of studies is small, and the use of different HRQOL measurement tools, as well as tools that were not designed for children, make it challenging to draw definitive conclusions. Only one qualitative study was identified in this review, focused on the parents' experience and, although interesting, does not provide enough information about the children and young person's point of view.

**Experience of bronchiectasis, qualitative studies.** Given the complex and subjective nature of the experience of living with bronchiectasis and the lack of qualitative studies in children and young people, a further search was undertaken. A new search strategy was employed looking specifically for qualitative studies relating to bronchiectasis. The following search terms were used: bronchiectasis\* and qualitative\* plus combinations of the following terms; 'impact on'; living with'; 'experience of'. CINAHL, EBSCO, SAGE and Google Scholar databases were utilised as well as a general Google search. The search was limited to English and the years 1995-2019. This resulted in 17 papers; however, only those that used a qualitative methodology in patients with bronchiectasis were included. There were no studies that focused on young people with bronchiectasis; however, four qualitative studies and one qualitative conference abstract that addressed the experience of life with bronchiectasis in adult patients were identified. See Table 2 for summary of studies.

Table 2 Qualitative studies and bronchiectasis

Authors	Research Question/Purpose	Methodology/Methods/Tools	Participants	Key Findings
(Lavery et al., 2007)	To assess physical and psychosocial impact of bronchiectasis, to determine whether patients with bronchiectasis are receptive to self-management and to identify any obstacles or sources of support for a disease-specific self-management programme.	Focus groups Grounded theory	N=32	Bronchiectasis impacts on patients' physical and psychosocial well-being. Patients demonstrated the potential to self-manage with strategies including self-regulation of medication and airway clearance. Perceived obstacles to self-management included lack of information and confidence.
(Spinou et al., 2013)	To understand patients' experience of living with non-CF bronchiectasis.	Exploratory Semi-structured interviews Grounded theory	N=28 median age 61 (37-78)	Poster- presentation Most worrying issues for participants were physical (58%), functional (17%), social (17%) and 'planning activities' categories (8%). New themes not previously reported: People assume smoking history; people assume the cough is due to flu; invisible symptoms; avoidance of public places.
(McCullough et al., 2015)	To explore patients' perspectives on adherence, factors affecting adherence decision making and to develop a conceptual model explaining this decision-making process in adults with bronchiectasis.	One on one semi-structured interviews Thematic analysis	N=16 >18 years	Belief about treatment, practicalities of managing, trust in health care professional and disease acceptance impact adherence. A variety of barriers and motivating factors influence adherence decisions.
(Dudgeon et al., 2018)	To identify the major contributors to QoL in bronchiectasis and to evaluate existing health related QoL questionnaires in bronchiectasis.	One on one semi-structured interviews Thematic analysis (Strauss and Corbin)	N=8	Bronchiectasis symptoms are highly individual. 5 key determinants of symptoms burden and QoL. Symptoms are on a continuum where daily symptoms become more severe or persistent. Symptoms impacted on daily life even when well.

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(Wei-jie et al., 2019)	To determine the health perception and behaviour in adults with bronchiectasis.	Semi-structured interviews	N=60 Aged 18-75 years	Varying patterns of symptoms perception and willingness to seek help. Medication adherence was sub-optimal. concerns about the adverse effects of bronchiectasis on fertility and infectiousness.
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It was a challenge to find qualitative studies relating to the experience of living with bronchiectasis. Despite the small number, the five studies do provide some insights into the subjective experience of bronchiectasis including: the burden of symptoms and impact on daily life, the individual and uniquely personal nature of the experience, the discrepancy in QoL questionnaires and the life disruptions endured.

The burden of symptoms and the impact on daily life and/or QoL were a common thread in these papers. In the study by Dudgeon et al. (2018) the nature, variation and impact of symptoms in adults with bronchiectasis was explored. The intention was to assess what contributes to QoL in patients with bronchiectasis and to determine if the current tools used to assess QoL adequately reflect the patients' experience (Dudgeon et al., 2018). Cough, dyspnoea and sputum production were significant symptoms for all participants but there was variation in how they described the impact these symptoms had on QoL. Some of the participants described chest tightness as an additional prominent symptom. This study showed that participants monitored their symptoms in their own individual and differing ways, sometimes managing exacerbations on their own and sometimes acknowledging they needed help. All participants felt that bronchiectasis impacted on their QoL in various ways including social embarrassment (due to cough and sputum), disturbances to sleep, anxiety around exacerbations and the stress of having to modify activities. This variation in health perception and behaviours, as well as reports of how symptoms of bronchiectasis could cause social embarrassment, was echoed in three out of five of the other studies (Lavery et al., 2007; Spinou et al., 2013; Wei-jie et al., 2019).

Bronchiectasis was described by the participants in these studies as a personal, individual and unique experience. This was evident in the way they talked about how they monitored symptoms, and how and when they sought help for managing their illness or exacerbations (Dudgeon et al., 2018; Wei-jie et al., 2019). This individualness was also highlighted in the way that participants talked about adherence. One study set out to explore patients' perspectives on adherence, factors affecting adherence decision making and planned to develop a conceptual model explaining this decision-making process (McCullough et al., 2015). The study found that when it came to making decisions about adhering to treatment and self-

management practices, participants made a personal and individual judgment about whether to adhere based on how they perceived the benefits. Some participants would only adhere when they perceived themselves to be getting sick, whereas others recognised that adhering to ACTs, for example, meant that their lungs and breathing felt better (McCullough et al., 2015). Some participants reported that the burden of time the treatment took also influenced their adherence, even if they had the knowledge about their disease and treatment. McCullough et al. (2015) also found that participants viewed the management of their bronchiectasis as part of daily life and described how social support from family contributed positively. These findings illustrate how the experience of adhering to treatment requirements for bronchiectasis is unique to each person and that, through balancing the pros and cons, people with bronchiectasis find their own personal way of managing the daily requirements. Recognising and exploring this with patients is an important way that healthcare professionals can ensure the best and tailored management plan for teaching patients.

One study, which had a specific focus on QoL tool development, provided interesting insights into the experience of living with bronchiectasis. The study, undertaken by Spinou et al. (2013), asked 28 adults with bronchiectasis to describe what it is like to have bronchiectasis and how it affects everyday life. The methodology used to analyse the qualitative data was not described; however, it was reported that the participants felt social anxiety about the assumptions made about their cough, embarrassment about the cough and worry about the invisibility of symptoms. Hearing more of the rich experiential data from the interviews and greater detail regarding how the headings were developed for the bronchiectasis specific QoL tool would have been interesting, especially given the discrepancy noted between how patients were asked to evaluate symptoms on questionnaires and how they themselves described symptoms in Dudgeon et al. (2018). Participants revealed that 'their' focus was on whether their symptoms had changed from their own baseline and whether they could achieve what they wanted to. They expressed that it was not possible to quantify something without this frame of reference, saying it was easier to say "*worse than usual*" then it was to say they had "*moderate difficulty*" carrying out a task (Dudgeon et al., 2018, p. 7). These findings show the highly

personal impact of bronchiectasis on a person's life and, although a small study, provide useful information about how QoL questionnaires do not always fully capture chronic illness experience.

Bronchiectasis was also described as disruptive to daily life. Lavery et al. (2007) assessed the physical and psychosocial impact of bronchiectasis and looked to identify obstacles and sources of support for a self-management programme. The study found that bronchiectasis was disruptive physically and psychologically. Participants identified how bronchiectasis disrupted their lives in a variety of ways such as reducing their ability to do housework or take part in leisure activities such as swimming (Lavery et al., 2007). The participants in this study were interested and willing to self-manage their disease but felt that lack of information and lack of confidence sometimes impeded their ability to do so.

The second section of the literature review uncovered what is known about the experience of bronchiectasis. The HRQoL studies provided knowledge about the ways that symptoms, exacerbations and treatment in bronchiectasis negatively impacts QoL of children and young people and their families. The qualitative studies provided insight into some general aspects of the bronchiectasis experience and indicated that living with bronchiectasis is an individual and varied experience that can be physically, socially and psychologically disruptive to daily life for adult patients. Although it is possible to extrapolate some of this knowledge and apply it to young people, the review of the literature has identified a significant gap in knowledge surrounding the young persons' experience of living with bronchiectasis.

### **Young people with chronic illness**

The third and final part of the literature review will identify themes that highlight how young people describe their experience of life with a chronic illness. Given the plethora of literature on this topic, the search looked to identify studies that addressed the experience of chronic illness from the youth perspective where a qualitative method was used to explore this experience. Electronic searches of the databases MEDLINE, CINAHL/Ebsco and Google Scholar were conducted to identify potentially eligible studies for inclusion in this review. Literature was also searched by hand cross-referencing from identified studies. Various combinations of the following search terms were used including: 'adoles\*' or teenager or 'youth' or



‘young person’ AND ‘chronic illness’ or chronic disease or long term illness AND ‘experiences’ OR ‘perception’. Studies were eligible for inclusion if they involved youth 12-24, were in English, used qualitative research methods and were research studies from the young people’s own perspective. Studies were excluded if they:

- Included data from children (below age 12) and/or adults (above age 24);
- focused on parents’ perspective only;
- focused on both parent and child/young person’s perspective (of which the data could not be separated);
- focused on children and young person’s perspective together;
- were seeking information for education or tool development.

The 29 studies included in this literature review included young people with a range of chronic illnesses including: Type 1 diabetes, cystic fibrosis, asthma, cancer, inflammatory bowel disease, chronic neurological condition, human immunodeficiency virus, sickle cell anaemia, spina bifida and chronic fatigue syndrome. Examination of the main findings from these studies revealed a variety of themes that contribute to understanding how young people describe the experience of living with chronic illness.

**Burden of self-management.** Having a chronic illness as a young person provides multiple challenges that relate directly to health care issues and permeate multiple aspects of young peoples’ lives (Secor-Turner, Scal, Garwick, Horvath, & Wells, 2011). Several studies revealed how young people felt significant burden from having a chronic illness and described how the day-to-day challenges of managing various aspects of their condition was difficult and sometimes frustrating (Babler & Strickland, 2015; Cartwright et al., 2015; Higham et al., 2013; Jessup & Parkinson, 2010; Kola, Turner, & Dhingra, 2015). Common examples were: the daily challenge of managing the physical impact of disease on school and sports, knowing what to do when they were feeling sick or having a flare of their illness and having to adhere to medication or treatment regimens (Chew, Carpenter, & Haase, 2019; Kola et al., 2015; Secor-Turner et al., 2011). Some of the young people described disease management as a generally positive experience; however, for some, the unpredictable nature and the potential for future suffering worried and influenced

how they experienced daily life with chronic illness and how they felt about self-management (Higham et al., 2013).

Surprisingly, adherence was not an overly strong theme in the studies reviewed; likely because of the focus on the young person's perspective as opposed to the healthcare professional or parents' view of how young people live with chronic illness. However, in Heaton et al. (2016) study, participants did describe how they selectively adhered to some elements of self-management tasks, but not to others; for example, among the diabetic patients the young people described how they would take their insulin but not do their blood tests. Several studies described how young people knew what they should be doing but sometimes just did not do it, forgot or could not be bothered (Babler & Strickland, 2015; Cartwright et al., 2015; Heaton et al., 2016; Sligo et al., 2019). By selectively adhering to some elements of management, the young people felt they had more control over managing their illness and felt as if they were gaining independence

**Taking control/taking over from parents.** One of the common experiences described by the young people was the task of separating from parents and learning to independently manage their own condition (Babler & Strickland, 2015). Learning to take over responsibility for their own condition was part of a transitional process that occurred at different times and ages, and varied between conditions (Heaton et al., 2016). The transfer of responsibility for illness management from parent to young person was described as a positive experience by many young people who saw it as an indicator of their developing independence and autonomy. However, they also acknowledged this process came with challenges (Chew et al., 2019). They described how they were learning to take on more responsibility but that sometimes a struggle between them and parents made it feel like a tug of war over responsibility. A good example was in the Babler and Strickland (2015) study where the young participants described how they felt they were doing their own care but that their parents wanted to still be involved. There was a sense that they needed to gain the trust and confidence of their parents before they felt truly free to manage their own condition (Babler & Strickland, 2015). Young people talked about how it was important for them to have a balance of adequate supervision by parents and an opportunity to grow and learn to manage their illness independently (Cartwright et al., 2015; Chew

et al., 2019; Ridosh, Braun, Roux, Bellin, & Sawin, 2011). As they begin this move to independence, they realised that managing a chronic illness was hard, challenging and sometimes frustrating; however, recognised it was important to gain the skills to deal with their illness in everyday life (Kola et al., 2015; Ridosh et al., 2011). Related to this theme of independence from parents, some young people talked specifically about transition to adult services. From their perspective, the two most important things in transition were being part of the transition process and having information (Reisinho & Gomes, 2016), and tailoring health care transition to the individual person (Secor-Turner et al., 2011).

Regaining or maintaining a sense of control over one's body and life with chronic illness was commonly described in the literature (Cartwright et al., 2015; Heaton et al., 2016). Young people used a variety of measures and/or clinical markers to determine how well they were maintaining control of their condition. This was different depending on the condition they had. For example, in young people with arthritis, it was how often they had flare ups; for those with cystic fibrosis, it was how often they had chest infections (Heaton et al., 2016). Being informed about, and understanding, their condition was highlighted as an important way that young people felt reassured and gained confidence in self-management (Potì et al., 2018). In addition, these things improved feelings of independence and made transition more positive (Heaton et al., 2016; Kola et al., 2015)

**Normal life.** Young people with chronic illness want to live as normal a life as possible (Sligo et al., 2019). This was a strong theme that permeated all the studies in the review. The young people talked about this notion of a normal life in a variety of ways. Some studies highlighted how young people described themselves as a 'normal person' who just happened to have a chronic illness (Higham et al., 2013; Horky, Sherman, Polvinen, Saxena, & Rich, 2017), while others described young people's constant challenge of striving for an identity separate to their illness as helping them to feel more 'normal' (Cartwright et al., 2015; Ferguson & Walker, 2014). Ferguson and Walker (2014) described the strong 'resistance of the young people in their study to being seen as different' with the young people initially telling a story of a regular teenage identity and only later revealing how chronic illness complicated their lives (Ferguson & Walker, 2014). Similarly, Horky et al. (2017) reported that the young

people they interviewed had “lightly integrated” (p. 6) into their identity their illness referencing this when required or asked about it.

Support and acceptance from friends played an important role in shaping how young people perceived themselves to be either normal or different from their peers (Chew et al., 2019). Several studies reported how young people used comparisons to their friends/peers as a way of describing how their condition had stopped them from having a ‘normal life’ (like others their age). Young people described how they could do the same things as their peers do and did not let their condition stop them from doing what they wanted to do (Cartwright et al., 2015; Heaton et al., 2016). This common desire to project an impression of ‘being normal’ and doing ‘normal’ things included talking about how they could and would partake in drinking alcohol, eat sugary food, stay up late and take part in other normal teenage events like parties and concerts or even attend to normal school expectations like exams (Cartwright et al., 2015; Ferguson & Walker, 2014; Heaton et al., 2016; Potì et al., 2018). Spencer, Lewis, and Reid (2018) noted how the young people in their study described themselves as healthy like their peers by giving examples of how they exercised and ate well. Participants distanced themselves from negative labels of ill health and disability and downplayed the severity and impact of their illness.

On some occasions, young people are forced to recognise the physical restrictions or limitation of their disease and this sometimes contributed to young people feeling different from peers, more vulnerable and meant they did not feel as normal (Cartwright et al., 2015; Higham et al., 2013; Horky et al., 2017). Missing out on what other people their age were doing (e.g., missing school frequently), was seen as stressful and contributed to young people feeling unsettled and ‘not normal’ (Sligo et al., 2019).

The notion of adaptation to chronic illness is often a strong theme within studies related to chronic illness and this appeared in some of the studies reviewed. Young people in one study who were living with juvenile idiopathic arthritis revealed how the experience was often physically and emotionally difficult but that they eventually reached a point of acceptance and learned to adapt (Cartwright et al., 2015). Young people seem to maintain a sense of perspective about their lives despite the challenges posed by living with chronic illness (Ferguson & Walker, 2014).

They focused on the good and important things in their lives such as friends, family, accomplishments at school and/or in sports and retain clear goals and optimism for the future (Ferguson & Walker, 2014; Higham et al., 2013).

Overall, most studies indicate that young people with chronic illness refuse to accept physical limitations or let their condition interfere with normal activities. Maintaining normalcy through being with friends, taking part in sport and describing future identities was paramount for the young people in these studies (Cartwright et al., 2015; Pienaar & Visser, 2012)

**Illness disclosure.** While maintaining a sense of ‘being normal’ appears important to young people, there were times that young people must disclose their illness to others and the associated tensions emerged as a key theme within the studies reviewed. Young people lived a balancing act of disclosure versus concealment of their chronic illness, often having concerns regarding disclosing their condition to friends (Barned, Stinzi, Mack, & O’Doherty, 2016; Cartwright et al., 2015; Chew et al., 2019; Spencer et al., 2018). Young people found it challenging to decide how and when to disclose, and were strategic about *who* they would tell, for example telling a best friend and no one else (Barned et al., 2016). Although it seemed that overall relationships with friends were not negatively affected by disclosure of a medical condition (Chew et al., 2019), young people did describe the difficulties they sometimes had navigating relationships with friends and teachers while trying to avoid drawing attention to their underlying condition (Spencer et al., 2018). Unintended disclosure about chronic illness sometimes occurred because of having to account for or explain a specific behaviour or event; for example, a seizure (Chew et al., 2019) or due to an absence from school or activity because of acute illness (Barned et al., 2016).

**Peer and family support.** Not surprisingly friendships played a significant role in the lives of young people (Chew et al., 2019; Potì et al., 2018); social support and the importance of friends and peers was a consistent theme in the literature (Chew et al., 2019). Young people use family and friends as an important coping resource, both providing a connecting role and a sense of belonging (Ferguson & Walker, 2014) as well as reassurance and reduced feelings of isolation (Cartwright et al., 2015). Spratling (2012) described how most young people deemed it important to

be able to talk to peers about their experience and the ability to develop and maintain friendships to feel supported and a sense of self. When they have strong peer relationships and support, these factors functioned as protective processes for the young person's well-being (Ridosh et al., 2011). In addition to peers and friendship, family were also noted as key to the young people feeling physically supported (in terms of helping with adherence to therapies and treatment) and supported emotionally which was important in terms of coping (Kola et al., 2015; Pienaar & Visser, 2012).

This third and final part of the literature review has drawn attention to the day-to-day experiences encountered by young people with chronic conditions. The literature tells us that young people face several challenges and at the same time strive towards maintaining a positive attitude towards life, their own health, family and friendships and the future. It reveals the importance of peers and family, and how leading a normal young person's life is very important to their experience of day-to-day life.

### **Implications of the existing literature on this research project**

Bronchiectasis is a chronic illness characterised by chronic cough, sputum production and recurrent chest infections that is a significant health issue in New Zealand; particularly amongst Māori and Pacific young people and those living in areas of high social deprivation (Karadag et al., 2005; Redding, 2009). The literature review has described how bronchiectasis impacts on the QoL of children and revealed the significant symptom burden experienced by children and their parents/carers. The studies which reported the adult experience of bronchiectasis appear to also be supported within the paediatric studies in relation to symptom burden and highlighted how QoL in bronchiectasis is personal, subjective and specific to the individual. The literature surrounding chronic illness in young people illuminated the dynamic, challenging and diverse experience of navigating the social, psychological and physical impacts of disease daily life with chronic illness.

**The gaps.** Although this literature review has provided a solid grounding, within the existing knowledge surrounding bronchiectasis there remains several gaps to be addressed. Most of the studies reviewed were focused on children and parents or adults with bronchiectasis. This is problematic for two reasons. First, young

people with chronic illness have different health needs, perceptions and distinct health care priorities compared to adults and children (Bensted, Hargreaves, Lombard, Kilkelly, & Viner, 2015; Coleman, 2001). Second, adolescence is recognised as a key life stage where health habits and expectations about health are influenced by the extensive changes that take place during this time period. This unique period in the life of a young person with chronic illness will have particular challenges that can only be understood from their perspective (Dick & Ferguson, 2015). Given the large numbers of young people with bronchiectasis in New Zealand, and in order to inform healthcare provision for them, it is crucial that their experiences and views be heard. This study provides an opportunity to do this and will generate important knowledge for the New Zealand context and the wider bronchiectasis community. This will be the first qualitative study which exclusively seeks the view of young people.

Another important consideration regarding this literature review is that all the studies (except for those from New Zealand and Australia) were conducted in European derived general populations and did not include different ethnicities. It is anticipated that the participants for this study will show more ethnic diversity. This will offer opportunity to hear from those young people most affected by bronchiectasis in New Zealand as well as inform about variation (or not) in experience between different ethnicities.

As a chronic respiratory disease, with significant physical, social and psychological challenges, the impact of bronchiectasis on the daily life of a young person is potentially significant. Ensuring that health professionals understand this experience in a holistic way is key to successful and positive healthcare experiences for young people. However, this literature review has identified a gap in this knowledge. Given the prevalence of bronchiectasis in New Zealand, and the limited understanding of how young people experience this disease, the purpose of this study is to further the existing and emerging body of knowledge. The intention is to bridge the gap so that health professionals may understand the significance of bronchiectasis for the young person, come to know what is most important to them and then act and plan care to improve well-being and health outcomes.

## Chapter 3. Approach to Inquiry, Methodology and Research Design

### Introduction

Chapter two provided a thorough review of the literature and has highlighted the current knowledge about bronchiectasis, the 'experience of' chronic illness in young people and the gap in understanding relating to young people's experience of living with bronchiectasis. The purpose of this study was to gain understanding and insight into this subjective experience; therefore, a qualitative methodology was required. The qualitative methodology selected for this study was ID. This is a qualitative methodology that supports enquiries from an applied health perspective where the focus is on peoples' health and illness experience (Thorne, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004). This chapter has four sections. The first will outline ID methodology and provide information about its characteristics and credibility. The second section will outline the theoretical and personal assumptions that scaffold this study. In the third section, an outline of the overall research design will be discussed including sampling, data collection process and data analysis. In the final section, the ethical considerations relevant to the various stages of the research process will be discussed.

### Methodology: Interpretive description

ID is a discipline/practice-based methodology with roots in the constructivist paradigm and is primarily concerned with understanding peoples' experiences in an interpretive and humanistic way (Thorne et al., 2004). Philosophically aligned with an interpretive naturalistic orientation, ID recognises the constructed individual reality and contextual nature of human experiences that allow for shared truths (Schwandt, 1998). ID was selected for this study because it offered an approach that was analytical, inductive and enabled a way of understanding the health and illness experience of the participants in relation to the clinical and practice context (Parente Pinheiro Teodoro et al., 2018; Thorne, 2016).

**Origin.** Nursing researchers have long been advocates of qualitative research methodologies and have historically had interest in research questions grounded in



clinical problems where they seek answers to *how* or *why* a phenomenon occurs. These research questions often develop because they are important to patients and similarly important to nursing practice. The challenge has been that, despite the multitude of qualitative methodological approaches available, most of these originate from disciplines other than nursing; that is, sociology (grounded theory), philosophy (phenomenology), psychology or anthropology (ethnography). Therefore, researchers seeking the answer to a practical problem within the discipline of nursing found themselves in position where they had to strategically adapt the conventional social science methodologies in order to produce the method and findings that meet the needs of nursing (Sandelowski, 2000; Thorne, Stephens, & Truant, 2015). Borrowing aspects of a particular methodology or describing a study as *a version* of the conventional option meant that nurses found themselves questioned about 'methodological credibility and rigour' (M. Johnson, Long, & White, 2001) and accused of being 'intellectually sloppy' (Morse, 1989; Thorne et al., 2015). The choice given was to either follow the traditional methodological rules and expectations of the social science fields or produce research that was real and applicable to their disciplinary field (Parente Pinheiro Teodoro et al., 2018; Thorne, 2016).

The tension regarding the application of qualitative methodological approaches, outside of the context for which they were originally designed, sparked discussion about the need to develop approaches that were applicable to the applied disciplines (Thorne et al., 2015). Education took up this challenge and, in the late 1980s, new educational methodologies emerged (Lincoln & Guba, 1985; Patton, 1987). But given the esteem associated with positivist research and the scepticism surrounding qualitative research there was hesitancy within health research to move away from conventional options. Despite this hesitancy, qualitative research continued to grow within nursing and other health care disciplines. Some described this as generic qualitative research (Caelli, Ray, & Mill, 2003), while others called it qualitative description (Sandelowski, 2000).

In late 1990s, Thorne and colleagues first described and proposed a 'non categorical' approach to nursing research that suited the needs of clinically-based research (Thorne, 1997). Thorne, Kirkham, and MacDonald-Emes (1997) agreed that popularised qualitative methods, such as phenomenology, grounded theory and

ethnography, did not always align well with nursing's unique domain of inquiry and proposed an analytical framework that considered nursing's epistemological foundations ID emerged to meet this need and fill a methodological gap. Its authors did not intend it to represent a new and unique methodology; rather, an evolution of the qualitative research already being conducted within the healthcare context (Thorne et al., 2004).

**Philosophical assumptions of ID.** This methodology is philosophically aligned with the interpretive naturalistic orientation and, therefore, recognises the constructed individual reality and contextual nature of human experiences that allows for shared truths (Schwandt, 1998). Epistemologically, it is aligned to the constructivist/interpretivism paradigm; therefore, recognises both the created and distinct reality of health and illness experiences (Thorne et al., 1997). It takes an ontological perspective of relativism where multiple social, mental, cultural and experiential constructions continually evolve in response to the individual's experience and perception of the world (Denzin & Lincoln, 2000). Hence, when an ID study sets out to examine a clinical phenomenon, its goal is identification of themes and patterns among individual perspectives with consideration of the variation between individuals (Hunt, 2009). From a nursing perspective, this aspect of ID captures some of the complexity of how nurses develop knowledge through balancing the 'general' and the 'particular' (Thorne & Sawatzky, 2014).

Methodologically, ID is linked to grounded theory, naturalistic enquiry and ethnography; however, distinguishes itself from these traditional approaches in its health discipline specificity and interpretive focus on questions that emerge from clinical issues. It is a methodology particularly suited to those who wish to conduct research that is applicable to clinical or discipline specific practice (Thorne et al., 1997). Although developed in the field of nursing, by nursing scholars, in order to address applied clinical questions, ID is increasingly found to be good fit with other applied disciplines such as education (Wall et al., 2019), counselling (BarHava-Monteith, 2018; Kucukbumin, 2014) and health disciplines such as physiotherapy (Jepsen et al., 2018) and midwifery (Mellor, 2016).

The flexible nature of ID and its focus on practice-based knowledge generation appeals to nursing researchers. This is evident from the growing number of nursing

studies that have utilised an ID approach to explore clinically relevant questions across diverse areas. Some examples are: the experience of kidney failure (Ravenscroft, 2005); stigmatization of drug users (Paterson, Hirsch, & Andres, 2013); information needs of parents of children with asthma (Archibald, Caine, Ali, Hartling, & Scott, 2015); long term home visiting with vulnerable mothers (Dmytryshyn, Jack, Ballantyne, Wahoush, & MacMillan, 2015) and shared decision making from cancer patients' perspectives (Thorne, Oliffe, & Stajduhar, 2013). As time goes on, more and more nursing studies are seeing the positive attributes of this methodology.

The intention of ID is to explore a phenomenon of interest through "excavating, illuminating, articulating and dissemination of the kind of knowledge that disciplines with an application mandate tend to need in order to enact their mandate" (Thorne, 2016, p. 11). Thorne (2008) described how the knowledge generated is located in the space between "fact and conjecture" (Thorne, 2008, p. 15) or, in other words, between objective reality and subjective impression (Thorne, 2016). This notion of knowledge creation existing in an in-between space fits well with nursing because, as a discipline, nursing knowledge is thought by many to be created in a 'space' between theoretical objective knowledge and subjective personal practice knowledge (Stefanos & Melanie, 2008). The goal of the current study was to understand a complex experiential subjective clinical phenomenon (living a life with bronchiectasis as a young person). The mandate was to share this understanding with other health professionals in order that they might act and plan care in a way that positively influences the lives of these young people and enable the young people themselves to be more actively engaged in management of their bronchiectasis. The product of this study, in keeping with an ID approach and its reliance on interpretation, is a constructed truth rather than fact.

### **Scaffolding. Theoretical forestructure**

One of the central aspects of an ID study is scaffolding. Scaffolding is the initial position from which an ID study is built and from which the research plan is created and influences the entire project (Thorne, 2016). It is made up of two key elements: a) the literature review, and b) disclosure of preconceived personal assumptions.

The literature review enables the researcher to become familiar with the current knowledge and discourse surrounding the phenomenon of interest, in this

case the experience of bronchiectasis for young people. It also allows for expertise to be developed around the current literature and conclusions to be drawn about the phenomenon of interest. It provides insight into who has studied it, how it has been studied, the challenges encountered and the general conclusions drawn to date (Thorne, 2016). In chapter two, an extensive review of the literature was presented and contributes to element one of the structural framework or scaffold of this research project.

The second element in the scaffolding of an ID study requires the researcher to consider and account for their own personal position, prior knowledge and thinking about the phenomenon (Thorne 2016). In addition to thinking about what the researcher brings, this second element also requires consideration of the disciplinary orientation that shapes the study (Thorne, 2016). Understanding and acknowledging the theoretical, experiential, and practical knowledge the researcher brings must be accounted for because of the role the researcher plays in shaping the outcome of the study and are considered next under the headings: Theoretical allegiances; Disciplinary orientation and Personal position.

**Theoretical allegiances.** The first element in the theoretical forestructure entails locating one's theoretical allegiances. Clarity around this aspect is crucial as it guides and informs the enquiry approach. At the beginning of this project I explored several different qualitative methodological approaches but found myself having an affinity to interpretivism/constructivism because of its interest in *how* construction of meaning occurred, and its acknowledgement that individual and social context influenced construction of knowledge (Lincoln & Denzin, 2005; Lincoln & Guba, 1985). An interpretivist/constructivist ontological view posits that knowledge/meaning is socially constructed and that subjects construct their own meaning in different ways, even in relation to the same phenomenon. Thus, interpretivism/constructivism allows for, and expects, subjectivity and complexity; it appreciates differences between people. Given that the intention of this research was to describe how young people experienced day-to-day life with bronchiectasis, an interpretivist/constructivist paradigm fits well.

The next challenge was to determine which interpretivist methodology would be most relevant for this project. I acknowledged that investigating young people's

experience of bronchiectasis could reasonably be addressed from a variety of methodological positions; however, knew that *alignment* between the belief system underpinning the research approach, the research question and the research approach itself was a prerequisite for a rigorous qualitative research project. Several methodologies were considered including grounded theory, ethnography and phenomenology, before finally settling on ID. My understanding of these and how they may or may not have related to this study are explored below.

A grounded theory approach has a research goal of 'discovery' and would have required the development of a theory or theoretical model more suitable for a question such as "what are the day to day processes of living with bronchiectasis?" This study did not intend to yield new theory and was interested in looking for patterns rather than analysing data through line-by-line or word-by-word coding which is the process commonly utilised in grounded theory (Thorne et al., 2004). As a nurse, I recognised that observation and communication were essential to understanding a patient's experience. Therefore, when exploring ethnography, the idea of immersion with, and observation of, participants was appealing. However, I was less interested in a broad cultural/contextual interpretation of participants with bronchiectasis; rather, I sought answers to more practical and pragmatic questions. A phenomenological approach to this project held potential given its interest in participants' 'lived' experience; however, this study was not concerned with high-order abstractions and I wanted to go further than *describing* the phenomena of living with bronchiectasis. All these approaches fit with an interpretivist ontology; however, none matched the clinically derived nature of the research question or my own pragmatic approach to seeking the answer for 'so what?' ID offered a potential solution to this question because of its assumption that nurse researchers are not satisfied with description alone, that they are looking for clinical application of findings and, therefore, want to explore meanings and explanations. ID seemed to tick all of the methodological boxes, fit well with my disciplinary (nursing) orientation and satisfy my interest in developing knowledge applicable to clinical practice (Thorne, 2011; Thorne et al., 1997).

ID was developed as a methodological approach to developing clinical understanding (Hunt, 2009). It is aligned to a constructivist and naturalistic

orientation to inquiry but locates itself outside of the social science theoretical tradition. As such, it does not require a research study to explicitly position itself or adhere to one or another formal theory (Thorne, 2016). ID does, however, acknowledge and consider the theoretical and practical knowledge that researchers bring to a project. In this section I have highlighted the theoretical allegiances that form part of the scaffold of this study. I now turn to the second element of this theoretical forestructure.

**Disciplinary orientation.** An important guiding principle of ID is that the researcher be transparent about their disciplinary position. Recognition and acknowledgement of the impact that one's disciplinary perspective has on the research question, process and outcomes is integral to an ID study. This approach differs from some qualitative methods where the influence of researcher knowledge is discouraged, and instead the technique of 'bracketing' is used. An example of this is Husserl (1970) phenomenology where the researcher is asked to suspend judgement about the natural world in order to get to the core or pure essence of the phenomena being studied. In an ID study, the foreknowledge of the researcher is considered to be the platform on which the project is designed, it shapes the thinking behind the question and ultimately influences all processes through the project (Thorne, 2016). Thorne asserted that researchers in the applied fields, even without intending to, frequently make apparent their disciplinary orientation within qualitative research studies (Thorne, Joachim, Paterson, & Canam, 2002). This implies that the influence of one's disciplinary orientation is significant and, therefore, needs to be considered as having an impact. Not doing so, potentially impacts on the study's quality.

As a nurse trained in child and youth health care, the orientation to this study is grounded within the discipline of nursing. Throughout my 25+ year nursing career, I have worked closely with, and cared for, many young people with chronic illness including those with cystic fibrosis, chronic renal disease, liver disease, diabetes, rheumatological conditions and young people with bronchiectasis. The experience and knowledge I gained through working clinically with these different groups of young people framed my understanding and provided a platform and starting point for this project (Hunt, 2009). To maintain transparency, in relation to this study, it is

important to acknowledge how my background experience working with young people with bronchiectasis, influenced the research study in the planning stages (including the research design) and throughout the research process. In order to recognise and manage this influence from the onset of the project I utilised a reflexive journal to take stock of my preunderstandings.

In a journal entry entitled *person experience bias* I reflected on my experience as a respiratory nurse specialist in the respiratory service at Starship Hospital in Auckland, New Zealand and focused on my experience working with children with bronchiectasis. In this reflection I talked about the inequity I saw between the services provided for children with bronchiectasis and those with cystic fibrosis. I saw the bronchiectasis children as being sicker, more socially deprived, less adherent and often absent. I remembered feeling that we were not doing enough to support these children, young people and their families. I also had assumptions about the impact that bronchiectasis had on daily life. I assumed it would be hard, that treatment would get boring and take up valuable time, and that bronchiectasis would be front and centre in life. Overall, I had the sense that we (as healthcare professionals) were not really seeing what it was like for these young people and that we could do better. In terms of planning this study and developing the question, my way of thinking clearly fits with how Sally Thorne (2016) talked about nursing inquiry usually involving a “normal moral imperative” and requiring a clinically relevant problem and something to be improved upon (Thorne, 2016, p. 16). In addition to this moral imperative, nurses in practice and in research recognise that no matter how much is known about a phenomenon, for example how much is known about young people with bronchiectasis, we can never assume that we know all there is to know. Such awareness is imperative for the applied interpretive researcher so that they may search commonalities but remain curious and seek out the differences (Thorne & Sawatzky, 2014).

Understanding and believing that each of the young participants’ experience would be different and unique in some way from another’s, while at the same time considering the importance of patterns and commonalities across the participant group, was part of my pre-understanding coming into this study. This way of thinking is influenced by the knowledge that informs nursing practice as that which

“inherently requires knowledge about patterns and themes within people in general, so that it can better inform the care of the unique and distinct individual” (Thorne, 2016, p. 28).

It is also important to acknowledge how the key principles of Youth Centered Care (YCC) underpin my specialist paediatric nursing knowledge and ways of thinking. One of the key principles of caring for young people is ensuring the participation of young people in the planning, monitoring and evaluation of health services (Nair et al., 2015). In my own practice, I place great importance on considering the young person in the context of their family and as an individual who has a unique and personal perspective on their chronic illness experience. This perspective is acknowledged as having influenced the question posed by this study and the goal to gather the descriptions from the young people themselves rather than from parents or family members.

This section has outlined some of the disciplinary understandings and assumptions that frame my pre-understandings of young people’s experience of living with bronchiectasis. Acknowledgement of these disciplinary understandings and their impact on the design of this study will be discussed further in upcoming sections on research design.

**Personal perspective.** The final part of clarifying the theoretical forestructure involves acknowledging the personal position of the researcher within the research project. This study is set within the discipline of nursing, specifically paediatric and youth nursing. Thorne suggested that researchers not only position themselves within the discipline but *within* the research itself, taking advantage of their own clinical expertise as an instrument in the research process (Thorne, 2008; Thorne et al., 2004).

The impetus for this study began with my own professional interest and experience working with young people with chronic illness. I was first introduced to bronchiectasis patients as a chronic condition in 1999 and have been fortunate to have worked on and off clinically with this patient group throughout my career. I entered this study with clinical knowledge about symptoms, management and the psychosocial issues that face young people with bronchiectasis. I believed going into this study that the day-to-day life experience of young people with bronchiectasis was



probably, in some ways, like other young people with a chronic illness. But as evidenced by the literature review and through talking to colleagues who worked clinically with young bronchiectasis patients, a gap in the knowledge about what life was like for these young people was apparent. The focus of this research and the research question itself was influenced by both the literature review and by my personal position and interest. I was interested in learning about the day-to-day life experience of young people with bronchiectasis. I wanted to know what mattered most to them. I assumed that for each of these young people there would be different individual realities; yet, I also entered the research expecting that young people would talk about bronchiectasis as an all-encompassing and dominant factor in their day-to-day life. I made assumptions about what the participants might value, and the influence of bronchiectasis on their life.

In addition, I assumed that my position as a NZ European and my westernized view of health and chronic illness would impact on the participants comfort with sharing their stories with me as researcher. The participants came from different ethnic backgrounds to my own and thus I assumed they would have different perspectives because of these ethnic and cultural differences.

These preconceived notions or assumptions influenced both the research topic and question, and elements in the design of the study. In order to be as transparent as possible and manage the influence of these pre-conceived notions on the research process, I used constant self-reflexivity in the form of journal writing (as discussed in a previous section), memos and regular open discussion with my supervisors. Through this process of deep thinking and reflecting about my personal bias, I was able to capture changes of ideas and personal responses to the research as it unfolded. This process was part of the project planning, influenced the design of the study as well as data collection and analysis. Further detailed evidence of how this was achieved will be included in the third section which covers research design.

**Evaluation criteria for ID.** Within qualitative research there has been a long-standing debate on how to adequately and consistently evaluate the quality and credibility of a qualitative study. Several frameworks or guidelines of quality criteria exist and provide key general principles that are useful in guiding the evaluation of credibility in a qualitative study (Caelli et al., 2003; Lincoln & Guba, 1985; Thorne,

2016). The following key principles form the basis for articulating evaluation standards in interpretive description: epistemological integrity, representative credibility, analytic logic and interpretive authority. In the following section I discuss how I believe these evaluative standards have been met in this study.

**Epistemological integrity.** Qualitative research is expected to demonstrate epistemological integrity, which means that throughout the research process the researcher must maintain a commitment to the epistemological positions surrounding the research question and create strategies that respect and appreciate that position (Thorne, 2016). This includes ensuring clear links between epistemology, the type of research question asked and the methodological preferences for data collection. In this study, epistemological integrity was demonstrated by ensuring the design and implementation factored in the principles of ID. For example, rather than claiming to start the project as an empty vessel, I acknowledged and recognised my experience and disciplinary preconceptions. In addition, the critical review of the literature, outlining a thorough review of bronchiectasis in general and how it relates to young people in New Zealand, and the discussion of my theoretical and personal assumptions supported the epistemological integrity of this project.

**Representative credibility** is achieved “when the theoretical claims that the study purport are consistent with the way the phenomenon under study was sampled” (Thorne, 2016, p. 234). Credibility asks the researcher to clearly link the study findings with reality and requires that the participants selected represent those whom the study intended. In this study, triangulation of data sources occurred through face to face interviews with a representative group of young people with bronchiectasis, fields notes/memos and extensive reflective journaling. The purposive sampling used in this study also ensured and enhanced representative credibility. For example, at the beginning of recruitment there were many New Zealand European young people that came forward to be part of the study. Rather than include all these volunteers, I purposefully selected to ensure the participant group included a range of ethnicities that included a balance of Māori and Pacific as well as NZ European youth.

Analytic logic requires qualitative studies to be transparent about the reasoning of the researcher from the forestructure through to the interpretations and knowledge claims produced from the study (Thorne et al., 2004). This is achieved through more than just making a statement in the report confirming that inductive reasoning occurred. Instead, it is imperative to clearly describe the decision-making process throughout the study. In this study, analytic logic is demonstrated using Morse's (1994) cognitive process framework, which outlines my decision making, audit trail and research decisions. This is outlined in detail in the data analysis section.

Interpretive authority. Thorne (2008) asserted that all knowledge is influenced by perspective; therefore, it is imperative that a study assures the reader that the interpretations made by the researcher are trustworthy and external to personal bias or experience. One of the ways that I endeavoured to manage my own effect on the research process was to seek help early during the interview process. Following the first two interviews I sought help from my supervisor. I arranged a meeting time where we sat and looked at the interview transcriptions. This was not a meeting to begin analysis of data rather, an opportunity for me to seek support on interviewing technique. During this meeting, my supervisor provided guidance around my interview technique, pointing out that I was allowing my clinical bias to creep into my way of questioning. We looked at specific examples in the interview transcript and talked about ways to adjust my line of questioning to limit my clinical bias. Examples from two of the interviews and notes taken during this process are found in Appendix A. In addition to this specific focus on interview technique, throughout data collection and analysis I consulted and engaged in discussion about process and decision making with my supervisory team and kept a reflective journal.

Thorne (2016) suggested that there is more to critiquing qualitative research than the four traditional key elements discussed above and asserted that in an ID study it is also important to consider what can be made of the findings. She suggested five further strategies to enhance the trustworthiness and appraisal of an ID study. These include moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth (Thorne, 2016). The first criterion encourages the researcher to consider if there are convincing claims that the research is necessary and asks, what is the purpose in having the knowledge once we

attain it? The literature review provided information about the current knowledge surrounding young people's experience of bronchiectasis and showed currently a limited understanding. The intention and purpose of this research was clearly stated as hoping to bridge the gap in understanding in order to positively impact on young people with bronchiectasis. The second criteria states that the knowledge produced through an ID study must have disciplinary relevance and meet pragmatic obligations. This research was grounded within the discipline of nursing and is of importance to child and youth nurses as well as other health professionals that work with young people with bronchiectasis. Through the research I have generated new knowledge that contributes to our understanding of how young people experience day-to-day life with bronchiectasis. Through bringing this experience to the surface, young people will potentially feel a more collaborative healthcare approach and an increased ability to self-manage their bronchiectasis. Pragmatic obligation requires the researcher to present the findings in a way that acknowledges they may be put into practice. Recognising this means that I needed to consider if the findings from this study could in any way harm or be detrimental to a specific person or patient group. I do not believe the findings could be harmful or detrimental to the participants or to others who may apply them in practice. Contextual awareness requires that I deliberate how the findings from this research study should be considered in the context of which they were constructed. I acknowledge the contextual nature of this study's findings and realise that they represent a moment in time in the lives of these young participants and represent their perception of reality at that given time. The final criteria, known as probable truth, relates to the validity of research findings. Thorne (2008) emphasised that there is no way to guarantee the validity of research findings but instead asserted that "some kinds of knowledge are the best truths we have until more compelling ones emerge" (Thorne, 2008, p. 238; 2016). I recognise that this study has provided insight and understanding into the experience of young people with bronchiectasis and that this knowledge is not an absolute but a constructed truth.

## Research study design

Foundational underpinnings of an ID study. Unlike other methodological approaches, ID does not require or provide a rigid 'how to' approach or prescriptive

set of instructions on undertaking a research study. Instead, it provides a design logic model that allows for flexibility and generation of a “rigorous and credible methodological approach” to a clinically focused phenomena of interest (Thorne, 2016, p. 15). There are key axioms, however, that provide the epistemological and methodological foundation for an ID study and these are grounded in the naturalistic tradition (Lincoln & Guba, 1985; Thorne, 2016). ID should:

- Be conducted respectfully and ethically in as naturalistic a context as possible;
- Value subjective and experiential knowledge as fundamental source of clinical insight;
- Capitalise on human commonalities as well as individual expressions of variance within a shared focus of interest;
- Reflect issues not bounded by time and context but attend to the time and context in which human expressions are enacted;
- Acknowledge a socially constructed element to human experience that cannot be separated from its essential nature;
- Recognise that in the world of human existence, reality involves multiple constructed realities that may at times be contradictory; and
- Acknowledge an inseparable interaction between the researcher and researched where understandings are co-constructed, such that the inquirer and the object of inquiry interact and influence one another (Hunt, 2009; Thorne, 2016).

These common features and set of assumptions about human experience form the foundational underpinnings of an ID study and provide a coherent and accessible logic to orient the design of a study and ensure the credibility, legitimacy and rigour (Thorne, 1997; Thorne et al., 2004).

ID as a methodological framework allows for flexibility and a wide range of options in terms of study design. However, providing a clear explanation of the procedure related to data collection and data analysis gives structure to the study, assists the reader to understand why particular choices were made and demonstrates rigour and trustworthiness in the research process. The following section outlines the methods used.

**Sampling.** In an ID approach to research, purposeful sampling allows access to the people experiencing the phenomena of interest and their collective truths; however, there are firm rules regarding what constitutes the right sample size (Thorne, 2008, 2016). What ID does require is that it be defined in alignment with the nature of the phenomenon under study (including what is known about it) and the size of the sample should connect to the types/kinds of interpretations the study might want to achieve (Parente Pinheiro Teodoro et al., 2018). The plan for this research study was to recruit 12-15 young people and ask them to describe their everyday life experience with bronchiectasis. The intention here was not to find a 'representative group'; rather, to ensure that the participant group had the experiential background to produce findings that would ring true to the intended audience of healthcare clinicians in New Zealand (Thorne, 2008). Purposive sampling was utilised; the aim of which is to recruit a group of participants who will represent different features of the population under study (Thorne, 2016). Sampling aimed to ensure that individuals selected would provide variation of experience with the phenomenon, age, ethnicity and gender. A spread of ages was important because of the study's aim to focus on 'young people' (as per definition outlined below); an appropriate spread of ethnicity was an important element because clinical estimates of bronchiectasis in New Zealand are between 272 and 341 per 100,000 with 80% of the children and young people being Māori or Pacific peoples (Telfar-Barnard & Zhang, 2019).

**Inclusion and exclusion criteria.** Young people were invited to participate in the study if they met the following inclusion criteria:

- a) confirmed diagnosis of bronchiectasis by (HRCT);
- b) had fluency in English; and
- c) were aged between 12 and 24 years of age<sup>1</sup>.

No specific exclusion criteria were identified

**Ethical considerations prior to recruitment.** Ethics approval for the study was sought and granted from the Northern A Health and Disability Ethics Committee

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<sup>1</sup>This age group criteria was based on the definition of the World Health Organization definition of 'young people' and the age group defined as 'youth' in the Government's Youth Development Strategy (Ministry of Youth Affairs, 2002; World Health Organization, 2014).

(Appendix B) and the Auckland University of Technology Ethics Committee (Appendix C). Locality agreements were sought and granted from Auckland District Health Board Research Review Committee (ADHB-RRC) and from Counties Manukau District Health Board (CMDHB) Research Review Committee (Appendices D and E). Health Research Council guidelines around conducting research with children/young people were utilised to ensure that correct process was followed with regard to information sharing and consent and assent processes (Peart & Holdaway, 2007). This included the development of a participant information and consent form for those participants over the age of 16 years (Appendix F), patient information and assent forms for those under 16 and accompanying parent/caregiver information and consent form (Appendices G and H).

Given the epidemiology data indicating most youth with bronchiectasis would identify as either Pacific or Māori, and the contributing fact of my being a Pākehā<sup>2</sup> researcher, it was imperative to consult with Māori and Pacific cultural advisors. Within the New Zealand context, any research project undertaken must consider the principles of the Treaty of Waitangi in planning for consultation and the research process (Treaty Of Waitangi, 1840). In addition to maintaining obligations set out in the Treaty of Waitangi, clear ethical guidelines for research with Māori have been set out by the Health Research Council of New Zealand (2010) and these must be upheld during the development of a project and throughout. These requirements were attended to in several ways. At the commencement of the project, when it was decided to study participants with bronchiectasis, an advisory group was established that included a Pacific people's representative, a Māori health advisor (Te Poutokomanawa Māori Health Service Northland) and a bronchiectasis nurse specialist. This group was consulted in the development of the research proposal and ongoing dialogue and consultation occurred in the form of email throughout the course of the study. In addition to the advisory committee, the study proposal was independently reviewed and approved by both the CMDHB Māori Research Review Committee (Appendix I) and the Waitemata and Auckland District Health Boards Māori Research Committee (Appendix J).

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<sup>2</sup> Pākehā is a New Zealander of European descent - probably originally applied to English-speaking Europeans living in Aotearoa/New Zealand (Maori Dictionary).

**Recruitment strategy.** Participants were recruited through professional networks from the specialist respiratory services at Auckland District Health Board (ADHB) and CMDHB and through the New Zealand Bronchiectasis Foundation. Nurse specialists, specialist physiotherapists, respiratory paediatricians and the chairperson of the Bronchiectasis Foundation were provided with information about the study including consent and assent forms and approached participants that met the inclusion criteria. These intermediaries provided prospective participants with a written participant information sheet and, if the young person expressed initial interest, sought permission for the researcher to be given the participant's contact details. Some participants were recruited using the technique known as snowballing where the caregivers of participants recruited other participants for the study through their own social networks (Naderifar, Goli, & Ghaljaei, 2017).

The intermediaries then contacted the researcher with the names and contact details of the potential participants. The researcher then contacted them in a combination of ways including email, phone and text in order to discuss the study, answer questions and set up an interview appointment. Recruitment and interviews occurred over a period of nine months from October 2018-June 2019 and was a relatively easy process. I had many interested potential participants and setting up appointments was consistently straightforward and unproblematic. Interestingly, the most effective method for making connection and setting up interview appointments with young people was through mobile phone text messaging. In New Zealand, mobile phone text is one of the most widely used forms of communication technology so it is not too surprising that the youth in this study felt comfortable with this mode of communication (Gibson & Cartwright, 2014).

**Ethical considerations prior to data collection.** There were several important ethical matters to be attended to prior to commencing data collection. This involved ensuring good and ethical management surrounding participant information, voluntary participation and consent/assent, cultural support, confidentiality and anonymity.

**Participant information.** Potential participants and/or participants parents/caregivers were initially offered verbal information followed by written information (Appendices F-H). The information sheet outlined the research aims,



expectations of the participants, the role of the researcher and information about who to contact if questions arose for the participant. In some cases, this information sheet was provided by the clinical contacts within the DHBs and in other cases the information was emailed to the potential participant by me after initial phone contact. I contacted the participants via phone and text to arrange interview times and location.

**Voluntary participation. Assent and consent.** At the beginning of the interview I articulated the purpose and scope of the study and the participants and/or caregivers were questioned about their understanding of the study and given time to ask questions. I explained verbally and in the written information that participation was voluntary and that if at any point during the interview or prior to the completion of data collection they wished to stop or no longer be involved in the study they were free to withdraw. Given that the participants in this study were young people, some still under the care of their parents, participant assent and parental consent was required. In New Zealand, the Health and Disability Ethics Committees is a Ministerial committee that functions to ensure that research meets established ethical standards (Health and Disability Ethics Committees, 2019; Health Research Council of New Zealand, 2010). The following applies to informed consent regarding the research with children and young people and were the guiding principles in developing the consent and assent forms for this study:

1. Children must, if possible, provide their informed consent to participating in a study.
2. If a child is unable to provide informed consent, the child must provide informed assent if possible, and consent should be obtained from their parents or legal guardian.
3. Suitable information sheets and consent forms must be provided for studies involving children.

Separate assent/consent information was provided to the young person and to the parent if applicable. In 10 out of 15 participants, the parent was the first point of contact; therefore, ethically, it was important for me to determine the young person's competency and capacity within the context of the parental influences. In other words, the challenge was to ensure that the young person was well enough

informed and willing to participate rather than being pressured to participate in order to please their parents (Bassett, Beagan, Ristovski-Slijepcevic, & Chapman, 2008; Moolchan & Mermelstein, 2002). In all cases there seemed a genuine willingness and desire to participate. Once the consent/assent forms were signed, they were stored in a folder in a locked office and kept away from the interview data.

**Cultural support.** Once the participant had agreed to participate and meet, they were offered the opportunity to have a family member, friend, partner or cultural support person appropriate for their identified ethnicity and gender at the interview with them if they desired. The plan was to utilise cultural facilitators recruited through professional networks within the DHB and within Auckland University of Technology (AUT); however, despite the offer, none of the participants requested cultural support. I discussed this with my second supervisor, who has extensive knowledge and experience researching with young people from the Pacific Islands. He (and I) felt that it was possible that the participants did not take up the offer of cultural support because of their age and because of all being New Zealand born. Dr. Tautolo (personal communication, December 11, 2019) suggested that being born and growing up in New Zealand often equates to young people feeling more confident and familiar with these types of conversations, perhaps related to regular interactions with health professionals at appointments etc. In many ways this is beneficial for them and counteracts any cultural issues (D. Tautolo, personal communication, December 11, 2019).

Several of the participants did request a parent be present during the interview and this was accommodated. When this occurred, I reiterated the focus of the research being about young people's perspective and, although I was happy to have parents involved in the interview process, any data captured from the parent's perspective would not be used in this study.

**Confidentiality and anonymity.** Participant identity needs protection at all stages of the research, from site selection and recruitment, through data collection, analysis and publishing (Creswell, 2003). Participants were reassured verbally and within the patient information forms that participation in this study was confidential. They were informed that no information identifying them as a participant would be included in reports or publications. In some studies, researchers assign numbers or

aliases to individuals in order to maintain confidentiality; however, in this study, participants were asked to identify a pseudonym for themselves (Allen & Wiles, 2015). This was deemed to be another way of establishing rapport with the young participants while allowing them to be creative and part of the research process. Identifying names were used during the interview but replaced by the participant selected pseudonym on the interview transcripts (at the time of transcribing audio recordings), in this thesis and all other publications related to this study.

**Data collection.** The data collection process in ID allows for multiple and diverse approaches; however, given the interest of this study in gathering subjective data, the goal of data collection was to get as close to that subjective experience as possible in order to answer the research question (Thorne, 2016). The specific data collection techniques utilised in this study included semi-structured interviewing of individual participants, reflective journaling and field memos. In addition, demographic information about the participants was collected including, place of birth, ethnicity, age of diagnosis with bronchiectasis and severity of disease if known. This additional information was collected so the reader could have a better understanding of my sample group.

**Semi-structured interviews.** The semi-structured interview was the qualitative method of inquiry utilised in this study. ID supports the use of interviews as a data collection method because they fit well with the key axioms of its epistemological and methodological foundation. In addition to suitability with ID methodology, interviews fit well with the disciplinary orientation of nursing and nurses' inherent need to understand patient experience through 'talking to patients' as well as being considered an essential element in health care practice (Thorne, 2016, p. 136). The other important strength of the semi-structured qualitative interview is that it takes a conversational approach while attempting to understand, unfold and interpret the world view and experience of the young person (Kvale & Brinkmann, 2009). An interview guide was utilised as it is common with the semi-structured interview to combine a pre-determined set of open questions (questions that prompt discussion) with the opportunity for the interviewer to explore particular themes or responses further (Creswell, 2003). The interview guide utilised during data collection can be

found in Appendix K and more detail about how this was used will follow below under interview process.

**Interview process.** All research participants were interviewed in person. The goal of the interviews was to achieve understanding rather than breadth and to allow the discourse and interview to naturally emerge from the young peoples' experiences of living with bronchiectasis (Thorne, 2016). Interviews were conducted between November 2017 and July 2018. Once participants/caregivers had agreed to participate in the study via email, phone or text, an interview time and venue was arranged. Interviews occurred in a variety of different locations based on the participants' wishes and included: homes of participants, hospital clinic rooms and restaurant/café. This was an important aspect of the interviewing process as I wanted to ensure the participants were in a comfortable neutral location. Giving them the choice was part of the trust building process.

Prior to commencing the interview, and once it was clear that the participants (and or caregiver/parent) understood the purpose of the study, had been reassured about confidentiality (decided on their pseudonym) and signed the consent/assent<sup>3</sup> form, introductions were made and verbal permission to record the interview was gained from the participants. All interviews were digitally audio-recorded. The interviews lasted between 40 and 75 minutes. This timing allowed for depth while maintaining the interest of the young participants.

According to Thorne and colleagues high quality data will not come from simply asking questions and recording responses; rather, from a carefully thought out frame of reference, attitude and rapport building communication style (Thorne, 2016; Thorne et al., 2013). This is important for any participant interview but particularly so when interviewing young people. It is well known that encouraging adolescents/teenagers to converse and respond to questions can be fraught with difficulties (Bassett et al., 2008). Engaging young people in the research process requires the researcher to be flexible and attuned to cues and show and have genuine interest in their feelings and ideas (Mack, Giarelli, & Bernhardt, 2009). It was

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<sup>3</sup> Children and young people are potentially vulnerable study participants. Children must, if possible, provide their informed consent to participate in a study. If a child is unable to provide informed consent, the child must provide informed assent if possible, and consent should be obtained from their parents or legal guardian (Health and Disability Ethics Committees, 2019).

essential that I established rapport, engaged the young person to participate in the interview and clarified threads within the account as the interviews progressed. These techniques enhanced the quality of the interviews and assured a positive experience for the young participants because they knew their input was important and valued (Mack et al., 2009; Thorne, 2016).

The interview usually began with general 'getting to know each other' questions, friendly dialogue that allowed the participant and caregiver to begin to feel comfortable and open to the idea of sharing their experience. The interview started with 'warm up' questions that included prompts such as:

- Let's start with how old you are and what year of school you are in?
- What do you enjoy most about work/school?
- What else can you tell me about school? Tell me about the kinds of things you enjoy doing? (Prompts sports/afterschool activities/babysitting/being with friends/clubs).

Following on from these warmup questions, the interview guide included a range of questions that could be drawn upon as required, depending on the openness and fluidity of the interaction (see Appendix K). It was not my intention to enter the interview with a strong focus on prearranged questions, but the interview guide did help in the first few interviews to provide direction when I was feeling unsure about what to ask next or when the interview had stalled.

The interview guide was used for all the interviews but as the interviews progressed it was not adhered to in such a rigid manner. Rather, open-ended responsive interviewing was used to allow the participants to talk about what mattered most to them. New questions evolved with each interview based on experiences highlighted by previous participant interviews; for example, when participants talked about particular symptoms these would be used as prompts in subsequent interviews (some young people I have talked to have told me they sometimes feel sore... can you tell me about your experience with that?). However, I was cautious to not allow the conceptual linkages between ideas and accounts that I had collected always direct the interview but endeavoured to allow the young person to articulate and share their experience in their own way. This approach is supported

by the notion that a well-executed semi-structured interview should be flexible and encourage two way communication where the participant is enabled to explore “issues that arise spontaneously” thus allowing for the co-creation of meaning (Doody & Noonan, 2013, p. 31). Throughout the interview process, I was aware of my own bias and foreknowledge and endeavoured to minimise the impact of this on the interview process. This proved to be challenging but was a process of development that occurred over the course of data collection and analysis. This process was aided by continuous self-critique, self- reflection and regular discussions with my supervisors.

**Reflexivity.** The process self-reflection is an important and integral part of a qualitative study and acknowledges the fact that the researcher is a central character that influences the entire data collection and interpretation phase (Finlay, 2002). As part of declaring a study’s reliability and integrity, the researcher must find a way to acknowledge and analyse how “subjective and intersubjective elements influence the research” (Finlay, 2002, p. 531). After each interview, I wrote a memo about the interview which highlighted the key themes I picked out from the interaction straight away. I would jot down key words that sprung to mind upon reflecting on the interviews content—words like ‘getting to school is most important’, ‘often tired’, ‘activities sometimes get missed’, ‘family and friends are everything’. These words were just initial thoughts but served as initial interpretations and posed questions and directions for interview.

In addition to the memos, I kept an electronic journal. This was maintained throughout the data collection and analysis phase and was an important part of data collection as it provided a space to track my own reflections as well as develop concepts and potential themes and patterns from the data. This process of careful self-reflection and interpretation was useful for understanding my feelings, impressions and personal process of gathering and interpreting the data. In an ID study, engaging in journaling is important as it allows for ““active self-awareness of evolving insights and provides an audit trail of the inductive analytic process” (Thorne, 2016, p. 153). Interestingly, it showcased for me the challenges and assumptions I had made about the data gathering process and was a tool for learning and developing myself as a novice researcher. Prior to, and after, each interview, I

recorded my thinking in the journal, including my thoughts, the appearance and mood of the participant as well as notes on the environment. I also commented on initial impressions prior to reviewing the transcription of the interview. These periods of reflection and personal connection to the individual participant's story enabled preliminary analysis, where I began to look for comparisons between participants' data. This reflective process encouraged me to be considerate and analytic, and shift beyond intuitive inquiry to a carefully constructed crafted inquiry (Thorne, 2008, 2016). As the researcher, the reflexive journal recognises my position in the research and shows how my interpretation is influenced by my own historical, personal, cultural and clinical experiences; for an example excerpt from the reflexive journal see Appendix L.

Along with using the memos and the reflexive journal, I met regularly with my supervisors. During these supervision sessions, the reflections and memos I had recorded were discussed, along with my thinking about the data collection process and preliminary themes I began to see between the data collected. Feedback from my primary supervisor and reminders about being aware of my bias and being cautioned against jumping too quickly to conclusions ensured that my process had integrity and rigour.

**Data management.** The interviews were digitally recorded, and a master copy of these digital files was stored on a password protected computer. The first three interviews were transcribed verbatim by me. This process was laborious and took a long time, but I felt it was an important first step in data analysis as it allowed me to become familiar with the data collection process as well as familiarity with the data. The remainder of the interviews were transcribed by a professional transcriptionist whom had completed a confidentiality agreement (Appendix M). Each participant selected their own pseudonym to be used and attached to their data. The voice files sent to the transcriptionist were labelled by pseudonym and age of the participant. Transcription word files and voice recordings were saved in the researcher's hard drive and in a personal cloud backup system that were all password protected. Once all of the transcription files were edited to a standard word format they were uploaded to NVivo 11 (QSR International Pty Ltd, 2012).

The NVivo software was used to facilitate and consolidate data analysis after the initial thematic analysis was completed. Interview data were accessible only to the researcher and supervisors. Sharing sections of the interviews with supervisors throughout data analysis was an important way in which I developed and validated emerging themes. This will be described in more detail in the following section.

**Data analysis.** The objective for the practitioner-researcher employing ID is to produce “a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied and also accounts for the inevitable variations within them” (Thorne et al. 2004, p. 7). ID does not propose a recipe book or step by step approach for data analysis. Instead, it is characterised by a creative and flexible approach where a structure is created that allows the researcher to make informed choices that fit with disciplinary goals, relate closely to the phenomena being researched and fit with the researcher’s own on investigative inclinations (Thorne, 2016). Several ‘borrowed’ techniques are found within an ID inquiry and include constant comparative techniques, iterative analysis, concept mapping and reciprocal approaches. However, Thorne (2008) noted that the researcher must not become overly caught up in technique and remain mindful of the underlying epistemology. In an ID study, data collection and analysis occur concurrently. In this study, each element including data collection, coding, analysis, thematic construction and concept development occurred, to some extent, simultaneously throughout the research process.

As a novice researcher the process of analysing and developing raw data into useful and meaningful knowledge is challenging. Thorne (2016) acknowledged this challenge and advocated the use of Janice Morse’s cognitive framework to guide analysis in an ID study. Morse (1994) described four sequential processes—comprehending, synthesizing, theorizing and re-contextualising—as required for analysis of a qualitative study (see Figure 1).



**Figure 1.** *The four sequential processes as described by Morse (1994)*



These four processes were useful during the analysis phase and helped, as Thorne (2016) put it, to “steer me back on course when I found myself off target” (Thorne, 2016, p. 185). Additionally, they provide a useful way of framing and articulating the process of data analysis I followed in this study. Each of these will be explored in more detail in the following section, along with the suggestion from an ID perspective on how to transform data (Thorne, 2016).

**Comprehending.** In the first part of this cognitive process, the researcher learns everything they can possibly learn about the experiences of the study participants (Morse, 1994). For this study, the first step in comprehending was to conduct a thorough review of the literature, which is presented in chapter two. This provided me a strong knowledge base as well as confirmed the gap in the knowledge about how young people describe the experience of living with bronchiectasis. In addition to the literature review, I engaged in conversations with experts in the field of paediatric bronchiectasis, attended team meetings in order to learn about the clinical context and took part in two separate working seminars on paediatric bronchiectasis. I also attended meetings of the Bronchiectasis Foundation where I met parents of young people with bronchiectasis to hear about the work they were doing and their perspectives on caring for a child with bronchiectasis. Although I was familiar with the topic area, because of my clinical background, I believed that because of the significant time that had passed and my current role being distant from this clinical interface, I was able to be non-judgmental and receptive to seeing everything “remotely relevant to the topic of interest” (Morse, 1994, p. 28). I was mindful of the need to remain open to new ideas and expressions throughout the interview process and kept memos as well as a reflective journal before and after each interview. This helped to manage any potential personal bias or preconceptions. In addition, it allowed me to articulate initial ideas and thoughts about what I saw in the data. As I gathered more data, I was then able to draw parallels between the data sets and see distinctions.

Thorne (2016) described how making sense of the data begins the minute it is heard and continues throughout the data gathering process. Recurring threads of information will surface that the researcher becomes aware of and continually makes sense of. As described in the previous section, after each interview I would write a

memo about the interview and highlight key themes as well as reflect in a personal journal. In the beginning, the notes I wrote were more *descriptive*, where I summarised what the participants had said about their experience; then it evolved into *interpretation*, where I looked at the individual data, made sense of what was seen and located common threads. I did this through reading and re-reading the data as it emerged and compared it with my initial memos and reflections. The intention was to make sense out of what was heard and, as Thorne (2008) wrote, “to uncover insights that would not normally be accessible if you were only familiar with a single case” (Thorne, 2008, p. 159).

**Synthesising.** The second part of the cognitive analysis is where participant experiences are blended to describe typical patterns of behaviour or response within the data. Morse (1994) called this a sifting process where the researcher extracts or weeds out the raw data to describe typical or composite patterns. This part of the cognitive process occurred when I analysed the participant data and generated themes.

Following the transcription of the interview data, the transcriptions were printed and read through in their entirety. This initial read through was to get an overall impression and to see if any pieces of data stood out (Appendix N for an example). Thorne (2016) described how the initial phase of data analysis is a process of familiarisation and reactivity to the parts of data “floating around in the collective soup” (p. 157), and suggested that inevitably some will float to the surface and catch our attention. Each transcript was read and re-read multiple times. As I read through, I would scribble thoughts or clusters of ideas along the margins. This was not a process of line by line coding (as this is discouraged in an ID approach); rather, I was trying to comprehend and highlight the significant meaning units that related to the young participants’ experience, perception of a life with bronchiectasis. Sometime the clusters of the words in the margins were my words, interpreting what was being said, and sometimes they were key words used by the participants themselves. In the first couple of transcript read-throughs, the margins were filled. I searched for meaning in everything the participants said and then eventually would step back and look at the words in a broader way. Thorne (2016) recognised the importance of sorting and organising, and coding data; however, emphasised this as a

process of intellectual inquiry where the researcher looks at the data throughout the collection and analysis phases and constantly asks the questions, 'Why is this here? What does it mean? Having these questions in my mind throughout data analysis was helpful and encouraged me to think beyond any immediate conclusions I may have drawn about what I was seeing in the data. It allowed me to remain open to the possibilities in the data.

Once I had worked through the transcripts, and looked over my scribbled initial themes, I started to bring together bits of data that might be related. These data bits had similar properties, thematic patterns or recurring ideas (Thorne, 2016). I created many broad, general themes which I recorded first in a mind map (see Appendix O for an example) and eventually loaded as nodes in NVivo, along with word versions of the transcriptions

All the transcripts were loaded into NVivo and the nodes were recorded. When this was complete, I read through each transcript again, pulling out new data that fit with the themes I had already developed or adding in new ones as I went along. In addition, as I read through the individual interviews, I came across statements that struck me as striking and interesting and felt instinctively important. Thorne (2016) referred to these as "quotable quotes" (p. 163) and suggested that in order to manage the impact these have on our thinking, it is a good idea to constrain them by putting them in their own confined space. I therefore, created a quotable quotes node within NVivo and set them aside, so they were not lost, yet did not overly influence the ongoing process of analysis. Some of these quotes did end up in the findings report, but some held less importance as time went on and the overall conceptual frame was developed (see Appendix P for examples of NVivo nodes).

I moved back and forth between my hard copies of the transcripts with my scribbles and notes and the NVivo groupings/nodes; contrasting and comparing these along with referring to the reflective memos written at the time of interviews. Throughout the data analysis I consulted with my supervisory team to discuss and review my process. Together, we looked at several transcripts where I had identified thematic patterns evolving from the data. I then sought input on their interpretation of the data in order to compare conceptualisation of themes.

**Theorising.** Theorising is described as the constant development and manipulation of theoretical schemes until the best one is developed (Morse, 1994). Thorne (2016) described this more simply as “developing best guesses about explanations”. (p.185). Throughout data collection and analysis, I continually reminded myself of the research question, always returning to it when I became lost in the data. In my office I had the question posted ‘How do young people describe day-to-day life with bronchiectasis?’. As I worked through reading and re-reading the transcripts developing and fine tuning the meaning units, I returned to the research question; and as the main themes developed, began to organise these around the question. Several mind maps and concept maps were utilised and reviewed with supervisors throughout this inductive and iterative analysis process. Appendix Q has several examples of how I worked through this process.

It took some time see the link between the thematic groupings, and there were several iterations before finally reaching the conceptual framework that stuck. An important element that aided in this process, and kept me on track, was reminding myself about why I chose to research the experience of young people with bronchiectasis in the first place. It was my disciplinary orientation of nursing that inspired the study as well as informed my analytic lens. Keeping in mind the practical and applied purpose of this ID study provided me with structure and support in decision making throughout the analysis. At the same time, I remained open and tried not to allow myself to become set and restricted by disciplinary bias or allegiance. Journaling, and talking with my supervisors through what I was seeing and interpreting in the data, was helpful to balance the analytic process.

Once I had established what I believed to be the key themes, I returned and listened again to several of the recorded interviews. Re-listening, while keeping the thematic patterns I had developed in mind, helped re-affirm for me that my interpretation fit and challenged me to keep questioning my thinking and interpretations. Thorne (2016) suggested that re-entering engagement with the data in this way, once interpretations have started to take shape, is an important way to challenge thinking and ensures the generation of findings that will have meaning usefulness

**Re-contextualisation.** The final part of the cognitive process, described by Morse, is re-contextualisation. This part of the process brings the new knowledge or theory back to the applied practical discipline, and places the results in the context of established knowledge, identifies new contributions as well as supports established knowledge (Morse, 1994; Thorne, 2016). How this final part of the process occurred will be more clearly illustrated in the discussion chapter following the presentation of findings.

## Chapter summary

This chapter has provided the rationale behind selecting ID as the chosen methodology for the inquiry. It has given an overview of the methodological, theoretical and personal underpinnings that shape the study, as well as provided details about the study design and processes surrounding data analysis. Furthermore, this chapter has provided information about the principles that guided evaluation and credibility and the important ethical considerations. The next chapters will describe the findings generated from the data analysis.

## Chapter 4. Presentation of Findings

This chapter will begin with a description of the participants' demographics and geographical distribution. Following, a brief introduction to the findings and to the overarching conceptual claim will be provided. Chapters five, six, seven and eight describe the findings.

### The participants

Fifteen young people aged between 13 and 23 years, with a confirmed diagnosis of bronchiectasis were interviewed between November 2017 and June 2018. These participants shared their stories and experience of growing up and living with bronchiectasis. The topic interview guide questions were designed to allow participants to shape the interview and to talk about their own personal experience of day-to-day life (Appendix K). Youth were recruited through professional networks from the specialist respiratory services at ADHB and CMDHB and through the Bronchiectasis Foundation. Geographically, most participants were in the North Island of New Zealand with only one participant located in the South Island (see Figure 2).



*Figure 2. Geographical distribution of participants*

Nine females and six males agreed to participate. These participants identified as: New Zealand European (n=5), Māori (n=5), Samoan (n=2), Niuean (n=1), Tongan (n=1) and Tuvaluan (n=1) (see Table 3). Participants were asked either prior to, or at the beginning of, the interview if they could identify the age at which they received their diagnosis of bronchiectasis.

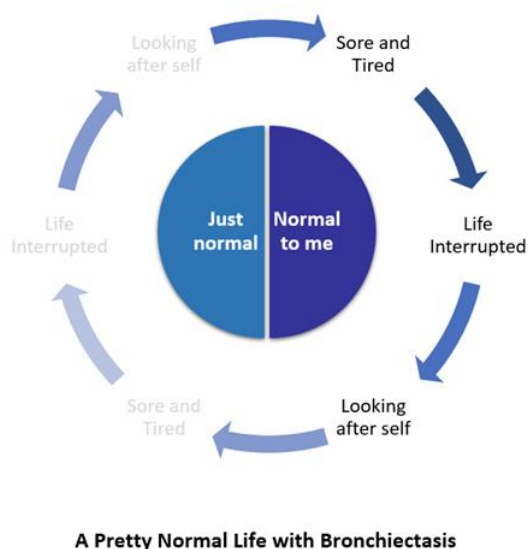
Table 3 Participant characteristics

<b>Pseudonym</b>	<b>Ethnicity</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Age of diagnosis (years)</b>
Kitten	NZ European	13	F	8
Messi	NZ European	13	M	7
Pickle	NZ European	14	F	5
Richie	Māori	13	M	9
Tiale	Tuvaluan/Filipino	17	F	9
Leigh	Māori/Cook Island	15	M	10 months
Rose	NZ European	16	F	6
Peaches	Māori	13	F	4
Kahu	Māori	13	F	4
Pona	Māori	14	F	9
Blud	Samoan	15	M	10
Liz	Samoan	21	F	11
Helena	Niuean	23	F	15
John Boy	Tongan	15	M	10
Nezha	NZ European	17	M	15

## Introduction to the findings

In the following chapters, the findings will reveal how young people described their day-to-day life with bronchiectasis. The first three findings chapters will describe the major thematic elements that first emerged from the data analysis. Sore and Tired (chapter five) is the first key thematic element and describes how participants experienced the symptoms of cough, soreness and tiredness. Detecting, monitoring and interpreting what these symptoms meant for them, was part of how participants

learned to live a '*pretty normal life*'. Life Interrupted (chapter six) is the second thematic element which will reveal how participants talked about the most important aspects of their life such as school, peers, family and sports. In this section, participants revealed how bronchiectasis could sometimes cause interruptions to these important aspects of life. Learning to cope with, and adapt to, these interruptions contributed to participants' view of life as '*pretty normal*'. The third thematic element, Looking after Self (chapter seven) describes how participants were amidst a journey towards self-care independence, including learning how to keep themselves well, safe and learning how to take control and make choices. Chapter eight, the final findings chapter, describes the overarching conceptual claim of the thesis which is pictorially represented in Figure 3.



**Figure 3. Pictorial representation of findings**

This overarching concept has, at its centre, two co-existing views of life. *Just normal* represents how participants endeavoured to see and portray themselves as 'normal' and as living a similar life to their healthy peers. In this view, the influence of the three thematic elements is less visible and bronchiectasis is in the background. The second half of the circle, *Normal to me*, represents the view of life where the influence of the three thematic elements is more strongly felt. When participants described this view of their life, they acknowledged that through varied coping strategies they learned to accommodate and integrate a new version of normal life



that included bronchiectasis. Balancing and oscillating between these two views of life led to the description by participants that overall life with bronchiectasis was *'Pretty Normal'*.

## Chapter 5. Sore and Tired

The first major theme, Sore and Tired, describes how participants experienced the symptoms of bronchiectasis. Three key sub themes that relate to the most commonly described symptoms of cough, soreness and fatigue, will illustrate how participants monitored, interpreted and managed these symptoms. This chapter will illustrate how the participants talked about, and experienced, symptoms in different ways. Sometimes symptoms were described as ‘just normal’ and clearly regarded as part of regular daily life; whereas at other times, the descriptions clearly indicated a significant impact on the quality of ‘normal life’.

### The symptom of cough

In practice, the most commonly described symptom of bronchiectasis is a mucous-producing cough. Based on this, and prior knowledge and experience working with patients with bronchiectasis, I was not surprised that the symptom of cough featured in the participants’ symptoms experience. This sub theme illustrates how the participants talked about coughing in different ways. Some would describe cough as ‘*just normal*’ and clearly regarded coughing as part of normal life; whereas others described it as ‘*embarrassing*’ indicating an impact on their QoL. Participants also related coughing as a trigger for diagnosis and an important signal of impending illness, referred to as ‘*getting sick*’.

Participants all experienced cough; however, the degree to which the symptom of cough impacted on daily life varied among the participant stories. Sometimes cough would not be mentioned unless I enquired or prompted the discussion.

*I only cough in the morning see. I don't know eh. I am just normal I don't really cough that much. I don't cough every day just sometimes.*  
(Blud, 15)

Blud initially appeared to have grown accustomed to coughing and viewed it as a background symptom. In his mind, coughing was no big deal and *coughing in the morning* or just *coughing sometimes* represented a normal pattern. Leigh shared Blud’s experience of cough and appeared to have accommodated it into life in such a way that it was ordinary and did not seem worth emphasising.

Researcher: What about coughing, do you cough?

*Um, not really no.*

Researcher: When you are sick do you cough?

*Um, Sometimes I cough a little bit more when I'm sick. (Leigh, 15)*

Leigh initially denied that coughing was a significant symptom for him. He did not view it as a symptom that was present and linked to his day-to-day life with bronchiectasis. Even with prompting from specific questions, Leigh insisted that cough was not an overly important feature in his life. He admitted that cough did worsen when he was getting sick but emphasised other symptoms as more significant for him during an exacerbation, such as having a sore chest and feeling tired. Other participants downplayed the symptoms of cough and described the symptom as an afterthought. Several used the expression '*I cough a bit*' when they talked about their experience of cough which indicated that cough was a symptom that was present but not of great significance.

Several participants associated cough with the time of diagnosis. They reflected on how changes in the pattern of their cough, intensity and frequency of their cough were the catalyst for receiving the workup and eventual diagnosis of their disease. Participants described how their frequent worsening cough, or a wet constant cough, led them (or rather led their parents) to seek medical help and treatment.

*So I would just cough. Like you know when you wake up the first thing I would do is cough. Then before I go to bed I would cough. I would have a coughing attack before I go to sleep and then when I wake up I would cough and then throughout the day I would cough and cough and cough. (Tiale, 18)*

Tiale explained how for a long time her mum thought she had a cold but could not understand why she kept getting colds with such a bad cough that would go on and on. Eventually, when the coughing had gone on a long time, her mum took her to the doctor to get antibiotics. Tiale also recalled several admissions to hospital with a '*bad cough needing antibiotics*' before she finally received her diagnosis. For Tiale, learning about how the symptom of cough was integral to her diagnosis of bronchiectasis was a shared experience between her and her mum. Other

participants shared similar stories about the time of diagnosis and how the increasing cough led them to seek help from health care services.

*I kept on getting sick and coming into hospital and they tried to, they ran tests to try figure out what it was. They did like all the tests except for one and then my mum told, begged them to do it, the one test and they did it and something came up and I had bronchiectasis yeah.* (Leigh, 15)

Participants' description of the vigilant and persistent attention by their parents to chronic cough leading to the diagnosis was a recurring theme. Liz tells a similar story where her persistent cough was the starting point that linked her mother's concern to diagnosis.

*Coughing. So when I first got it, I think it was hard for the diagnosis, like I was just coughing a lot, that's it. And I went to the doctors and they said my chest is clear. It's clear? And I'm like well I've been coughing so many times. But my mum knew something was wrong... we finally got the CT scan and I ended up staying for like three weeks. Yeah so that's how it started. Coughing.* (Liz, 21)

For Liz, Leigh and others, cough was part of how they came to understand and learn what bronchiectasis was; therefore, 'coughing' was forever inextricably linked to the condition. While some participants talked about cough and its connection to diagnosis and others viewed it as relatively unimportant background noise, there were many participants who viewed cough as an important warning signal that they were 'getting sick'.

*Yeah when I get sick now um it's just coughing, coughing and coughing. It's like somebody's taking an audio recording of coughing and looped it.* (Nezha, 17)

Nezha, in the above quote, describes how this important symptom change provided him with a way of monitoring his bronchiectasis and enabled him to recognise impending illness. Along with recognising the importance of increasing frequency as a sign of getting sick, participants also relayed stories of how cough accompanied with an increase in or change in sputum was another important sign of impending illness.

*Coughing bringing up mucous. When I am well I don't really bring up mucous at all but when I am sick I do.* (Kitten, 13)

Kitten recognised that although coughing would sometimes feature in a regular day it was the change in cough, and particularly the increased mucous production, that signalled to her that she was getting sick. Recognising this change as significant was an important way that Kitten was learning about her own symptom experience of bronchiectasis. For other participants, 'being sick' was not only associated with increased mucous production but also with changes in the colour, consistency and the taste of sputum.

*I, my phlegm goes yellow or green. And I get tired. And I just feel sick.*  
(Pona, 14)

Several participants described it as the '*green slime*' or '*that green stuff*'. For Pona, this notable symptom change was a signal of an impending exacerbation. The change in sputum and the cough often also occurred in conjunction with other symptoms she describes such as fatigue, chest pain and a feeling of being generally unwell. These symptoms will be explored in more detail later in this chapter.

Although quality of life was not a specific focus of this study, participants referred to several experiences that indicated that coughing and the production of sputum had a negative impact on their lives. This ranged from feeling inadequate to social embarrassment and avoidance of activities and bullying. A common description of this symptom was '*gross*' and/or '*disgusting*'.

*Sometimes you wake up in the morning and you just have like this gunk build up in your throat and it's absolutely disgusting to cough out and it makes you feel like you're going to vomit and it's just not very nice.* (Rose, 16)

Cough was not an everyday occurrence for Rose but despite this she had a strong negative emotion attached to the experience. For Rose, the taste and the volume of sputum coughed up made her feel terrible and this symptom impacted on her perception of bronchiectasis as a negative experience. Participants also felt social embarrassment about the cough and sputum. The degree of embarrassment varied between participants but the fear of coughing in front of peers had a big part to play, where they worried their cough would affect relationships. Sometimes it was the sound of the cough (when it was productive) that was embarrassing and something they did not want others to hear.

*And I kind of think it's disgusting, like people didn't like me enough already, I won't hoik all the time. (Nezha, 17)*

Nezha talked a lot in his interview about how he felt that he was different from his peers and sometimes had trouble fitting in. This was not so much in relation to his bronchiectasis but to other aspects of his personality. For Nezha, having a noisy and productive cough that might alienate him further from his peers was a concern. He feared they would judge him poorly because of it.

For JohnBoy, coughing was one of the worst things about his bronchiectasis. It was annoying, embarrassing and a hindrance, especially when he wanted to run.

*Yeah. Like when you run. I don't like going for a run because when I run I cough and phlegm comes out. So when I cough the phlegm will come out. I swallow. I am scared to spit it out... It's yucky, it's smelly. It's just yuck. (JohnBoy, 15)*

JohnBoy was an active and sporty person, therefore the fact that running resulted in coughing and sputum production was problematic for him. He talked about how he had been told that he should always spit out his sputum. He knew what he should do but was embarrassed and did not want his peers to see him doing it. He was aware of this symptom experience and how he deemed it to be a negative one but had not yet found his own way to manage this.

Others talked about how the symptom of cough would sometimes have to be suppressed or 'held in' so as not to be disruptive to life. Several participants revealed that sometimes holding in their cough and sputum was required in order to get through an event or stressful time. Tiale recalled a time in high school when she knew she was getting sick (because her cough had changed) but she had too much going on in her life to acknowledge it. She had exams; she was in a school production and was involved in a cultural performance all at the same time. She made a conscious decision to work her way through it but in the end became very sick and needed hospitalisation.

*Yeah coughing up sputum it was disgusting. And then I held it all in until everything was over and then I was like heh now that everything's over I'll go to hospital and my mum was like you should have done this before. And I was like no I couldn't. (Tiale, 18)*

Tiale knew that if she revealed to her mum and her teachers that she was coughing more they would tell her to stop; and for her that was not an option. At the time, being able to participate and take part in all of the things she wanted to was more important than revealing symptoms. In hindsight, she recognised that this was a bad decision as it resulted in a prolonged hospitalisation. For Tiale and others who reported similar stories of suppressing their cough, the process of learning about their bronchiectasis and how to manage it occurred over time and was a process of maturing developmentally to a point where they could see the necessity of acting when these symptoms occurred. Tiale admitted that she would never ignore her cough now; rather, she would actively try to manage it by doing her physiotherapy and seeking treatment early.

Liz reflected on a scenario from when she was younger and highlighted how coughing up phlegm was embarrassing but a symptom you needed to learn to manage.

*Yeah and I think that was one thing for me because I was bringing up so much phlegm and you want to get rid of it but you can't. So I think for me I was a bit embarrassed at that age because just coughing up phlegm in front of kids and kids are mean. So I just held it in til the end of the day and I'd go home and I'd just yeah do my thing [physio].*  
(Liz, 21)

She recalled having to make changes to her home schedule to accommodate doing physio before school so that it gave her '*a chance to not have a congested chest throughout the day*'. This illustrates how Liz was learning how to monitor the symptoms of her bronchiectasis and trying out ways of managing these symptoms so that it would make her day-to-day life and interactions with peers more normal.

### The symptom of soreness

The word 'sore' was used by every participant to describe some aspect of how bronchiectasis made him or her feel. By using the word 'sore', participants implied they experienced feelings of discomfort, aching or pain (in a part of their body). Participants talked about soreness in a variety of ways and experienced it along a continuum which included the co-occurrence of other symptoms such as coughing, runny nose, sputum production and fatigue. Soreness featured in the participant

stories as a signal of impending illness occurring in a different part of the body with varying intensity and sometimes linked to exertion and shortness of breath.

Participants reported a variety of locations where they would experience soreness, including the head, throat and chest. They drew attention to this symptom of soreness and its connection to *getting sick*.

*I often get a sore throat. Sometimes it's nothing like just a cold but usually it means I am going to start coughing.* (Kahu, 13)

Although a sore throat did not always lead to an exacerbation of Kahu's bronchiectasis, and could sometimes just indicate a simple cold, she did see it as an important sign that often meant she was getting sick with bronchiectasis. For Kahu, the sore throat was a symptom that occurred as a precursor to getting sick. This was a shared experience among the participants with 8 of the 15 reporting sore throat as a common symptom they related to getting sick with bronchiectasis.

*Then like normal sick would be I'd get headache. Then a sore throat and all that. Then the mucous coming down from here, to down my throat. And then the coughing.* (Nezha, 17)

In this quote, Nezha describes a headache and sore throat as 'normal sick' which indicates how he saw these symptoms as ordinary for him. At the same time, they signalled that other more predictable symptoms such as coughing and sputum production were imminent. His sore throat was experienced along a continuum which started with a headache and progressed to further symptoms acting as a warning signal for impending illness. Similar stories from other participants highlighted this idea of a constellation of symptoms appearing along a continuum.

*I get cold. And then I get a sore head. And then I start coughing and then I get green slime...* (Blud 15)

For Blud, a sore head was one of the early warning signs that co-occurred with other symptoms. For him, this experience of getting sick started with being cold and ended with a change in sputum. The 'green slime' acted as the definitive sign for Blud that he was sick and would need to seek treatment. Each participant experienced their own unique pattern of symptoms that indicated to them that they needed to seek help, increase their treatment, go to the GP or, if they were 'very unwell', go to hospital.



Participants also experienced a sensation of ‘feeling sore’ or ‘tight’ in their chest. This varied in quality and intensity between different participants, where for some it was described as ‘sharp’ and for others it was a feeling of ‘fullness’ or a ‘tightness’ in the chest that was uncomfortable. Participants commonly used the words ‘I get a sore chest’ as the first and seemingly best way to describe a symptom that occurred with either an impending or an exacerbation of bronchiectasis.

Participants experienced differing degrees of soreness in the chest. For some it was a pain that indicated they were getting a chest infection and needed to increase their physiotherapy.

*And sometimes, I'll get pain somewhere in my lungs and it will hurt every time I breathe and then I'll use my acapella, which you know what that is? Yeah and then I'll, I'll upchuck [vomit] it... (Nezha, 17)*

For some participants it was an intense overwhelming discomfort that indicated they were sick and needed to go to hospital.

*It's mostly just sore in my chest. Like when I breathe in it hurts, yeah so. When I breathe out its fine but it's just when I breathe in yeah it's sore. (Leigh, 15)*

For Leigh, the chest pain would come on gradually often preceded by changes in his sputum and his cough. The progression of these symptoms indicated to him that there was a shift or impending exacerbation of his bronchiectasis. Others identified with this feeling of pain on inspiration. For Liz the pain was ‘sharp’, ‘tight’ and made deep breathing difficult.

*Just a real sharp pain like. I don't know it's just a real sharp pain when I take deep breaths it's like I stop halfway through because the pain is just too yeah. Or I just feel like my chest is really, really tight. (Liz 21)*

The intensity and severity of this soreness was a strong memory for Liz and was part of her learning to identify and connect these severe symptoms to her experience of exacerbation.

Tiale, Richie and Rose also defined the intensity of the chest discomfort as ‘really bad’ and had learned that this was a potential sign of an impending illness. In the quote below, Tiale talks about her experience of having a sore chest during an exacerbation of bronchiectasis that required hospitalisation.

*This whole area (pointing to front of upper chest) was so sore. My back like you know how your backs like this. You know your back? Just like the top bit whenever I breathed in my spine it will like a sharp feeling like getting stabbed. It was like... uh... And I would like cough up... you know what's that green stuff. (Tiale, 18)*

The strong descriptive words in the quote from Tiale, particularly the words ‘*like getting stabbed*’, indicate that her experience of chest soreness was intensely uncomfortable. Tiale described how this experience of pain in her chest had occurred only this one time and, therefore, will always be associated with being very unwell with her bronchiectasis. Other participants described situations where this level of discomfort and where the pain in the chest stood out as so significant they learned to associate it with an episode of a chest infection

*I can remember how I felt with my last chest infection. I felt miserable... I got really bad like chest pains in my ribs. (Rose, 16)*

Richie, who despite significant developmental delay and learning difficulties, was able with some assistance from his parents, to paint a clear picture of what his chest felt like when he was getting or being sick. He also clearly articulated an experience of significant discomfort.

Researcher: What are the signs that you show mum when you are sick?

*Headache.*

Researcher: What else happens?

*Sore chest.*

Parent: Explain to the lady about what happens when your chest is sore son?

*I um, I can't breathe that well if I have full chest.*

Researcher: What does it feel like when you can't breathe and your chest is sore?

*Yeah feels like it is glass. (Richie, 13)*

This excerpt from Richie's interview provides a strong visual impression of the character and nature of the pain experienced and how he had learned to detect in his own way that these symptoms were associated with ‘being sick’.

Two participants were very specific about the location of pain in relation to where they understood their bronchiectasis to be. Helena, for example, talked about how parts of her lungs were ‘weaker’ and identified that pain occurred there more frequently.

*So like my, my back on my left side will be always sore. I think it's because the lower part of my left lung I think it's getting weaker. But I don't know. But yeah, it gets really sore sometimes. (Helena, 23)*

Of all the participants Helen had the most severe disease and experienced the greatest impact of physical symptoms on daily basis. She was the only participant who described her chest as '*always sore*' indicating that this was her normal baseline with worsening soreness at the times of exacerbation. Constant soreness undoubtedly impacted on her quality of life.

Rose, who had much milder disease, also seemed to identify the pain in her chest to a specific location related to her bronchiectasis. She used the comparison of the pain felt when she had cracked a rib to the pain she felt with her bronchiectasis.

*Sometimes I do get like a casual chest pain but that's just mostly where my bronchiectasis is so I'm just like oh yeah it's just my bronchiectasis I haven't cracked a rib or anything. (Rose, 16)*

Thinking about the location of her bronchiectasis in this way was helpful because it enabled her to make sense and rationalise the discomfort. This was another way that she was learning to detect and interpret what these symptoms meant for her.

Soreness was most commonly described as a symptom which participants were learning to recognise as relating to impending illness, or '*getting sick*'. However, there were some participants that associated feeling sore or tight in the chest in relation to strenuous physical activity. Two of the young participants talked specifically about their chest '*feeling sore*' during events where they had to run for a long distance. This soreness was not in relation to muscular pain nor did it appear to be in relation to shortness of breath. Initially, I believed this may have been their own individual way of describing shortness of breath; but, given the age, developmental stage and length of time living with respiratory illness, it seemed unlikely that the participants would not understand the concept of shortness of breath; regardless most did not describe this feeling in that way. Instead, participants described how their '*chest was sore*' or their '*breathing gets sore*'. For JohnBoy (15), this experience of pain and soreness in the chest while running was bothersome but something he was aware of and managed. He talked about how sometimes while playing rugby he would have to stop because of the pain in his chest. He did not relate the pain to a chest infection during this reflection but talked about it as

something that happened occasionally when playing sport. He managed these events by stopping for a minute, breathing slowly and then resuming running again. It may be that JohnBoy was experiencing shortness of breath but he did not describe it in this way, nor did he use any words that indicated he was short of breath.

Liz and Helena did, however, describe an association between pain, shortness of breath and its relationship to impending illness. The shortness of breath experienced by both participants was accompanied by the feeling of chest tightness and sharp or intense pain.

*It just gets really tight. And I get short of breath and I can't sleep because it's sore when I lie down. There's like sharp pain and stuff. So I, I know if it's not right, I just go straight to the hospital. (Liz, 21)*

Liz articulates how the symptoms of an exacerbation impact on her ability to sleep and how a shift in the intensity of symptoms signifies to her that she is sick and must seek treatment. For Helena, soreness was a word used to describe the symptoms she experienced as an all over body sensation and feeling of weakness.

*Like for me sometimes it's hard for me... I'll wake up in the morning to do my baby... my body's really sore. ...it makes my body weak and so I have to take medication for myself to be not sore anymore and so I can be motivated to do things around the house. (Helena, 23)*

Helena talked about the struggles of doing basic things like housework, moving around the house and interacting with her daughter. She talked about how this 'soreness' invaded many aspects of her day-to-day life. For Helena, the symptoms of her bronchiectasis pervaded and interrupted her life and her ability to function in the way that she wanted. However, Helena had learned how to interpret these symptoms and knew what was required to make day-to-day life more tolerable.

### The symptom of tiredness

Right from the outset, with the first interview, tiredness and the experience of tiredness as a key symptom of bronchiectasis permeated almost every participant story.

*No it [bronchiectasis] doesn't affect anything... but it makes me tired. (Messie, 13)*

When the descriptions of tiredness initially appeared in the interviews, I related these to the age and stage of the participants, given that a certain amount of tiredness and lethargy is usual during the adolescent period (Viner & Christie, 2005). However, as more interviews were completed, it became clear that the tiredness and lack of energy the participants described was something more than typical adolescent fatigue. Feeling tired was a symptom common to all the participants at various points during the illness experience, including when they were getting sick, being sick and in the recovery phase.

*Probably the tiredness is what I would notice first. And I would start feeling unwell and then I might start coughing up mucous and then I'd say parent I'm a bit sick... (Kitten, 13)*

Kitten illustrates the notion of noticing tiredness with her quote which shows how she had come to know and understand the connection between tiredness and the onset of an acute illness. In her experience of bronchiectasis, the symptom of being tired preceded the other symptoms. She talked also about how sometimes her mum would notice that she was tired and comment about her '*getting grumpy*'. Kitten felt this was '*sometimes annoying*' but acknowledged that her mum had helped her to see the connection between tiredness, her mood and the onset of illness.

Other participants shared a similar experience to Kitten where parents helped them to notice how tiredness was a red flag for them getting sick. Pona talked about how her mum would notice her tiredness often before she had even noticed it herself. When that happened, her mum would insist she rest and stay home from school. Pona was still reliant on her mum to help her to identify how this symptom of tiredness preceded getting sick. Some of the participants talked about how prior to getting sick, they slept a lot and became '*exhausted from doing nothing*'. Whereas others used words such as '*just tired*', '*I'm always tired*' or '*I get so tired*' to illustrate how they felt prior to getting sick.

*And sometimes I can tell when I'm about to get sick. Like if I'm having a hot shower and it's hot but I'm cold, I'm sort of shivering yeah um. Or like if I'm really tired, sleeping heaps... (Leigh, 15)*

Leigh felt that most of the time when he was not sick, he was the same as his peers, '*felt normal*' and lived a completely typical life. Leigh, however, also

understood how for him tiredness was a symptom that was ‘*different*’ to how he felt when he was well. Being able to identify these warning symptoms of getting sick were part of his own journey of learning about his bronchiectasis and helped him to identify when he was ‘feeling normal’ and when there was a change that warranted attention.

Not all participants noticed the tiredness on its own or noticed they were sleeping more. Kahu, Pickle and JohnBoy described how being tired became noticeable when it impacted on daily activities such as school or sport. Kahu was a good athlete and involved in lots of sporting activities. She noted how sickness and tiredness negatively influenced this aspect of her life.

*When I’m not sick I can like do basically everything but when I’m sick I get... like it’s quicker for me to get tired when I’m sick. Like, because when I’m sick I can like easily get tired if I’m like doing even one lap.*  
(Kahu, 13)

For Kahu, the symptom of tiredness either indicated she was getting sick or that she was still recovering after an illness. She knew this because she was confident in her ability to be the same as her peers when well but acknowledged that this differed when she was sick. She recognised that tiredness was sometimes a momentary set back and that she might need to ‘*take it easy*’ until she was feeling back to her normal self. Pickle shared a similar experience about being sick with bronchiectasis and how the subsequent fatigue impacted on her ability to take part in activities at school.

*Doing PE. That’s probably the hardest. All the running that we do and keeping up with everybody... I was always at the back and couldn’t do things for very long and it was very frustrating and I only just made it through cross country. And sometimes tag games I get tired even though I am only just running across a little strip it does get very tiring. Yeah I get very tired.* (Pickle, 14)

In this quote, Pickle expresses frustration over the tiredness and subsequent difficulty keeping up with peers. She recognises tiredness as an important symptom of her bronchiectasis and notes how this was different to her peers, even those whom she knew might also have a chronic condition like asthma. Pickle had friends with asthma and she felt they seemed better able to cope with physical activity than

she could and they did not get as tired. JohnBoy also drew attention to the symptom of tiredness and how this was different to other kids his age.

*I am just tired. I get tired in class. I fall asleep in class... Yep cuz mostly my friends, they stay awake. They are awake and I am at the back sleeping. (JohnBoy, 15)*

For JohnBoy, this symptom of tiredness occurred most often when he was getting sick or upon returning to school after an acute illness. Other participants shared similar stories of being tired at school. Kitten, Pickle and Messi all talked about how they would ‘*get tired really easily*’ especially in the winter months and would sometimes have to text or ring a parent to come pick them up. Tiredness was a symptom they associated with getting sick or being sick, and something they learned how to manage. Some participants did this by coming home early from school or cutting back on full days in order to make time for rest. Some participants talked about resting after school if they were particularly tired. This would enable them to ‘*look after*’ themselves and potentially reduce the chance of getting sicker.

Participants noticed that there was a difference between how they felt every day and how they felt when they were sick. Participants talked about how tiredness warned them they were *getting sick*, but also how it got much worse when they *were sick*. The description of how the tiredness felt was similar across the interview data. Words like ‘*exhausted*’, ‘*drained*’, ‘*low energy*’, ‘*weak*’ and ‘*all over body tired*’ were commonly used by the participants. Pickle described the experience of body tiredness she felt when she was sick.

*When I do get sick though I get tired. Like my mind is awake but my body is tired so I can’t fall asleep always. Does that make sense? So it’s like my eyes are really hard to open... My arms might be getting tired. My body needs a rest, but my mind is thinking nonstop and keeps me awake. (Pickle, 13)*

The young people described how when they were sick and home from school, they spent a lot of time in bed or lying down and how even the smallest normal daily activity could be very tiring. Pona described herself as ‘*exhausted*’ and talked about how ‘*even the littlest things are hard, even going for a shower*’. The tiredness associated with being sick seemed to be an overwhelming body tiredness or

‘exhaustion’ that made simple tasks such as showering, doing housework or playing/hanging with friends or siblings difficult to manage.

*Felt like I was weak. My whole body couldn't... I couldn't like carry myself. And I was cold. I always feel so cold. And I was sleepy yeah.*  
(JohnBoy, 15)

The lack of energy that JohnBoy and Pona highlight as a key symptom of being sick was described in a similar way by other participants. Several participants talked about how they would have little ‘*internal conversations*’ with themselves to convince themselves to get up and move. The tiredness symptom that occurred when they were sick was much more than just ‘*normal tiredness*’.

For most participants, the extreme fatigue and tiredness was not continuous but intermittent and usually associated with times of acute illness. But for Liz and Helena, two of the older participants, this state of fatigue seemed to be unremitting. There was a sense that as the bronchiectasis progressed, the symptom of tiredness became more prominent. Helena was a mother and had significant physical affects from her bronchiectasis. Her frustration over her inability to keep up, play and be active with her young daughter was palpable. She acknowledged that her lung disease had worsened over time and that she was no longer physically able to do what she had been able to do in the past.

*I used to run around a lot. Then now of course... But yeah I, I was tired when I was a little kid but, not as tired as how I am today. It's, it's a big difference from when you're a kid to now. A lot changes.*  
*Yeah.* (Helena, 23)

Helena was frustrated by the physical limitations placed on her by having bronchiectasis and clearly identified that although fatigue had always been a feature for her, now it had become more pronounced. Helena talked about how she had once had dreams of being a policewoman, but that physically she knew that she was often too tired to pursue that dream and, therefore, had to change her goal. She decided that despite frustration over the impact of the disease, she knew she needed to stay strong and focus on living the best possible life she could. Helena coped with these strong symptoms of fatigue through an incredibly positive approach to life and her Christian faith.



Liz also made clear links between her fatigue and the progression of her bronchiectasis. She referred to periods when she was younger and recalled being tired and sick but noted that this had got worse as she had got older

*Oh I get tired really fast now. Yeah I would say, yeah... because of, of bronchiectasis... Um I, I get, yeah. I guess it's both. I get tired and shortness of breath. (Liz, 21)*

Liz looked out for and monitored these symptoms; it was an important way that she managed her bronchiectasis and looked after herself. For her, shortness of breath was a sign that intervention was needed. Tiale was the only other participant who directly described shortness of breath and linked this subjective experience to being tired. Using the words '*a tiredness in my chest*' to describe how she felt when she was sick with bronchiectasis, Tiale paints a picture of overwhelming tiredness and a heaviness in the chest that may also relate to difficulty with breathing. This connection between shortness of breath and tiredness was hinted at in some of the other participant stories; for example, Pickle describes a feeling associated with sickness as '*breathing tired*' and Peaches articulated how when she is sick it '*gets hard to breathe*'. Both descriptions offer a glimpse into the subjective experience of these participants and seem to imply a connection between being sick with bronchiectasis, tiredness and shortness of breath. However, it is not clear in the data if fatigue and tiredness is always linked to being short of breath or if it is associated with some other aspect of their bronchiectasis.

### Chapter summary. Sore, coughing and tired.

The symptoms of cough, soreness and tiredness are the three key sub themes highlighted in this chapter. The first major sub theme illustrated how the symptom of cough was linked to different things for different participants. For some, it was just part of a regular day where cough was viewed as normal; whereas others, linked cough to part of the diagnostic process. Most participants at some point in their life experienced cough as a signal for impending illness and it had a negative impact on some aspects of QoL. The descriptions of both 'soreness' and tiredness were surprising given that these are not commonly described or acknowledged as common symptoms in bronchiectasis. Soreness and tiredness occurred commonly among the participant stories both as a signal of impending illness and as persistent symptoms

during an acute exacerbation. These symptoms influenced and impacted participants' view of life and were all part of the experience of living day-to-day with bronchiectasis. Learning to monitor, interpret and manage these symptoms was part of how they were living their own 'pretty normal life with bronchiectasis'.

## Chapter 6. Life Interrupted

The young participants in this study were asked to describe their day-to-day life with bronchiectasis. In answering this question, they talked about life at home and family, their friendships and school, and the sports and other activities they liked to do. They described themselves as the '*same as everyone else*' or '*just like everyone*' and they described their life with bronchiectasis as '*normal*'. However, despite this initial assertion of a life largely uninfluenced or impacted by bronchiectasis, the participants described daily and intermittent disturbances that affected day-to-day life.

Physiotherapy, medications, clinic appointments and the physical symptoms of the disease were inconvenient but inevitable interruptions that sometimes temporarily stopped them or delayed them from doing things they wanted to do.

This chapter will describe the second major theme which emerged from the data; that of a life occupied with tolerable and intolerable interruptions. Participants described this within the context of four sub themes relating to school, social interactions, sport and family. This chapter will illustrate how participants learned to cope and adapt to these interruptions in order to achieve and maintain a life as close to normal as possible.

### School life interrupted

School is an important part of life for young people. Most participants when talking about their day-to-day life included descriptions of a typical day which inevitably involved attending school. Participants also talked in general about subjects they liked and those they disliked, about teachers and friends, and how high school was more challenging than intermediate school.

*I really thoroughly enjoy school so I'm kind of sad that next year is my last year. I like learning about new things and improving my skills and I also like seeing my friends. It just gives me time with my friends and also learn at the same time so it's just a fun situation really! (Rose, 16)*

Although not everyone loved school as much as Rose, most participants shared her enjoyment of learning new things and the opportunity for social interaction with friends, which of course is an important part of a young person's life. Other participants shared stories of how school and social life went hand in hand and

how school was the place where they experienced success and failure in the social setting and learned how to fit in with others.

*Sometimes the girls can be a bit annoying... like a lot annoying actually. I've known them all since last year and we can have our dramas. Sometimes all they want to talk about is boys on the bus... which is so boring. But I just go along with it. It's no big deal, it's just yeah. (Pickle, 14)*

Pickle spent a fair amount of interview time talking about her friends at school and the 'dramas' they encountered. Pickle was navigating the usual social activities of adolescence and bronchiectasis did not feature in these stories. This highlighted how school and friends were topics of much greater importance in the day-to-day life of a 14-year-old girl, than coughing and chest physiotherapy.

In addition to talking about school in a general way and emphasising the important role that school life had in their day-to-day life, participants revealed how bronchiectasis could sometimes interrupt normal school life. Participants talked about these interruptions to school in relation to the daily tasks required, the time missed and how they coped and managed the interruptions.

On a day-to-day basis, fitting in regular medications (vitamins, antibiotics, and/or inhalers) and completing airway clearance techniques were part of their daily routine and had to be incorporated into a school day.

*If I am well going to school I will wake up get ready for the day. Maybe do my PEP<sup>4</sup>. End up at school late, right before the bell, um do all my classes and have morning tea, more classes, lunch more classes, go home and go to bed and watch anime. Get up about 5 have dinner, do all of my medications have a shower, go back to bed until about 9 still watching anime then go to sleep. (Kitten, 13)*

Even though Kitten had incorporated physiotherapy and medications into the pattern of her day, she subtly refers to how doing physiotherapy did impact on the timing of getting to school. She talked about how when she took the time to do her physiotherapy in the morning she would often arrive late for school. Kitten was not particularly bothered by this interruption, but had accepted being late to school as

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<sup>4</sup> Positive Expiratory Pressure (PEP) is breathing against resistance, which can be performed either through a device or against pursed lip (Fagevik Olsén, Lannefors, & Westerdahl, 2015).

normal, for her. Other participants shared this view and as they accommodated physiotherapy into their routine.

*I just make sure I get up early and get my breathing done. It's a pain but that way I know I am set for the day and my chest will be clear. Stops me coughing too much at school. (Pickle, 13)*

Pickle acknowledged that doing physiotherapy added extra stress to her morning routine; however, clearly appreciated how this self-care task was beneficial to her in terms of reducing her cough at school. She had weighed it up and concluded that coughing during the day was a far worse scenario than having a minor interruption to her morning routine. It is likely the social stigma and embarrassment of coughing in front of peers, as previously discussed, had a role to play for Pickle in this scenario. Nezha and Messie talked about how they would 'do physio before I leave for class' or 'try to do it before showering in the morning'; and, like other participants, noted these tasks were sometimes disruptive to normal routine. The minor adjustments in routine were not insurmountable and being a bit late for school or having to get up a bit early were viewed as tolerable interruptions. It was a different story, however, if these interruptions impacted on school attendance.

Missing days of school was one of the more stressful effects of having bronchiectasis. Lengthy and numerous interruptions due to clinic appointments, acute exacerbations and/or hospitalisations interfered with attendance, the ability to keep up with schoolwork and affected academic goals. For Messi, missing school was a frustrating disruption that he felt other kids could not truly appreciate. He felt that those who talked about not liking or not wanting to go to school were talking about this in the context of being well; whereas it was quite a different story when you were off school because you were sick:

*For some people missing school would be a good thing but not for me. When people have time off school it is when they are not sick it is different when you are forced to. I tried to explain to my sister that it is not fun being off school. It is not like I enjoy it or can do anything fun and then I feel stressed about what I have missed. (Messi, 13)*

Managing fatigue, sickness and potential absence from school was a balancing game for some participants. Sometimes participants faced the decision about going to school, when they knew they should stay home. Several participants talked about

how it was hard to make the decision and they found themselves facing an internal battle in their head.

*I'm always like adamant that I can still go to school when maybe sometimes I should have the day off to maybe recover a little but I'm, I'm kind of the one that likes to have perfect attendance. (Rose 16)*

For Rose, attendance at school was important. Thus, on the days she was feeling 'a bit sick' and more tired, she would make minor adjustments and persevere. There were also times when participants would feel they were 'getting sick' at school. This sometimes revealed itself to them by feelings of tiredness. They found themselves struggling with the decision about going home and resting (knowing they were going to miss important information or even a test they would have to make up) or staying at school (and potentially getting sicker and ending up in hospital or off school for longer). Some participants talked about how they would reluctantly go the sick bay or ring home because they knew the likely outcome was that they would have to leave school. This was a tough decision.

For many participants, it was the physical symptom of tiredness which sometimes made it difficult to concentrate at school or focus on tasks like homework. During times of acute illness, and especially during hospitalisation, tiredness became even more of a factor.

*Probably homework can be a bit hard. Especially when you first go into hospital when you're still quite sick because you are always really tired and you can't do your homework because you're too tired. (Pona, 14)*

Participants noted that the significance of missing school became more and more pronounced the older and further advanced in school you went. The pressure of catching up after prolonged absence was due to the number of different subjects, different teachers and the volume of content covered each day. Getting sick or being sick was problematic. As one participant reported:

*If you have been sick for a while and haven't really been back to school it's really hard to go back to school, especially if you are a teenager because it's like a lot happens within like 2 weeks or something that you are away. And in high school you've got a bunch of different teachers, you don't have the same teacher for every subject so it's harder to keep up with all of the subjects. (Kitten 13)*

The perception that absences from primary and intermediate were okay and somehow manageable, whereas absences from high school were more stressful, was shared among several participants. Liz, an older participant, reflected back on her own experience during high school years and related how *'missing out on classes, getting behind and then trying to catch up and then keep up'* was one of the most challenging things about having bronchiectasis in high school. She talked about how it was somehow *'not so bad'* when she was younger but that *'once you get to high school you just can't afford to be away or you fall way behind'* (Liz, 21). Absence from high school was more significant because of the pressure and academic requirements of the National Certificate of Educational Achievement (NCEA)<sup>5</sup> standards. Several participants relayed stories of how school absences due to being sick or in hospital amplified the normal pressure of NCEA exam time.

*The hardest thing was when I had NCEA exams and I got really sick and had to go to hospital. I would try to do work there, but I missed all the revision, which sucks.* (Liz, 21)

Liz articulates clearly how significant the interruption of treatment in hospital was during this period of her life. Tiale related a similar story where she talked about how hospitalisation had added an extra dimension to the usual stress of studying for NCEA exams.

*In year 11 I remember I was in hospital when I had my exams on. I was like really like stressing out saying oh my God it's my first year of NCEA and like I'm in hospital! Like My mum would like bring in my stuff I needed to hospital, but I was like so tired... but I also like really wanted to go into school like myself but because I was really sick back then the doctors wouldn't let me like go to school. They said I was really bad. They said that I had to wait a couple of weeks. I was like I can't wait a couple of weeks...* (Tiale, 18)

As Tiale reflected on this time, the stress that missing out on exams caused her was palpable. She reflected on how she had struggled with balancing her own desire to return to school, the fatigue that accompanied being sick and the restrictions put on her by having to stay in hospital for treatment.

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<sup>5</sup> The National Certificate of Educational Achievement (NCEA) is the main national qualification for secondary school students in New Zealand.

When the inevitable absences from school did occur, participants talked about two key things that helped make this more manageable. The first common thread in the data was support from school and schoolteachers who connected with them, provided catch up work and made it easier to stay on top of their schoolwork.

*I feel I miss like heaps of school because I was in hospital, with asthma and bronchiectasis but oh one of the teachers sent videos and she'd like video call and I'd go like, she'd video call me while I was in hospital and like I'd join the class. (Pona, 14)*

For Pona, being in hospital meant being a long distance from home. She talked about how helpful it was to have catch up work in hospital and connect with her classroom who were back at home. Other participants shared stories of being in hospital and having work brought for them.

*I would say my worst year was year 11 because that's when it was really bad back then and I missed basically a whole term because of bronchiectasis... My teachers understood a lot. I think my media studies teacher came up to hospital and visited me and brought everything I needed and I said 'oh I wish all my other teachers did that'... (Tiale, 18)*

Tiale and other participants felt that support from teachers was an important way for them to cope with and manage the stress of schoolwork when they were sick and missed days of school. For Tiale, who in the example above had missed a significant amount of school, supportive teachers contributed positively to her ability to cope with the time away from school and made the interruption tolerable.

Several participants reflected on how sometimes parents would contact teachers by phone or organise a meeting to explain the reason for absences. In cases where this had occurred, participants felt that it was helpful because teachers had a better understanding about why they had missed classes or tests. This made the interruptions to school life more manageable and tolerable. When teachers did *not know* about their bronchiectasis or when the young person felt that the teacher '*did not get it*' they would sometimes feel judged as 'not looking sick' enough to warrant extended absences. When this happened the interruption to school life was less tolerable.



The second helpful thing highlighted in the data was the Northern Health School (NHS)<sup>6</sup>. The services of the NHS, which provide help in hospital, at home and in support centres, gave opportunity for these young people to keep up with schoolwork while also providing a break from normal school routines during recovery from illness. Many participants had been, or were currently, engaged with the NHS and talked about the role that it had played for them in terms of making school disruptions more manageable.

*It is... a school for chronic illnesses that go there... well I use it just to get a bit of a rest. I just go one day a week... My teacher at health school she is good. She can notice whether I am more tired so just do some baking and relax on couch or if I am good we can do some schoolwork and she will help me with that. (Messi, 13)*

Messi appreciated the fact that teachers at the NHS understood the nature of his bronchiectasis and the potential impact this could have on his ability to do planned activities or schoolwork. For Messi, NHS was beneficial and helped him to cope in a couple of ways; it provided him rest when he was feeling overwhelmed and it was a place where he felt supported by a teacher who really understood.

For Kitten, regular school was not something she particularly enjoyed, with or without the added interruption of bronchiectasis. She did not enjoy doing schoolwork, had recently moved schools and was struggling with some of her new friendships. The NHS provided Kitten with a new outlook about school.

*It's kind of weird because you don't know any of the students there but after you get used to it its kinda fun. The teacher can come to the hospital there is also Manaia house a building in there with a room that's where they like set up and students can go there. That's what I have been doing recently. And just do my work there. It's better. (Kitten, 13)*

Although Kitten initially felt uncomfortable with the idea of attending school where she did not know many people, she came to view NHS as a positive benefit of having a chronic illness. She came to appreciate the help, support and even grew to like attending.

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<sup>6</sup> The Northern Health School (NHS) is a government funded program which provides education and support services for children and young people who are recovering from serious illness.

Other participants who had used the NHS services spoke positively about how it had helped them manage and balance day-to-day life with bronchiectasis and still achieve their academic aspirations. The service was utilised by participants in different ways. Sometimes they were in hospital and could not go to school at all or sometimes they were at home but only able to manage school part time due to fatigue and ongoing illness. In both situations, participants related how the NHS had helped them manage the interruption and live life as normally as possible in the context of being a person with bronchiectasis.

### Social life interrupted

The second sub theme of 'Life Interrupted' will explore how frequent absences from school and the sometimes physical limitations of bronchiectasis impacted on the young participants' friendships and social life and activities.

Participants talked about their friendships positively. Time spent with friends hanging out, listening to music, talking and going to movies etc., were among the most important things in their day-to-day life. Participants described how being sick and away or missing out because of their bronchiectasis was an unwelcome interruption to social life and relationships. This was particularly true when participants had been away for a longer period, due to hospitalisation. Some suggested that coming back into the social arena of school could be tricky as friends had '*carried on their usual stuff*' and they found themselves having to reintegrate and fit back into the social group. Kitten (13) and Pickle (14) both talked about how when they returned to school after an absence, their friend groups would have stories and experiences *they* had missed out on. For both participants, this was challenging as it made them feel like outsiders in their own peer groups. Liz recalled a time when she had been away from school for an extended period and during this time friendship groups had changed, with new groups formed.

*Being away too long was not great. I missed my friends and stuff and when I came back everyone had moved on to new groups and stuff... And I didn't really understand it. And so that wasn't really good in a way. (Liz, 21)*

Liz recalled feeling sad and out of place when she returned after an absence and how all important this felt to her at the time. '*It's not such a big deal now but it*

*was then'*. As she reflected as a 21-year-old, she could see how being away from school for long periods had impacted on her relationships and how for her younger self this was a challenging interruption.

Other participants shared similar stories of how missing school due to illness or hospitalisation impacted on relationships with peers. Pickle talked about how she tried to maintain the connection to friends while in hospital but then realised that contacting friends by phone or having friends to visit was not always easy as they were busy with their own normal life and activities.

*You can't really have friends over in the hospital because they are normally usually busy, and they have school as you don't, so sometimes you might feel like calling them in the middle of the day and they might be in class so you can't really call them or talk to them much. (Pickle, 14)*

The feeling of isolation and not being able to hang out and talk to friends while in hospital was difficult. Participants found hospital boring and the social isolation from regular activities with friends and other young people was viewed negatively.

*It's so boring in hospital and there's like there's no one my age. (Leigh, 15)*

Some participants suggested that having to explain to peers about absences (being away from school or missing events) provoked a disturbance to social interactions. Friends wanted to know where they had been, why they were not participating or sometimes thought they were not coming back at all. Some peers concluded they were bunking school [being truant] or using their bronchiectasis as a handy excuse to avoid school. One participant recalled a time when a peer did not believe she was in hospital at all and told others at school that she was '*faking it*' after seeing an Instagram of the participant in hospital. This made the return to school and friends stressful. The participant felt indignant that she had to justify and somehow prove that she was legitimately away due to illness.

*I am normally nervous for the first day back and I know I am going to have to explain where I was... and people are all like were you ditching or what. No not really... So once that's done then they kind of get used to it. (Peaches, 13)*

Here, Peaches highlights the significant stress she felt upon returning to school after an absence. Once she can explain why and what has happened, the initial period of nervousness is resolved. Once her friends at school had the information, they lost interest in the fact that she had been away, and relationships returned to normal.

Whilst many participants mentioned how bronchiectasis influenced social activities and time with friends, the majority described this influence as bothersome rather than intrusive or overwhelming in their day-to-day life. All of the participants talked about these 'interruptions' in a way that did not convey irritation but instead seemed to recognise and accept these were inevitable events that they adjusted to and '*got on with*'. Most acknowledged that with support from teachers, friends and family they were able to adjust and cope and get used to the small changes. These events became part of their version of normal day-to-day life.

### Physical and extracurricular interrupted

When the participants talked about the influence of their bronchiectasis over sports and leisure activities, they were much less tolerant of the interruption. Physical and extracurricular is the broad category given to the numerous activities and events described by the participants that included organised sports such as football (soccer), basketball, volleyball, running and karate. It also included school camp, waka'ama<sup>7</sup> and music. Every single participant in this study talked about how bronchiectasis interrupted sports and leisure activities; and they described this interruption in different ways. Some felt that bronchiectasis inhibited their ability to perform their chosen sport or activity at the level they wanted, while others described situations where it prevented them from taking part at all. There were a small number of participants who initially vehemently denied that bronchiectasis had any impact on their day-to-day life but then proceeded to relay stories of how sports and running were sometimes affected. The participants revealed that they self-managed the interruption in different ways.

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<sup>7</sup> Waka'ama is the New Zealand term for the sport of outrigger canoeing.

*When I did Kapa haka<sup>8</sup> I missed out on going to nationals. I missed out on going with them because I got sick. Like right the night before, the day we before we left. (Pona, 14)*

The sense of disappointment felt by Pona of not being able to attend this event was tangible. In her mind this was an opportunity to experience something good and important to her, and bronchiectasis had prevented her from doing that. Other participants talked about how they would join groups or sign up for activities or lessons and then find themselves too sick or unwell and unable to attend.

*So I started a Pippins groups which was just a whole lot of 6 year olds hanging out on a Friday night with their parents and I ended up getting, I just got really unwell didn't I? And I ended up having to stop going altogether. Oh yeah I dropped out of tap dancing as well. Just missed too many classes. (Rose, 16)*

Rose talked about how missing a session or lesson made it harder to go back. The feeling of getting behind or having to catch up on elements of a lesson missed made it easier to abandon the activity. In addition to sickness, attending appointments was another common reason cited for missing extracurricular activities.

*In Year 6 we had a check-up and it was on group action day and we really wanted to do it but we had to go to our check-up... My mum didn't bother to take us to school but we really wanted to go but we couldn't really because the doctor took too long. (Peaches, 13)*

For Peaches, missing school was a shared disappointment she felt with her sister, Kahu. She recalled how before they went to the appointment they had planned on still making it to school in time for group action day. The memory of missing out on this event and the disappointment she felt about the appointment running late was still clearly felt.

One of the most talked about extracurricular events was school camp. This was a popular topic among the younger participants, and several gave examples of how bronchiectasis affected their camp experience. Kahu recalled two different incidents, one where she had to miss out on school camp and another when she got sick and had to come home early. 'It was so annoying' or 'that time really annoyed me' were common expressions used when talking about missing out on camp.

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<sup>8</sup> Kapa haka is the term for Māori performing arts and literally means to form a line (kapa) and dance (haka).

*Last year's camp I felt sick one night and it stopped me doing some games. I missed out on spotlight. I really wanted to do that but I was feeling really sick and tired. So I went to bed early. That was kind of annoying. (Kitten, 13)*

Here, Kitten articulates her frustration over the fact that bronchiectasis stopped her from doing something she wanted to do and socially separated her from her peers. Pickle tells a similar story of disappointment about a time bronchiectasis interrupted her experience of camp.

*After I got diagnosed with bronchiectasis at first I wasn't actually going to camp then I only went for a day. Then in intermediate, my parent came with me. And we actually slept in a cabin together. I didn't get to share with all the girls. (Pickle, 13)*

Missing out on activities or missing out on camp altogether negatively impacted on social interactions and peer connections. At an age when fitting in is paramount these interruptions highlighted how participants were different from peers.

Sports and physical activity were other areas participants described as being impacted by bronchiectasis. Initially, some participants softened the influence or seemed to be in conflict about how to describe the effect. They often started by using statements like 'it's no big deal' and 'it doesn't really affect me' or 'I can do anything anyone else can do'. However, once they began relaying more of their day-to-day experience, it became clear that the discourse surrounding sports and leisure revealed a different story. For many, bronchiectasis did influence sporting goals and aspirations. Sometimes this change occurred during an account, as in Messi's interview below:

*No. No. Not really. Maybe. If it's a really challenging game, afterwards but not during. Like I don't get any kind of breathing problems usually. I do get out of breath faster than other people do but I don't get real breathing problems it's kind of just gradually I will get sick. Like the next day I might feel really sick. (Messi, 13)*

Running featured as one of the most talked about sports and most effected sporting activities. All the participants, in one way or another, talked about running and the way that bronchiectasis made it harder than normal, precluded them from participating, caused pain and/or got in the way of running well. The young

participants in this story described not being able to run and keep up with peers as something that made them feel envious and admitted that it was '*hard to see people doing more stuff than you*' (Kahu). Comparing one's own ability to friends was a common theme among the participant recounts.

*I think it's taken a real big toll on my life sometimes. It's hard to keep up with the kids at school if I'm trying to do like sprints or something. Yeah I'll be tired and they won't be.* (Peaches, 13)

It was significant when participants, like Peaches, recognised a difference between themselves and friends as it highlighted the negative aspects of bronchiectasis. Some participants talked about how friends would slow down for them or alter the pace while running so they could keep up. Sometimes friends would offer to sit out with them if they were unable to participate due to coughs and colds. One participant talked about a cross country event at school and how, although her friends were very fit and competitive at sport, one friend would stay with her and jog slowly to keep her company. Having supportive friends made the differences seem less significant and helped participants feel part of the peer group.

The participants all had their own personal level of fitness or sporting ability to which they aspired. This varied among the participants, with some showing little interest in sports and fitness and others keen sportspeople. Regardless of what end of the scale participants were, '*Getting sick or being sick*' was highlighted as the tipping point that influenced participation in sports. Leigh was proud that he could keep up and even surpass his friends at sport but reluctantly admitted that when he was 'sick', his breathing did have an impact on his fitness.

*It only really affects me when I'm sick kind of. When I'm not sick it's, I don't, like I can keep up with others yeah like in sports and stuff that I'm like not meant to. Yeah like my breathing seems fine but it's just when I get sick it goes down yeah.* (Leigh, 15)

There was a clear tension for Leigh in how he downplayed the impact of his bronchiectasis on his sporting ability but at the same time admitted there were sometimes setbacks, particularly when he was sick. In New Zealand, many of the primary schools have outdoor unheated pools and this provoked some negative memories for participants. Many of the participants explained how '*getting sick*' or '*being sick*' would prevent them from being able to participate in swimming.

*And like the teacher's like oh why can't you swim? Well I have a chest infection because you made me do swimming in winter. And like they're like oh that's kind of a let-down. (Rose 16)*

Having to sit out and be different from their peers was likely a primary catalyst for the negative memories and highlighted again how they were different from others. Having to explain to teachers was sometimes problematic with teachers at extremes of understanding. There were *'those that understood'* and were sympathetic when participants could not do the run or finish a swimming event at school; and those that would insist they keep up or imply they were being lazy. Along with having to explain to teachers, participants also felt pressure to justify to their friends why they were not able to join in activities. Some felt that they were being judged as that *'person who always sits out'* and found that some friends did not *'get'* that *their* chronic illness was *'different from someone with asthma'* or someone who was *'just not feeling good'*. Messi articulates this well.

*Ah yeah sometimes it does stop me doing stuff. If I am a bit sick then it's... no, no, no, not today Messi is not feeling good. But I still want to go and stuff like that. And so it's a lot different like if someone else is not feeling well they would still go. But I kind of need or have to say no and go and stay home and rest it off. Yeah. It's not really often. But when it happens it's annoying (smiles). (Messi, 13)*

Several participants related similar stories where they had to justify and explain to a friend how having a cough and a cold or being exposed to a simple virus, meant something quite different for them when compared to the average person without bronchiectasis. Many of the participants acknowledged (as Messi did) that they were different from others. Feeling okay about this difference was sometimes challenging, particularly if there was a feeling of grief over losing physical capability. Helena felt this and missed how she used to be and feel *'fit and healthy'*.

*Oh I was healthy. Running everywhere. I used to be able to do the mountains like twice, but yeah, I just look at it now. Which is sad but it's okay But sometimes I just motivate myself to move, to get walking up that hill and I say I'm going to make it up the hill and I end up making it up because I just keep motivated. So I think my key is when I think oh the world's ending, it's not! (Helena, 23)*

Helena often found herself frustrated by the interruption that bronchiectasis caused in her life. She did not want to see life negatively and through support of



family and friends managed to stay positive and motivated to keep moving and keep her life as normal as possible, in the context of living with bronchiectasis.

Sports and the ability to take part in physical activities at school were extremely important to the participants in this study. Most talked about how the connections to friends, the fun and the pride they felt participating was an important part of their day-to-day life. When interruptions to these activities occurred, it was annoying and challenging as they felt they were not only missing out but were made to feel different from their peers. Participants found ways to manage this tension through supportive friends and teachers who understood and helped them normalise the interruption.

### Family interrupted

All the participants recognised and talked about the important role that family had in their life. Participants used many positive phrases to talk about their family and the role they played in helping them to manage and share the burden of bronchiectasis. However, because the burden was shared, participants acknowledged that sometimes interruptions to the family occurred as well.

For most participants, the interruptions to family were most keenly felt at the time of acute illness and/or hospitalisation. Participants described how parents, siblings and grandparents were affected by hospitalisation.

*But when I first started going into hospital all the time it was really hard for my mum to stay the night because of my two brothers and so my nan would come in and stay the night. But now that I am older I just stay there by myself and my mum comes in during the day.*  
(Pickle, 13)

In this quote, Pickle acknowledges how hospitalisation was a significant interruption to her mum and family life. She recalls the tension felt by her mum as she tried to balance being there for her, while juggling work and other family commitments. Pickle admitted this was more problematic when she was younger because she needed someone to stay with her while in hospital. As she grew older, it was less an issue, but it was clear Pickle understood the challenge this had been on her mum's time. Other participants shared similar stories about how family life was interrupted; often it was the mother's time that was interrupted.

*Yeah ...mum ...it's always been mum. If I am sick. I don't sleep... so mum doesn't sleep. If I am at home sick, she is too. (Tiale, 18)*

Tiale talked about how her mum unfailingly supported her during times of sickness. She would be up with her in the night and by her side when she was in hospital. She spoke of how her mum would rearrange work in order to be available at home if she was unwell or to take her to appointments. Tiale acknowledges that this equated to significant interruption to her mother's working life. Liz also talked about her mum and how much acute illness and hospitalisation had impacted on her ability to work.

*I think she had to quit maybe three or four jobs because I got really sick and, she had to take me to doctors' appointments, hospital visits and she just knew that's not going to work. Anytime she gets a new job, two weeks in, I'm back in hospital. (Liz, 21)*

The sense of guilt Liz felt about her mother was evident as she reflected on the time around diagnosis when she was younger and frequently sick. Many participants seemed to share feelings of guilt about the interruption that they or their bronchiectasis could sometimes cause. Pona, when asked what the worst thing about having bronchiectasis replied:

*Going to hospital. Like everyone has to wake up in the middle of the night just to take me to hospital. (Pona, 14)*

Pona relayed this story and was outwardly concerned about the disruption to her family members because they had to wake up in the night to take her to hospital. She felt guilty because her younger siblings had to go as well and saw this as a difficult intrusion on everyone in the family. Pona felt a sense of responsibility and almost embarrassment as if this was something she had control over. She could not see that her family would not likely have seen this interruption in the same way that she did.

Whether waking in the night for an acute admission, attending regular appointments or hospitalisations, the participants described how interruptions due to bronchiectasis were significant for the family.

*My mum would take me some days (\*for clinic) and then my sister would sometimes do it. ...sometimes when I was already in Starship staying in that was hard. There were daily trips to see me and bring me food and we live all the way in Manurewa. So that was like a daily thing... (Liz, 21)*

The distance the hospital or clinic was from home was significant, even for those families who lived in Auckland where they would often have to travel some distance to get to appointments. This was both a time stress and a financial stress. Liz and others talked about how the cost of petrol, paying for carparks and extra food while in hospital placed a great deal of financial pressure on their families. She looked back at these times and admitted the significance of the financial burden, both for their parents and other family members.

*So it's always, 'okay we've got to save this amount of money so we can go visit your sister' and there was I think I don't know but it was tough for them. So because mum had to stop working so then it was just dad and all of my siblings, that's when everyone was young so no one could really get a job, it was just one income. And then, the add on my medications and oh, it was, I think it was too much for them you know.*  
(Liz, 21)

Liz reflected and acknowledged that it must have been tough on her whole family when she was in hospital and financial resources were scarce. She talked about how her siblings missed out during times when money was tight, and the family had to ration funds in order to visit her in hospital. Liz spent a great deal of time reflecting on this during the interview indicating the significant guilt and personal worry she felt about it.

The participants in this study had strong connections to and valued their families. They were grateful for the support, love and presence of family in all aspects of their life but recognised the impact that bronchiectasis had on them in terms of maintaining normal life. Participants felt guilt and responsibility for the interruption that bronchiectasis sometimes caused their families,

### **Chapter summary. Life Interrupted**

In this chapter, four key thematic areas related to the concept of a Life Interrupted, have been highlighted. The young participants talked about their bronchiectasis and the effect it had on school, social interactions, sport and family. Within each of these sub themes, participants described how bronchiectasis temporarily interrupted events and activities, academic endeavours, relationships, social life and family. They talked about the interruptions as if they were short stoppages of activity for a time or short breaks in the continuity of day-to-day life. Despite these intermittent and

sometimes stressful interruptions, all the participants remained positive, optimistic and accepting of the way their life was. They made small adjustments, adapted and accommodated these interruptions, all the while aiming to maintain a '*pretty normal life*'.

## Chapter 7. Looking after Self

This chapter describes another aspect of the participants' *'pretty normal life'* with bronchiectasis. So far, the findings chapters have described how the participants experienced physical symptoms and significant interruptions to daily life. Looking after Self is the third major theme and illustrates how the young people were amidst a complex, transitional and evolving journey to developing self-care independence. Although learning to look after self is a common journey for a young person in general, the participants' journey was unique because it was taking place in the context of being a young person with bronchiectasis.

Three sub themes entitled: 'Keeping well', 'Keeping safe', and 'Learning to look after self' will show how participants were learning how to look after themselves. Keeping well describes how participants were learning to know and coming to believe in the various self-management tasks required to keep themselves from getting sick. Keeping safe describes how participants were learning how to protect themselves and learn about limitations in order to reduce the risk of getting sick. Making choices and taking control describes the participants' evolution towards independent decision making. The participants' journey of learning how to look after themselves was influenced by how they responded to and accepted these things as usual and typical for them. It was part of their experience of a *'pretty normal life'* with bronchiectasis.

### Keeping well

Like other chronic illnesses, bronchiectasis requires patients and their families to undertake specific health practices to control and reduce symptoms, decrease the frequency of infective exacerbations, minimise complications and improve quality of life. Successfully navigating, and learning how to manage, these health practices over time is an important part of the experience of living well with chronic illness. When children are young, it is usual for parents to assume much of the responsibility of managing these health care related tasks and children rely on their parents and caregivers. As they mature towards adulthood, they learn to take over the responsibility of managing their disease themselves. The data from this study would indicate that learning to look after self was related to the young person's evolving

knowledge about the how and why of self-care tasks, and, importantly, about their evolving belief in how these things contribute to keeping them well. This sub theme will look at three specific self-care activities that participants described as significant in their journey towards learning how to keep well: performing chest physiotherapy, eating well and taking medications.

**Chest physiotherapy.** People with bronchiectasis experience chronic cough and excess sputum production as part of the common symptoms of the disease and are, therefore, encouraged and taught to undertake activities that facilitate expectoration of sputum from the lungs. These activities fall under an umbrella term called ACTs<sup>9</sup> and the participants all referred to these activities as being part of their experience of living with bronchiectasis. They referred to ACTs in a variety of ways; some describing these as their ‘breathing’ or ‘Acapella’<sup>10</sup>, some talked about their ‘huffing’, but most referred to them in a general way as ‘physio’. ‘Physio’ seemed to be an ever-present part of the participants’ day-to-day experience of bronchiectasis. Some of the participants seemed to have integrated it into their daily life, whereas others struggled with the interruption it could cause. Regardless of how participants felt about physio it seemed to have a place in every participant’s story. Learning to know and coming to believe in physio was a dynamic and individual journey for each participant.

The first step in learning how physio contributed to keeping well involved learning to know the ‘*the right way*’. The ‘right way’, in this context, is related to learning the skill of doing and using the equipment, and was integral to the earliest memories of bronchiectasis. Participants talked about how they were taught to do their own physio, often initially in hospital. The participants did not mention parental involvement and perhaps this is because their memories of physiotherapy only reached as far back as the time when they themselves learned the ‘*right way*’. It is likely, however, that when participants were younger, parents would have been more involved in the doing. In the memories and stories provided by the participants,

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<sup>9</sup> Airway Clearance Techniques are physiotherapy treatments prescribed to facilitate expectoration of sputum from the lungs (Lee et al., 2015).

<sup>10</sup> Acapella is a handheld airway clearance device that has a valve that interrupts expiratory flow generating oscillating PEP (positive expiratory pressure) (Hristara-Papadopoulou, Tsanakis, Diomou, & Papadopoulou, 2008).

doing physio was something they did themselves and learned the 'right way' through the expectations and modelling of health professionals.

*And that time I had bronchoscopy, that when I found out, right? And they started... gave me the physio and stuff to do and help it... um the physio... Oh yeah the physios came around like three times a day to make sure I did my physio and I had to do it properly. (Pona, 14)*

Pona, who was 9 years old when she was diagnosed, illustrates in her quote how the task of physio was something *she* was taught to do and required to do 'the right way'. Other participants talked about how '*the physio (therapist) showed me to do it*' or '*she came in and showed me the equipment and how to set it up the right way*'. Participants talked about the skill of chest physio in relation to the equipment used. Each participant talked about the device, 'toys' or equipment they utilised to carry out their chest physio.

*I have this thing in my room I breathe out and put it in my mouth and you breathe in and out. And it clears the tubes in your lungs so that the air can come through. Yeah. (JohnBoy, 15)*

JohnBoy comfortably talked about his understanding of how to do physio the right way and clearly made the connection between the doing of physio and looking after his lungs. Other participants reported awareness of these long term benefits, as evidenced when they used expressions such as '*it helps me to breathe properly*', '*it's supposed to clear up the lungs*' or '*it gives me healthier lungs*'. All the study participants seemed comfortable articulating their understanding of the purpose of doing physiotherapy and reported knowing that it was beneficial to their lungs. For most participants this articulation of knowing how physiotherapy kept them well was because they had been told by health professionals and by parents.

*Oh I do heaps at the hospital but not really at home yeah. I only do it when I'm feeling sick like you blow into this thing to try and make it go into the middle 10 times and you huff and then cough and spit, stuff out. And you do like 6 cycles of it. I know from the physio, I should be doing it like once a day maybe, even when I'm not sick yeah. (Leigh, 15)*

Leigh speaks of how knowing what was expected and knowing the right way, did not always equate to doing. He was still developing his own knowledge about his illness and had not yet made the personal connection between doing physiotherapy

regularly and feeling good or having a reduction of symptoms. There was an obvious internal tension between knowing the right way (what he should do) and what he *did do* in day-to-day life. Leigh acknowledged that the physiotherapist was an important part of his learning what to do, as was the case for many participants. Interactions with the healthcare team, where expectations around frequency and technique were prescribed by doctors, physiotherapists and nurses and reinforced at every healthcare visit, helped support participants to learn about the skill and develop knowledge about why it was important for keeping them well. Participants came to know the '*right way of doing physio*' through reminders and being asked directly about their commitment/adherence to the plan. '*Have you been doing your physio?*' was a commonly heard question. Participants learned through these interactions that healthcare professionals (and particularly physiotherapists) placed value on ACTs and expected that participants would and should comply with the recommendations. Many participants had cheeky smiles as they talked about how *they knew* they were '*supposed to do it every day*' and how *they knew* the physiotherapist would hassle them for not doing it, but despite this knowledge admitted that it did not always happen as prescribed.

*Oh yeah, physio. According to am supposed to do it every day and 20 minutes of exercise a day but I don't really get there... I do it sometimes... When I am feeling sick then I might do it more.* (Kitten, 13)

Kitten demonstrates that knowing how to carry out a healthcare task does not always equate to it being done. This is true amongst all age groups but is most relevant for adolescent patients like Kitten. At 13, Kitten has not yet developed abstract thinking (i.e., she lives in the now) and her priorities are social, family and fun, not physiotherapy. For her, physiotherapy was something that needed to be done when she had symptoms and she had not yet reached the point of perceiving and internalising the necessity of the treatment at times when she was well. Other participants reported a similar connection between increased adherence with physio treatment at times of sickness or when symptoms were more apparent. For the participants that shared this notion, it was apparent that the connection between doing regular treatment and maintaining a level of wellness had not yet been made. They knew what to do because of what they had been told, but having this



knowledge did not equate to action. As participants matured, they started to internalise the knowledge they had been given by the health professionals about doing physiotherapy even when they were well; yet, still found it hard to prioritise.

*I do it once in a while like I did it two times last week because I was feeling quite stuffy in my throat but this week has been fine. I just feel like when I'm not so sick, like if I'm not drowsy and coughing then I'm fine but yeah, like to me I am okay, then when I start to cough then I say... oh I need to do my physio. But I know I need to do it every day even if I am not sick. (Rose, 15)*

Rose's understanding and belief in physio was connected to how it relieved and helped reduce symptoms when they worsened, and this is an important part of self-care. However, the tension that exists for Rose as she is still coming to believe in the need for physiotherapy as part of daily self-care is evident. Rose recognises and acknowledges she *should* do it daily, but still places most value on its effect on acute symptoms, rather than seeing its usefulness for keeping her well day-to-day. Other participants also struggled with prioritising daily physiotherapy and had not yet come to internally believe in its value; or at least believe in it enough to carry it out without being reminded.

*I am really bad at it. I never do it at all (laughing). Like I know I am supposed to do it and she [physiotherapist] always reminds me, and she's like 'you have to do your physio' and I say I know and she says no don't say that. You have to remember to do your physio. She is like ...she counts on me to do my physio. I'll do my bit and they'll do their bit to keep me in line, keep me healthy. (Tiale, 18)*

Tiale had a great deal of respect and fondness for her physiotherapist and expresses a sense of responsibility and guilt about not meeting expectations. Tiale had not yet come to believe in the benefits of treatment herself but was more concerned about letting people down than worried about how '*not doing physio*' would impact on her health. She knew what she had to do and how to do it but still relied on reminders and guidance from health professionals on how best to look after herself. Tiale also articulated knowing how physio would benefit her lungs and recognised that she had a role to play in self-management, but this knowledge did not yet provide enough incentive for her to prioritise it into daily life. Age was clearly not a deciding factor in Tiale's developing self-management skills because despite being

at an age where health professionals would expect greater autonomous self-management, her journey to self-care was still evolving.

For three of the younger participants (Messi, Pickle and Pona), learning to know and coming to believe in physiotherapy was still being strongly influenced by parental support and expectations. All these participants talked about how their parents encouraged them to do their physio daily, even when they sometimes did not feel like doing it. The parents were likely more aware of the long-term benefits and used this knowledge to help their young people adhere to treatment. Pona talked about how *'mum has been pushing me to do it regularly'* and others reported that parents would say things such as *'have you done your breathing?'* or *'let's do your physio now c'mon'*; admitting that these reminders were what helped them to adhere to doing these treatments.

*Like sometimes I need a reminder to do my breathing the night before I go to a friend's house... mum will say okay c'mon you have to do your breathing tonight because tomorrow you will be at your friend's house... (Messi, 13)*

Having parents that believed in the need for, and benefit of, physiotherapy influenced the participants' adherence. They did it because their parents expected it rather than fully understanding or believing how it helped to keep them well. This fits with the age and developmental stage of Messi, Pona and Pickle who at 13 and 14 years of age are still learning about how to look after themselves and keep themselves well through parental support and guidance.

In contrast, some of the older participants, for example Helena, Nezha and Liz had developed a greater appreciation for the long-term benefits and outcomes of regular physiotherapy and were therefore more motivated to do it.

*It does help. I know I need to do my physio, I'll feel my lungs around the bottom area, just feel really uncomfortable against my ribs. So like when I know that and it's like oh shit I need to do therapy, physio. (Nezha, 17)*

As they got older and matured, they gained an understanding of the role *they* themselves had to play in maintaining health and wellness. For some, this was gaining awareness of symptoms and learning about the best actions to self-manage these. Participants experienced coming to know how particular self-care tasks not

only made them feel better but lessened the time they would spend being sick. This was a process where they reflected on and learned to appreciate how, prior to the introduction of therapies or treatment, it may have taken longer to get better.

*Well I know when I'm sick and... obviously my chest gets worse ...I have my acapella and sinus rinse and all that and ways that I can clean my chest and get better. ...which is really helpful now. I used to be out for a week now I can be out for a day or two. (JohnBoy, 15)*

Experiencing positive results and learning how these tasks were beneficial for improving recovery and reducing sick time, resulted in greater adherence and a more positive attitude to self-treatment. For both Nezha and JohnBoy, these positive and mature thought patterns around self-management practices were possible because they had gained an understanding that physiotherapy would make them physically feel better and it minimised the interruption to their life and got them back into their normal activities. Reducing time away from school and peers, and limiting the time spent in hospital, was an important motivator and reinforced the value of doing physiotherapy.

Liz, Tiale and Helena also shared this understanding and experience of growing up and coming to know how over time physiotherapy improved their breathing and kept them well. They had a desire to go back in time and tell their younger self to get on with doing chest physio, not put it off and to 'just do it'. Liz (21) talked about how she wished she had understood sooner how important chest physio (and taking medications) was and that she could tell herself to 'accept it and make it part of your life'. Learning to know and coming to believe happened at different times for each participant and was not a linear process. There were times when even those who knew and believed struggled with the daily burden of treatment.

*I should be doing it every day but! It just gets, I just get really tired of it sometimes I'm like yes I'll do it and then sometimes I, I'm not bothered. But I should be bothered doing it and keeping motivated so I'll have like healthier lungs the next day. (Helena, 23)*

Helena uses the word 'should' to articulate her sense of obligation and responsibility about doing what is expected in terms of physiotherapy treatment. Helena's guilt in this quote is less about meeting the expectations of healthcare professionals and more about her own understanding of the benefit of

physiotherapy. She recognised that doing it regularly was helpful to her lungs and by not doing it she was only hurting herself. Despite this knowledge, the burden of daily physio was clearly felt, demonstrating that even when participants had come to believe in the benefits, prioritising daily treatments and self-care activities was hard to maintain all the time.

**Eating well.** One of the other ways that participants were learning about self-care was in relation to food and its role in keeping them well. When asked the question ‘how do you keep healthy and look after yourself?’ most participants responded with some combination of ‘exercise, getting rest, eating healthy food and drinking lots of water’. Most of the participants were strongly influenced by parents and family attitudes towards what was ‘good’ food, what was enough food and foods’ connection to togetherness. It seemed that the parent’s opinion about what constituted a healthy diet influenced the youngest to the oldest of the participants. Parents would encourage the eating of healthy food, either by providing healthy choices or by discouraging the participant from ‘*eating junk*’.

*Mum always makes us eat healthy food and makes sure we do not eat too much McDonalds.* (Peaches, 13)

Peaches reflects her mum’s values about healthy eating and how limiting McDonalds was part of that thinking. For Peaches, this was one way that mum helped keep her healthy, but it was not seen as something that she herself controlled or influenced. ‘*Mum makes us eat healthy*’ implies that, by herself, Peaches may have made a different choice.

The parents’ attitude towards food and the value they placed on eating well and eating food prepared at home was also an important influence over how the participants were learning about how to look after themselves. Strong examples came through when the participants talked about hospital experiences. Blud, who lived with a large extended family that always cooked and ate together, expressed his dislike for hospital food. He talked about how his family would visit him in hospital and bring him food from home, which they would eat together. Eating together provided Blud with relief from the boredom of hospital and kept him connected to normal life.

*Home-made food is best. It's the most healthy and good for you when you are sick. (Blud, 15)*

This was an important way in which Blud was learning about food where he had internalised his family values in relation to food and believed in the role it played in keeping him well. JohnBoy shared a similar story and reflected on times in hospital where family would '*come bring food and you know look out for me*'. For JohnBoy and Blud, food from home was a source of nourishment and represented connectedness and relationships with family. In this way, they were both learning about the role of family connection and food and how these were also part of learning to care for self.

Liz, who was older than JohnBoy and Blud, recalled a time when she was in hospital and her mother was insistent on bringing her in food every day. She recalled feeling guilty because she knew her family were tight on money and tight on time; yet her mother continued to insist on bringing her food.

*So I kind of knew they were going through money from you know just buying me food and stuff so every time they asked me for something I say, don't bring food I'll just eat the hospital food you know just to save but of course they end up bringing food. (Liz, 21)*

In this excerpt, Liz reveals how she believed that it was her family's (and particularly her mum's) distrust of the hospital food that resulted in extra costs for the family, due to travel to the hospital and the cost of extra food. When she was a teenager, she had not yet come to understand or believe in the importance or value her family placed on this gesture. At the time of the interview, and at an older age (21), Liz admits that she appreciated the sacrifices they had made, and recognised how important food was in keeping her healthy and well physically, and how important it was emotionally to have these connections with family while in hospital. Gaining this knowledge and belief in this important part of self-care was integral to her learning how to look after herself in the context of being a young person with bronchiectasis.

For some of the younger participants, hospital stays were associated with treats and junk food. Peaches (13) and Kahu (13) were sisters and separately recalled how family would bring them food.

*What wasn't good about hospital was having the food there because my aunty would always like bring something like Maccers or something like Subway or something like that ah for a treat for me... and she would like bring some chocolate. It was always good when she came. (Kahu, 13)*

Kahu had not yet come to believe in or make the connection between healthy eating and keeping well. Given her age, Kahu's attitude towards food is to be expected as she is looking for it to be pleasurable and fun. It seems that her joy comes from the treats and seeing and being with family members.

Other participants, for example Helena and Rose, had progressed from knowing because they had been told, to believing themselves, in the importance of 'looking after self by eating well'. They had internalised this knowledge and reflected on how for them it was important part of managing their health and wellness.

*It's important to me to eat and drink the right things. Your body needs the right nutrition to work. We are learning about this, about the nutritional side of food at school. So, very interested in that type of stuff yeah. (Rose, 16)*

For Rose, this process of coming to know occurred over time and was helped by her developmental maturity and her own experience of feeling better when she ate well. She was also influenced in this learning and coming to know by her parents' values and by what she had become interested in at school, including a more formal knowledge about food and its connection to health. Helena's coming to know and belief in the importance of putting the right things in your body was through experience and relationships.

*I'm avoiding like, energy drinks because it's bad for you. For people who have bronchiectasis. A lot of people that I know, like my cousin for example she used to drink like a lot of fizzy drinks, and I used to be like no here drink water instead. I'd rather water than fizzy because it's more healthier... Because when she was drinking a lot of that stuff she used to be really sick. (Helena, 23)*

Helena saw the importance of drinking water over sugary drinks and she adopted this approach to self-management based on her experience and what she had interpreted and learned from watching her cousin's experience.

For some of the participants, eating enough and keeping well by maintaining a healthy weight was a challenge. These participants talked about the need for

supplemental calories in the form of a high calorie drink such as Fortisip. The participants that required these supplemental drinks disliked them and it was challenging to see such drinks as ‘good for them’. Support and encouragement from parents were once again the primary way through which participants came to terms with and learned to accept this as a necessity for keeping well. Messi, in addition to the high calorie Fortisip, was also learning how to manage and maintain his health with the aid of extra calories.

*Yeah because my body loses energy a lot quicker so I have to make sure I put it back in through food. Yeah. Is that right (looks at mum)?... Well I understand I always have to eat a lot more. Sometimes when I am outside having fun doing lots of activity I always have to come in and have a snack. Yeah that's kind of annoying. Stuff like that. Yeah. I do understand why I have to do that but it can get a little annoying. (Messi, 13)*

Messi had come to know the reasons why he needed the extra food, although he still relied on his mum for reassurance that he had the knowledge correct. It was clear this requirement to have extra calories was a burden because it interrupted his normal activities.

**Taking medications.** Regular medications such as antihistamines, vitamins, steroid inhaler and saline nebulisers were described as part of the regular day-to-day life of the participants and were viewed as important for keeping well, staying safe and keeping out of hospital. In a similar way to chest physiotherapy, antibiotics were part of every participant's story, right from the beginning of diagnosis. Often early memories were associated with multiple courses of antibiotics.

*Just because I was constantly sick basically they gave me antibiotics and I'd be sick again in two weeks. I also had my sinus problems as well which needed a different medication. (Nezha, 17)*

For Nezha, believing in medication took a little while and was a process of trial and error. This is fitting with his developmental age and stage where often adolescents need to learn by doing or experiencing. For Nezha, the first step was getting his diagnosis and then finding the right combination of medications that worked best for him.

*The most important thing for me is diagnosing it because once you find out that you have it then you can sort it out easier... so if my sputum will be green basically and if it's green or really thick, um, I'm*

*sick or I could have an infection. So then I take it. It's a drug that basically kills the infection. (Nezha, 17)*

Nezha's positive experience with the medications helped him to know and come to believe in how medications helped him to stay or get well. This was a shared experience among the participants where antibiotics were viewed favourably and as the all-important cure for worsening cough. Participants would '*take the coughing pills*' or '*drink antibiotics*' or just '*take the medicines*' so that they would get better and '*not have to go to hospital*'. Worsening cough, chest pain and tiredness would signal the need to act fast to '*get on top*' of the cough. Most of the participants had faith in the medications and believed they were necessary to keep them well. It was not clear for every participant whether this was a process of learning through experience or if it was because they had been told these were necessary by health professionals and parents. Likely it was a combination of both.

### Keeping safe

The second sub theme looks at the specific protective behaviours that participants described as significant in their learning to look after themselves. Protecting self and understanding limitations highlights how parents and health professionals influenced the participant's progression to self-management. As with the previous sub theme of Keeping well, this was not a linear progression. Instead, participants oscillated between being directed by parents/health professionals and eventually finding the way to their own acceptance and understanding.

**Protecting self.** The most common way that participants learned about keeping safe and protecting themselves was through their parents, family members and health professionals. All the participants talked about the various ways that parents and family acted to monitor and keep them safe and described how family '*took care of them*'. This notion of being '*taking care of*' meant different things to different participants.

*Yeah, you know they always looks out for me. Make sure I do my physio take me meds you know. Yeah my sister and mum were always taking care of me and stuff. (Liz, 21)*

The way in which Liz's sister and mother '*looked after her*' could be simple things such as driving her to appointments or reminding her to take her medications.



They also undertook more time-consuming tasks such as staying with her in hospital or bringing her food and/or taking her out for leave from hospital. Leigh also talked about how his family took care of him and protected his health. He talked about how his mother made healthy food for him and took him to appointments, and how his family helped keep him healthy and strong through physical activity.

*Yeah, like we train together. My brothers and dad. And they help me keep motivated. The sport is good for that... for my lungs. (Leigh, 15)*

For Leigh, being active with his dad and brothers was an important way that he protected his physical health and emotional wellbeing. Being fit and active was an important part of who he was, and it made him happy to spend this time with his family doing what he loved.

For some of the participants, the primary way that parents and family members protected them was through encouraging and supporting them to reduce exposure to 'sicknesses'. Liz recalled warnings from her mum about places that were risky and how exposure to sick people was 'bad for her'. This was a common thread throughout the interviews. Participants gave examples of parents warning them; for example, about clinic because 'there's a lot of sick people' or hospital where they would say 'when people come and visit, they must put gowns on and masks'. Participants sensed that their parents feared them getting sick and this was a strong motivator for their warnings. The young people also learned about themselves and how exposure to people who were sick could impact on their own health.

*...I try to keep myself safe so that if people are sick and coughing everywhere, I just keep away from them really. Because, if they cough on me I'll be sick the next day, I know for sure. Which really sucks because, some people it takes them awhile but for me it's the next day. (Helena, 23)*

Helena's self-awareness and experience with exposure to sickness in the past strongly influenced her approach to protecting herself. She had learned over time that vigilance around protecting self from exposure was paramount. Helena's home environment made this self-protection challenging as there were eight people living in her home, three of which were children, including her own daughter.

*Yeah so I just stay in bed when I'm really sick and keep away from my daughter when she's not and when I'm sick I'm just like, you stay there and I'll stay here okay. I love you from afar! Yeah try not to get her*

*sick when I'm sick because then it just goes all around the house and back to me! (Helena, 23)*

Helena's personal journey and experience of living with bronchiectasis had, over time, taught her about how to look after herself. Knowledge about the impact that contracting a virus or 'a bug' would have on her bronchiectasis was the primary motivator for Helena. She viewed herself not only as more at risk but also held a strong belief that 'being sick' meant something different and more significant when you had bronchiectasis.

*It'll be okay for them but it will be 10 times worse for me because I have bronchiectasis and all of these symptoms will come out. (Helena, 23)*

Other participants echoed the sentiment that the experience of being sick as a person with bronchiectasis was different and much worse than those without bronchiectasis. Peaches talked about how friends at school would get coughs and colds and would still go to school and be okay. However, she saw her experience of being sick as being different and worse than peers and family members. '*When I get sick, I get really sick*' (Peaches). Kitten and Pickle shared this view and talked about how '*they had to be extra cautious*' and how getting sick, even a cold was '*different for them*'. Through a combination of parental influence and their own personal experience of living with bronchiectasis, participants learned to know and came to believe that reducing exposure to sick people and/or sickness was something they needed to actively do in order to protect and keep themselves safe.

One of the greatest challenges in this process of learning about how to keep themselves safe from sickness occurred when they had to explain it to peers.

*Yeah, so when people ask me, I try to explain it but they just don't get it. I usually start with my lungs sometimes gets clogged up from getting sick from bugs at school or my brother brings home their bugs from school and then they say 'what do you mean, is it like asthma?' (Pickle, 14)*

Pickle's story of trying to tell peers about her bronchiectasis and how they thought it was just like asthma is partially a reflection of the age and stage of her development. Using concrete explanations such as 'getting sick from bugs at school' was thought to be the best way to explain about how the risks were greater but most

peers did not understand and re-interpreted it as something they knew about—asthma.

As participants got older and matured their peers played a more positive role in supporting them to keep themselves safe and well. For Helena, friends played an important role both in supporting her to be safe and protect her physical health, and protect her emotional health:

*But my friends they come from church they come over sometimes and they're like what are you doing? And I'm like lying in bed. They're like no get up, get ready we're going. I'm like going where? Going for a walk or something, do something. Be motivated. I'm just like, okay! It's good to have friends that motivate you because you do need that.*  
(Helena, 23)

Helena valued how her friends encouraged her to get out, to move and be social and try live life in the most normal way possible. She recognised and talked about how easy it was to only focus on the physical side of bronchiectasis and how it was possible for this to get you down, particularly if you were not feeling great. She reflected, however, on how her friends could provide a distraction and motivation, and that by improving her mood she also felt better in herself.

Participants all talked about how various environmental factors, such as cold wet weather or a damp house, were potential threats and/or catalyst for 'getting sick'. Participants learned about the connection between being cold and wet and getting sick through parents and caregivers, warnings and words such as 'keep warm or you will get sick' or 'she always says to keep warm because the cold is bad for me'. Rose referred to how her parents had done several things at home to protect her, including the installation of heat pumps and an HRV (heat recovery ventilation) system which helped to keep the house warm and dry. She also talked about the ways in which she protected herself from environmental factors.

*In winter I wait for my friends sometimes just wait outside their classes and I'm like okay I need to go to J Block I can't sit outside in the cold for too long because I could develop a cold or something. So sometimes I do choose to sit in a warm area rather than a cold area because I don't want to get sick.* (Rose, 16)

Rose, in this excerpt, has to make a choice about how to keep herself protected and safe, and acknowledges her own understanding of the potential risk of

being cold. Either through her personal experience or through her parents telling her, she had learned and come to know that being or getting cold posed a risk for her. Other participants had their own way of averting this risk which ranged from staying home if it was too cold, wearing extra layers or, in the case of Liz, missing out on classes at university.

*Yeah but I notice especially in winter it's, really bad and when it's cold yeah. Cold and it probably affects uni as well. So, when it's uni and I have an early, early class I don't, I don't go. Because I just, I know it will be too cold and I just can't risk it yeah. (Liz, 21)*

Liz had learned through experience of living with her bronchiectasis over time that getting cold put her at risk for getting sick. She therefore acted in a way to avoid the situation where possible and had reached an age and stage where she made these decisions independently and appropriately self-managed her health.

**Understanding limitations.** Sometimes keeping safe meant understanding limitations, knowing what was okay to do and what might pose some risk of getting sick. The limitations or restrictions ranged in impact from something as simple as not being allowed to swim in the wintertime or avoiding walking too far on a rainy winter day to missing out on planned activities and/or not being allowed to go to school.

*I quite like surfing, horse-riding. But both have their disadvantages though because I am allergic to horses and I can't go surfing when it's cold cuz otherwise I will get sick... Swimming in winter. Can't do that or I will get sick. (Kitten, 13)*

Kitten accepted these limitations of not swimming or surfing in the winter because her mother had told her it was not good for her. However, this advice did not always make her happy; she would have preferred the fun of swimming and surfing. She was still learning to appreciate and internalise how these limitations would benefit her and keep her safe.

This growth of understanding around risks and benefits of keeping safe was not necessarily related to age and varied between participants, likely in relation to parental influence and their own experience. Sometimes, as in the example of Pickle below, participants were more receptive and likely to adhere to the restrictions or limitations when they equated the risk with potentially getting sick.

*Like the Christmas parade... I started getting a headache and was feeling tired just before my parent and brothers left so, I was like... I*

*probably shouldn't go. There would probably be lots of people there, car fumes etc so I decided not to go. (Pickle, 13)*

Pickle provides a good example of how she had weighed up the risks and benefits of attending the parade and independently made the decision to keep herself safe. Her own experience and knowledge about the warning signs of impending illness helped her to proactively self-manage.

Participants were also learning about self-managing in relation to limitations to school attendance. For some of the participants, this was still very much shared management between themselves and their parent.

*So, if I am just getting sick then I might still go to school but if I am really sick, mum usually says I should stay home. Sometimes after being sick in hospital I might I go to health school. Yeah, half day once a week. And that's good. (Messi, 13)*

Messi was still very reliant on his mum to instruct him about how to manage and look after himself, particularly in relation to school attendance. Limiting days and times at school was helpful on occasions when he was feeling tired; and he reluctantly agreed that this was of benefit. Kitten recalled a time when she also had to use 'hospital school' to help her manage and keep herself safe.

*Recently I got sick and can't really go back to school... So I really don't want to get sick because I have to have a surgery... because my port can't be used and its gonna take forever to get IVs in and stuff so I am trying not to get sick so that's why I am not going to normal high school... going to Northern Health School instead. (Kitten, 13)*

The restriction of not going to 'normal school' was significant for Kitten. However, as she weighed up the risks between going to normal school and getting sick versus going to NHS and staying well, the restriction was worth the benefits.

### **Making choices. Taking control**

The final sub theme reflects how the participants were at various levels of independence regarding self-managing their own healthcare decisions. This evolution towards autonomous self-management was aided by support from parents and through their letting go; through experimentation with shared decision making and through the transition to adult services.

**Parents letting go.** For a few of the younger participants the journey to independence and autonomous management of their bronchiectasis had just begun. This was evident during the interview process where some participants specifically requested their parents stay during the interviews to support them. The focus of the interviews was on the young people themselves; however, the presence of parents influenced the way in which the participants responded to some questions, where they would sometimes look for reassurance that the answers they had given were 'correct'. This was particularly pertinent when they were talking about something that happened when they were younger or a detail they could not quite recall in relation to the time of diagnosis.

*I remember being in hospital not really well... I can remember the recent times but not... I remember being in the room where you are first put before you get a room before admitted... I can remember that what is that called?... Triage yeah that's it... I remember that and that's it. I think I had a chest infection that was like ...out of hand, kinda left too late. Is that right? (Messi, 13)*

In this excerpt, from the beginning of Messi's interview, he is often questioning his answers and double checking with his mum. Checking occurred the most at the beginning of the interview but improved over the course of the interview. Although this indicated he was getting comfortable and developing confidence in his own ability to talk about his condition independently, he still relied on his mum to confirm some aspects of the experience of bronchiectasis (even though it was his own). Messi's mum interjected occasionally but mostly encouraged Messi to tell his own story. Through modelling this behaviour and allowing Messi to answer the question in his own way, his mum was encouraging his independence. Other mums also present during the interviews prompted and encouraged their child to provide answers to the interview questions. In these cases, it seemed that the parents themselves were still working through their own process of letting go and allowing their child more independence.

Most participants conducted the interviews on their own without parents present or else parents were present briefly at the time of introductions and then insisted the young person tell their own story without them being present to influence it. This encouragement through action and role-modelling was an

important way that parents were helping their young people develop autonomy. Liz, one of the older participants, reflected on how she felt that the presence of parents in the healthcare setting could sometimes be a negative thing and how she wished that she had had more opportunity to talk to the healthcare team on her own.

*I wish someone told me, or at least talked to like me. I feel, I don't feel comfortable talking about my condition when my mum's around. Like I know she's there, but I just find it weird yeah. I think it's you get more of an answer if it's just you and the kid yeah. Because then mum's not watching them give a good answer. (Liz, 21)*

Liz felt being able to talk without her mother's presence was an important part of growing up and learning about how to look after oneself. In the reflection above, she highlights how she could see that presence of a parent could influence the answers a young person might give. She also felt that having opportunities to experiment at being independent earlier would have been a good thing.

**Shared decision making.** Most participants relied on parental support to co-manage their illness and help them make decisions. Through experimenting and using their parents as a backstop, they were able to test out independent decision making. Tiale recalled a time after a prolonged stay in hospital where she was finally discharged home. She felt more than ready to be back at school full time but everyone around her (doctors, nurses, parents) were telling her she had to ease her way back. She was told she must adjust her school schedule so that she would not get too tired or sick again and she found herself having to negotiate a return to full time attendance.

*Yeah so after that... my mum made a deal with the principal and I could only come to school like half a day. So the first half of the day I'll just go get my thing (school work) and the second half I'll go home, do my exercises and just stay at home. So, I did that I think for like three or four weeks. Then I told my mum I wanted to have a full day at school. (Tiale, 18)*

Despite her desire to go back to full days at school at the onset of her discharge from hospital, Tiale still took advice from her mum and the healthcare team about planning and managing her health care. She showed signs of wanting to take more control by 'telling mum' what she wanted; but did not yet fully appreciate the best way to be safe and look after herself autonomously. She was still sharing the

decision making with her mum and healthcare team while practicing and testing out the skills of self-management. Leigh provided another good example of how he was being given opportunity to practice skills in self-management.

*My mum asks me if I want to... if I want to go into the hospital. Or if I want to try and manage it at home. And I always say manage it at home... so yeah like lots of physio, exercise, sleep and eating well... Yeah. Its better home... not missing out on anything at home or with friends yeah. (Leigh, 15)*

Leigh talked about how his mum would allow him to decide about managing his bronchiectasis at home for a maximum of two days. If within that time period he did not improve enough, Leigh agreed he would go to the hospital. Leigh's family were helping him to gain independence with decision making within a safe and supportive environment through enabling him to share in the decision making. He recognised in himself that if the time frame boundary did not exist that he would likely not make the decision to go to hospital on his own. He was still learning to know and coming to believe that sometimes going to hospital was a necessity.

Participants were also learning how to make decisions about healthcare by being empowered to share in treatment or management plan decisions.

*Recently with port<sup>11</sup> and stuff getting a new port put in. I do really want to have surgery done to fix it. Like I do make decisions about this. If it is serious like that. The surgeon is coming up next week and we will see him about surgery... I am glad I am getting another port put in because my veins do not work. (Kitten, 13)*

Kitten talked about how the healthcare team and her mum involved her in decision making around her new PORTacath. This was a big and important decision in Kitten's eyes and, therefore, made sense that she should have a say. She was able to see the benefits of the port, because she had previous experience and knew it was better and less difficult and painful than having multiple IV attempts. This was a good example of how Kitten felt included in the decision-making process around her healthcare despite not being legally old enough to make the decision on her own.

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<sup>11</sup> Port is short for PORTacath® which is an implanted device used to draw blood and give treatments, including intravenous fluids, drugs, or blood transfusions. The port is placed under the skin, usually in the chest.



She felt that she was the one making this decision and felt a sense of control over the plan.

**Transition.** For some of the participants, awareness of learning about how to make decisions independently and taking control occurred at the time of transition to adult services. This transition highlighted for Rose that she needed to step up and take more ownership of managing her bronchiectasis.

*It was definitely a lot different than what I was used to because normally it would be directed at my mum asking... has she been having chest infections for the last 6-8 months and she'd say no. Then in adults they'd be like... have you had chest infections for the last 6-8 months and I'm like... can't remember! But she (mum), she steps in sometimes! (Rose,16)*

Rose reflects in this quote how her experience in paediatrics was different to adult services. She noted the shift of attention from her parents to her and how, because of this, she did not always know the answers to questions posed about her own history. She had always previously relied on her mum. Rose acknowledged that she was amidst a changing time and needed to start developing her decision making and taking responsibility but was still co-managing with her mum and relied on her as a backstop.

*Oh, it made me feel I need to stop being so dependent on mum and being dependent on myself which is different because normally I'm like oh mum I can't remember what I'm allergic to can you tell me? (Rose, 16)*

Rose recognised a shift in the responsibility of looking after self. She acknowledged this shift as something that the move to adult services had forced her to start thinking about. Liz shared a similar story where she recognised that at the time of transfer to adults' services, the healthcare professionals were more interested in what she had to say than what her mum had to say.

*So like at the kids like when we go doctors it's usually our parents answering for us. At superclinic that's different and something to get used to. (Liz, 21)*

Helena also talked the difference between child and adult services and how much she valued the opportunity to be involved in decision making.

*For me it's good because I need to know like what's happening and what's going on with my lungs. Are they going great or are they getting worse? What can we do to fix that? Should I take more antibiotics or should I just, stay on the ones that I am on or should I be on a new medication? Which is good? (Helena, 23)*

Helena highlights how she has gained more control over her healthcare in the adult setting. She has a better understanding about the condition of her health and what the options are for helping her to live the best possible life with her bronchiectasis.

Developing confidence in making choices and taking control was part of the way in which participants moved towards self-care independence. The participants in this study were all at different stages of this learning progression. However, parents letting go, opportunities to share decision making and the transition to adult services all influenced the shift to autonomous self-management.

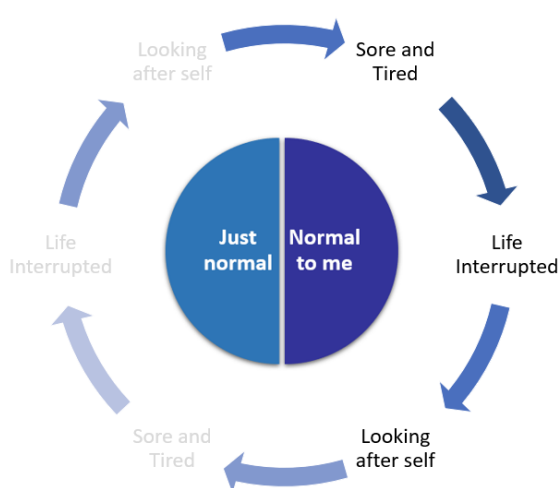
### **Chapter summary. Looking after self**

This chapter has addressed the participants' journey of learning to look after self. It involved learning what was expected in terms of self-managing their bronchiectasis and how they were coming to (or had come to) internally believe in and value these things. Initially, participants came to know what was expected and considered to be 'the right way' to look after self and do self-management tasks through understanding the expectations of parents and health professionals. Many participants relied on this knowledge but admitted that 'knowing' did not always equate to doing. Others who had progressed to their own understanding and belief in the benefits were able to more independently manage their self-care. These participants—through time, maturity and experience—had come to believe that these specific health practices were worthwhile and an important way to keep well. Participants were also learning to know and come to believe in how to keep themselves safe. Protecting self and understanding limitations was part of this journey where parents and health professionals influenced the participants' progression to self- management. The final sub theme emphasised the transition from dependence on parents making care decisions to autonomous self-management/care as an evolutionary development where participants moved from just doing what they were told to do, to sometimes challenging, to sharing decision

making and then eventually finding their way to becoming independent managers of their health.

## Chapter 8. Life with Bronchiectasis is ‘Pretty Normal’

In the preceding findings chapters, the participants’ rich descriptions of life with bronchiectasis have been illuminated. Through listening and interpreting the experiential data from the interviews, it became clear that participants used the words (or some version of the words) *‘pretty normal’*, as a way of describing an *‘almost’* normal life. The diagram below (Figure 4) visually illustrates this concept and depicts how participants held two views of their life. When participants were able to participate in desired activities, maintain relationships with friends, feel part of a community and describe future goals and aspirations they viewed life as *‘just normal’*. When this view of life was dominant, the three key thematic elements faded into the background. In the second view of life these thematic elements become more visible and the symptoms, self-care tasks and interruptions of bronchiectasis challenge participants’ ability to see themselves as *‘just normal’*. Instead they were compelled to modify and add a qualifying descriptor to normalcy. *‘Normal to me’* represents this modified view and symbolises how the young people accommodated, coped and accepted the challenges of living with bronchiectasis. Both views and three key themes *‘sore and tired’*, *‘life interrupted’* and *‘looking after self’* will now be considered as thematic elements in relation to the overall conceptual claim of the thesis, that life with bronchiectasis is *‘pretty normal’*.



**A Pretty Normal Life with Bronchiectasis**

**Figure 4. Concept drawing a ‘pretty normal life’ with bronchiectasis**

## Just normal

In the conceptual diagram, *'Just normal'* holds a position as one of the two central thematic elements. It represents one of the views of life held by the participants. Initially, when asked to talk about their day-to-day life, participants described themselves as the *'same as everyone else'* and *'just like everyone'*. They talked about their home life and the importance of family, they described their friendships and school, and the sports and other activities they liked to do. *'Being normal'* or *'normal life'* was highly important and characterised by the ability to maintain life patterns and activities that were deemed to be like, or typical of, their healthy peers. There were several things that indicated to them that they were 'normal', including: participating in desired activities, maintaining relationships with friends, belonging to a community and having future goals and aspirations.

Prior to the interviews, I anticipated that when asked to describe a typical day or talk about their daily life that some aspect of bronchiectasis would feature highly in these accounts; however, this was not always the case. Participants seemed to generally appreciate the opportunity to talk about their life. Some talked about troubles with friends, some talked about the challenges of transitioning from intermediate to high school, whereas others talked about issues happening within their family. The interview seemed to give them permission to talk about the good and the bad in life. For many of the participants these good and bad moments were not in relation to having bronchiectasis but were challenges commonly faced by young people. For some of the participants, having this time to talk about themselves appeared cathartic.

Early in the interviews, participants were asked to describe the things they most enjoyed doing. For most participants, joy came from being able to participate in activities such as sports, going to the beach, going to church, eating, going to the movies, using social media, watching Netflix™ and going to school. These activities were highlighted in several ways throughout the first three findings chapters but particularly in 'Life Interrupted' where the sub themes highlighted school, social interaction and sports as being very important. Attending school, for example, was described in a general way and participants emphasised the important role that school life had in their day-to-day life. Making social connections and doing well at

school relied on being present and not missing out; therefore, participants placed value on school attendance. Doing exams, taking part in school activities or even navigating the challenges of attending a new school, for example, were all deemed part of being a 'normal' young person.

Participants also talked a great deal about sports, including the sports they played, their position, whether they were proud of their accomplishments in the sport and what they loved most about playing. Most of the participants in this study were active and interested in sports and described themselves as very capable and, in some cases, more capable than friends. They talked about this with pride. They recognised and compared themselves to their peers and described situations where they not only kept up with, but surpassed their friends in terms of skill, speed and strength. One young male participant talked about how he was '*as good as any of his friends at rugby*' and that it was important to him that he was treated the same as everyone else. Participating in sports and feeling good about accomplishments in sports affirmed to the young participants that they were a young person no different from peers. In addition to helping them feel normal, these activities were important because they brought joy and opportunity to spend time with their friends.

*I like to play. Sports. Cuz I like to run with the ball yeah... I just play rugby for fun and to talk with my friends. (JohnBoy, 15)*

These connections to friends and the value that young people placed on these relationships was a strong thread present in all the interviews and was one of the important indicators to these participants that they were leading what they felt was a normal life. Participants spent time describing what they did with their friends and how much fun they had. Not surprisingly, peers shaped the day-to-day life of the young participants and had a significant role to play in how they normalised a life with bronchiectasis. Time spent together hanging out, playing sports or doing other activities enabled the participants to be, feel and see themselves the same as their peers.

*I feel like I am the same as everyone else. Just like everyone. Ah yeah, we talk, and we make people laugh. We hang out. We just do normal kid stuff. (JohnBoy, 15)*

Like most young people, friends were an integral and valued part of everyday life. Being with peers was about having fun and being a typical young person. It seemed that if they were able to blend in with peers and be the same as everyone else, everything was fine.

*It's just as long as I get along with my friends and we can like do the same kind of stuff. (Kitten, 13)*

These two quotes from JohnBoy and Kitten illustrate how peer relationships provided enjoyment and a sense of belonging. This belonging to a community or a group was another way that these young people could feel normal in their day-to-day life. Pony clubs, school, sports teams, youth groups and church were some of the key community groups young people referred to as significant. Having something in common and sharing the same values helped the young people to develop their identity and contributed to their well-being. A good example of this was Helena who talked about the work she did with the youth in church.

*I go to church. So, I help with the youth ministry, I've been doing it for 7 years... so connecting with ah new people, getting new people to connect with new people. Sharing their testimonies and stuff and hearing what they've done in life which is good. (Helena, 23)*

For Helena, church was a place where she could feel positive and where she felt that she was able to contribute something back to her community. She felt she belonged and fitted in to the group. This sense of belonging and having a purpose contributed to her definition of normal life.

Another important way that the participants maintained and upheld the notion of their life as normal and typical was through maintaining goals and aspirations. All the participants talked about their plans, including their hopes and dreams, such as attending university, getting a good job, 'becoming famous', having a house and a family of their own. Tiale talked about how she was happy in her life and how she looked forward to the future. She felt optimistic and believed that 'life started' once she had a job, house and a family of her own. For the participants in this study, future goal setting was an important indicator that they were living an ordinary life.

*I don't want to look back and think, I should have done that and not this and did that. Because I am doing my nursing at least I will have*

*done something with my life... Hopefully like, build a house (laughing) and like have my own cute little family, look after my mum and dad.*  
(Tiale, 18)

For Peaches, aged 13, future goals and aspirations were varied. Her thoughts about potential occupational choice were influenced by her own experiences and interactions. For example, she started telling me how she thought she might like to be a doctor as she felt she would like to *'help people'*; but then also talked about how her *'friend wanted to be a receptionist'* so maybe she would do that. She was also open to *'becoming a netball star'*. Through this examination of future jobs, Peaches displayed how she was exploring and working out whom she was going to be. This identity exploration fits with what one would expect from most young people at Peaches' age and stage. Ensuring that hopes and goals were not interrupted by bronchiectasis helped support the pursuit and maintenance of what was deemed by the participants as a normal or ordinary life.

### Normal to me

*Normal to me* is the second central thematic element in the conceptual framework. It represents a modified view of life where the participants acknowledged how the presence of bronchiectasis influenced, challenged and reshaped their notion of themselves as being *'just normal'*. *'Normal to me'* were the words used by participants that addressed and acknowledged how they knew that their life was not always the same as their healthy peers. Each of the key themes described in chapters five, six and seven circles around the participants *Pretty Normal Life* and contributes to how they learned to accommodate the various aspects of bronchiectasis into a new modified view of life. This view of life as normal to me developed as participants went through a process of integrating and sometimes minimising the influence of symptoms, interruptions and the self-management responsibilities associated with having bronchiectasis.

Symptoms are normal to me. In chapter five, participants described their symptoms within the theme *'Sore and Tired'*. They articulated how cough, soreness and fatigue occurred as part of their normal experience and how certain symptoms indicated that they were getting sick. Participants related to their symptoms in different ways, but all had developed their own individual subjective definition of



what normal was and what ‘doing well’ looked like for them. *‘Coughing in the morning’*, for example, was described by Blud as normal for him; whereas others, such as Leigh, described how coughing was only present when he was sick. Soreness and fatigue were also experienced in different ways by different participants. Helena, for example, who had more severe disease, experienced these symptoms as part of her daily life; whereas for others, those symptoms were only associated with getting or being sick. Participants were on their own personal journey with bronchiectasis and were all learning how to monitor and interpret what these symptoms meant to them, while at the same time trying to live as normal life as possible.

The presence or absence of symptoms helped participants judge the severity and/or current status of their illness. Rose (16) illustrated this point when she talked about how she had *‘only had two to four chest infections in the last year’*. She clarified this further when she added in the statement: *‘That’s really good for me’* (Rose, 16). The idea of two to four chest infections per year would not necessarily be considered normal or typical for most young people; however, Rose was judging this by a different scale—a scale that fitted with her view of normal as a young person with bronchiectasis. Others talked about their bronchiectasis in this way and referred to times in the past when their bronchiectasis was more problematic, when they were younger or when they were sicker. They talked about how they were *‘better now’* and *‘it’s not so bad now, not like when I was in primary school’*. Their measure of how good or bad life was, was influenced by how severe their symptoms were and was an individual subjective experience.

*I haven’t been to the hospital like, like this whole year except for um my ear appointment yeah. I haven’t been to the hospital. I haven’t been sick that much actually. So that’s good.* (Peaches, 14)

Peaches’ twin sister Kahu, who also had bronchiectasis, reflected on how, when they were younger, they spent more time in and out of hospital or at the doctors. Peaches compared her life and experience of bronchiectasis to Kahu, who in her mind had had a much tougher time.

*I wasn’t that bad when I was younger though. She got the worst part of things. She was the smallest baby. I came out really big and she came out small, like very small, and she was very skinny.... And she had a hard run, like upbringing like she was like mostly affected by*

*the bronchiectasis, I think. But I wasn't really that bad and she was the worst one. (Peaches, 14)*

Peaches considered her own health and experience of bronchiectasis to not be as bad as that of her sister, and although she articulated how it had impacted and interrupted her life, she still felt better off, because she had been the bigger and healthier of the two. It was clear in the interview that she felt guilty and felt that her life had been easier. She deemed her life as more typical to healthy peers and Kahu's life as more challenged by bronchiectasis. However, Kahu also minimised the impact of bronchiectasis and did not seem at all occupied with thoughts about how the symptoms of bronchiectasis had impacted on her daily life, unless she was sick. When she was sick, she acknowledged that tiredness would affect her ability to play sport, but she saw this as a temporary setback and was in no way overwhelmed or bothered by it. She did not view her life as significantly different or worse than her sister. This shows how Peaches' experience of a 'pretty normal life' with bronchiectasis was shaped quite differently than her sister. This experience of only noticing symptoms when she was sick was usual to her.

Interruptions are normal to me. Life Interrupted is the second circling theme in the conceptual diagram and was described in detail in chapter six. Bronchiectasis interrupted family life, social life, sports and school. In order to accommodate these interruptions, participants described the things they did to minimise the impact and subsequently reshape their view of life. This required them to re-define normal to fit their own individual circumstances.

*I don't even know it's there, it's just normal for me. I just um do what normal people do. (Blud, 15)*

Blud, initially describes his bronchiectasis as '*just there*' and not something he ever notices as standing out or overly significant. However, when he elaborates further it is clear that his perception of what '*normal people do*' is a more medicalised version of life to that of a healthy young person.

*It just feels normal. I see all different doctors. They ask heaps of questions. So how was school? How are your lungs going? And I was like you're the doctor you're supposed to be telling me how my lungs. (Blud, 15)*

What Blud describes above (going to doctors, not having normal lungs) is far from the usual experience of other young people; however, for him, this is normal. It could also be seen that Blud is denying his illness or denying the seriousness of it, particularly when he puts the assessment of how he is feeling (*how are your lungs going?*) back on to the doctor. Although more than denying any problems with his lungs, it seems likely that he has integrated and adapted to the bronchiectasis and, therefore, reassigned a new definition of normal that works best for him.

Kitten, provides another example of a participant who had included what might be deemed as 'not typical or usual' activities of a 13 year old into her description of a normal day. As she describes getting up and getting ready for school, she casually mentions how she accommodates PEP as part of her daily routine. This account which can be found on page 89 implies, on first impression, that Kitten was somewhat disconnected from (and could not see) the interruption that her bronchiectasis caused. In her own way, she had integrated the abnormal activity related to bronchiectasis into her daily routine and, in doing so, minimised the impact. Minimising the impact of bronchiectasis was a common thread amongst the participant accounts and, like Kitten, participants downplayed the significance and impact of bronchiectasis in different ways. Some did this by using abstract terms to describe their bronchiectasis, such as '*my breathing problem*' or '*my lung problem*'. It seemed that they disconnected themselves from the seriousness of their bronchiectasis by using these terms to describe it. Kahu (13) described her bronchiectasis in this way and articulated how '*this really bad cough I get sometimes*' meant doctors' appointments, breathing exercises, and check-ups. Kahu reluctantly admitted that it sometimes interrupted her sporting activities and school but denied the significance of this and made out as if this was not a big deal.

*Yeah so my netball game, I was sick and um had a sore throat and fever sort of. But we were playing team 1 and we could of won, but my team went down. Because I was like the main player that plays defence and yeah I played but yeah was sick sort of. I don't really know sometimes... most of the time I'm alright. It's fine. (Kahu, 13)*

In this quote, Kahu acknowledges, in her own way, that her bronchiectasis impacted on the game; but still showed reluctance to admit to the degree of influence and/or how much it bothered her. For Kahu, it seemed important to

portray the image that her bronchiectasis was '*no big deal*' and that most of the time she could minimise the interruption. This was her way of rethinking and redefining the interruption as normal for her.

Thinking this way about bronchiectasis, denying the impact, appeared to be much easier to do when feeling well. When symptoms arose or when interruptions became more disruptive to daily life it was harder to ignore. Participants used variations on the expressions '*only when I get a cough*' or '*unless I get sick*'. These examples demonstrate how the participants saw themselves as normal except for when they were physically reminded about their bronchiectasis. When coughs and colds influenced their normal performance or interrupted some aspect of their life, they were forced to acknowledge that they were not the same as everyone else. However, they worked hard to reduce and minimise these differences.

Another good example of how they worked to minimise the impact of bronchiectasis was illustrated in their descriptions of whom they chose to tell about it and under what circumstances.

*Ah like I don't really talk about it with my friends. But some of my friends already know. Like friends I grew up with yeah. And, some, some people know that I have a condition, like a lung condition but they, that's all they know yeah. I just keep it that way. (Leigh 15)*

It was important for Leigh to be treated the same as his peers because if he was able to do stuff like his peers it was easier to minimise the impact of his illness. For Leigh, this meant not calling attention to himself by telling people about his bronchiectasis. He did not want his friends to perceive him as different and admitted thinking that if friends knew, they would '*go easy on him*'. Other participants used this approach to minimise their disease and strived to keep their illness in the background of their life. Behaving and acting like everyone else, blending in and not revealing bronchiectasis, was deemed a good way to keep up this image of living an almost normal life. Messi talked about how he '*enjoyed running and cross country and doing events with his friends*' and how he really '*didn't like*' how his bronchiectasis affected his ability to do these things. He was obviously frustrated by how his bronchiectasis impacted on his life (and his sports with friends in particular) but tried hard to portray an image that made light of the impact.

*I just don't bother telling people because I try not to let it stop me from doing stuff but sometimes it just does but I am not really sure I just haven't really told people. It's just not important. (Messi 13)*

For Messi, not telling peers about it, or only telling certain people, was a useful way of minimising its influence. However, even when he described how he tried to do this, it was apparent that his bronchiectasis was not always easy to ignore.

Helena, Pickle and Tiale took a different approach and saw how it was helpful to have friends that understood and knew about their bronchiectasis. Friends helped them to feel okay about their illness and the things they had to do as part of it.

*For me it's just normal but I guess for my friends it's probably not normal. It's cool when you have friends that like don't mind you telling stories about gruesome stuff and like blood tests and stuff like that. It's good having friends that don't mind that. Which I do have. (Kitten, 13)*

Kitten acknowledged that she had a different take on what normal was. compared to her friends, but if her friends understood and accepted the abnormal parts of her illness then the impact of bronchiectasis was minimised. Friends provided support and understanding, and helped participants be and feel normal even in the context of having bronchiectasis. Tiale talked about how peers grounded her, made her feel better and reminded her about being and doing 'normal things'. Tiale gave the example of how friends helped distract her during a time when she was sick in hospital. She talked about how good it was to have her friends come and chat about 'the gossip at school' and how this made her feel 'part of the normal flow' of peer group activity.

**Managing self is normal to me.** Accommodating and integrating, self-management activities such as physiotherapy and taking medications, attending appointments and monitoring the intermittent flares of symptoms were part of the day-to-day life experience of the participants as described in chapter seven 'Learning to look after self'. As participants learned to cope and incorporate these things into their life, they developed a new distinct view and meaning of normal that was unique to their individual experience.

*It's a bother but you like, get used to it. (Pona, 14)*

Pona talked about how physiotherapy was an interruption, but she had resigned herself and adapted to it. She, like other participants, recognised, acknowledged and learned to appreciate these as temporary interruptions that they had to '*get on with*' in order to live their pretty normal life. Variations to routine (and by default adjustments to the view of normal life) occurred all the time. This could be related to a change in medication or a change in condition that warranted changes to therapy. Liz recalled when she was first introduced to PEP for her chest physiotherapy and how it took a little while to get used to doing it and to establish it as part of her new normal.

*It was different because I had to do the chest exercises at home. I think I used the little PEP thing. Yeah I think it was just getting into the habit of it... (Liz, 21)*

Establishing a habit and incorporating this 'out of the ordinary thing' into daily life was a way in which participants redefined their notion of normal life. Most participants did not love doing their chest physiotherapy and most complained it was a '*nuisance*' or '*a pain*' or it '*takes up time*'; but most all admitted that it was something they got used to.

*I just sit there with it in my mouth while I'm playing a [video] game whatever. I got used to it, it took a while to get used to. You know wearing this weird plastic thing in your mouth. Sounding like a Darth Vader that's being drowned. I don't mind it. (Nezha, 17)*

Nezah, while using humour about doing his physiotherapy, provides a good example of how participants adapted life to accommodate their illness. Completing his physiotherapy while playing a video game showed how he had adapted his preferred activity to fit in with self-management of his bronchiectasis.

Participants also described how they were learning to keep well and recognise worsening symptoms in order to self- determine when and if hospitalisation was necessary. Participants saw hospitalisation as part of the '*pretty normal*' experience of living with bronchiectasis and, therefore, defined how well or not they were doing based on how many hospital visits they had had.

*Back then I was away quite a lot because I was always sick but I am lot better now. Last year I was only off school (I think) I was only in hospital 3 times. (Kitten, 13)*

The idea that *any* hospital visits are okay, or a regular occurrence, presents a slightly different version of typical life for a young person. Kitten spoke with pride when she talked about how she had '*not been sick much*'; and even though she had been in hospital three times, she had her own version of normal which was different from healthy peers. She had adjusted and incorporated her bronchiectasis into her own new version of normal.

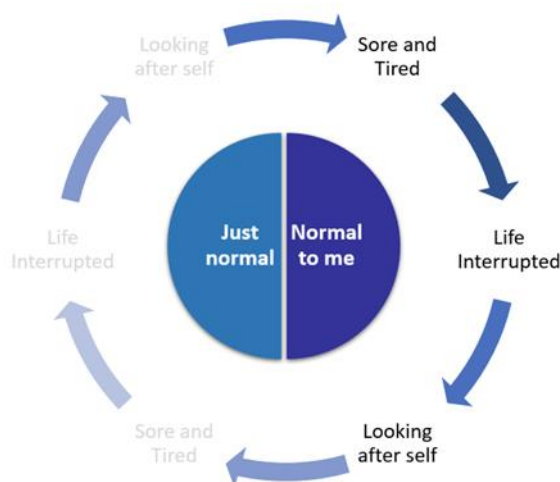
For Leigh, learning to manage his bronchiectasis at home was an important way that he was developing independence and learning to look after himself. It also demonstrated his strategy for integrating it into day-to-day life.

*It's really good now. I haven't been in for a while. I've been sick but we've managed it at home... It's better at home. I don't mind not going to school but, yeah just here with my family and with everyone. Feels kind of normal.* (Leigh, 15)

For Leigh, there was a need to portray that he had things under control and that his bronchiectasis was less of a problem than it had been in the past. Being sick at home (even if it meant missing school) was far better than being in hospital because it enabled Leigh to integrate his illness into the context of his life. This was his version of a '*pretty normal life*' with bronchiectasis.

## Conclusion. Pretty normal

This research study posed the question, how do young people with bronchiectasis describe their day-to-day life experience? The overarching answer to that question provides the basis for the conceptual claim derived from the data analysis, that life with bronchiectasis is '*pretty normal*'. The concept of a '*pretty normal life*' is composed of two different views of life that are represented by the semi-circles in Figure 5 below.



**A Pretty Normal Life with Bronchiectasis**

**Figure 5. A pretty normal life with bronchiectasis**

These two views, '*just normal*' and '*normal to me*' exist at different times for the participants depending on the visibility of the three key thematic elements '*sore and tired*', '*life interrupted*' and '*looking after self*'. These elements are ever present and encircle the participants' view of life.

This findings chapter has highlighted how life with bronchiectasis is a dynamic experience which can be understood as a constant attempt by the participants to live a typical young person's life. Day-to-day life for the young participants was sometimes described and perceived as '*just normal*'. This perception was supported and reaffirmed with the presence of important indicators that told them they were like their peers or the same as other young people their age. These important indicators included participating in desired activities, maintaining relationships with friends, belonging to a community, and having future goals and aspirations. At times, the symptoms, interruptions and self-management tasks of bronchiectasis made this view of themselves challenging to maintain. When these challenges arose, the first step was adjusting life in order to integrate and accommodate the differences. Balancing a life that was sometimes described as *Just Normal* and sometimes as *Normal to Me* meant that participants developed their own unique definition of a *Pretty Normal life* with bronchiectasis.



## Chapter 9. Discussion

### Introduction

Growing up with a chronic illness, like bronchiectasis, poses a unique challenge to young people. While balancing the physical, social and psychological changes associated with adolescent development, they must simultaneously balance the ongoing demands of illness management (Sawyer & Aroni, 2005; Yeo & Sawyer, 2005). Despite this challenge, young people with chronic illness continue to be underrepresented in health research (Grady et al., 2014). This research aimed to illuminate and gain deeper understanding about the day-to-day life experience of a group of 15 young people with bronchiectasis. The four previous chapters presented the analysis of data. This chapter will conclude the thesis and provide an interpretation and discussion about the findings in relation to the research question about how young people with bronchiectasis experience day-to-day life. Practice implications and recommendations for future research are presented. The final section of the chapter will close with a reflection on limitations of the study and direction for future research.

### Summary of findings

In this ID study, 15 young people with bronchiectasis were interviewed. The intention of the research was to bridge the knowledge gap, so health professionals could better understand the significance of bronchiectasis for the young person, come to know what is most important to them and then act and plan care to improve wellbeing and health outcomes. The original aim of this study was to answer the question: “How do young people with bronchiectasis describe their day-to-day life experience?”

Participants provided detailed and rich descriptions about being a young person with bronchiectasis. The interviews enabled participants to talk about the things they most enjoyed doing and the people they most enjoyed being with. It gave opportunity to talk about the typical ups and downs of transitioning through adolescence, as well as the challenges and hurdles of living with chronic illness as a young person.

Overall, the young people from this study described their day to day life as ‘*pretty normal*’. This expression, used by participants, was interpreted and came to

represent an overarching conceptual description made up of two co-existing views of normal life. *'Just normal'* and *'Normal to me'* represented how the young people simultaneously balanced the normative development of adolescence while learning to accommodate and adapt to the challenge of life with bronchiectasis. *'Just normal'* was the most favoured view of life and represented how young people desired to be typical and like other young people their age. They utilised and described several strategies and indicators that illustrated how they saw themselves as *'just normal'*. In this view of life, bronchiectasis was in the background and participants strived to minimise its effects and keep it out of sight. However, this was not always easy. Eventually participants revealed a second view of life in which their ability to keep bronchiectasis in the background proved to be more difficult. In this second view, *'normal to me'*, participants acknowledged the challenges of accommodating, coping and integrating bronchiectasis.

Three key elements influenced and encircled these two views of a *pretty normal* life. These elements entitled, Sick and Tired; Life Interrupted and Looking after Self, revealed more about how young people experienced and were challenged by bronchiectasis in day to day life. Sick and Tired described how and when the participants experienced the symptoms of bronchiectasis as well as the impact these had on physical and psychosocial aspects of life. Life Interrupted described how participants experienced interruptions and disruptions to their school, social, sporting and family life but learned how to accommodate and integrate these into a new version of normal. Finally, Looking after Self, described the participants' journey towards independent self-management of their condition. In the following section, the findings from this study are interpreted in relation to what is congruent with the current literature and what new insights were revealed

### **Bronchiectasis is not the focus of day to day life (*'just normal'*)**

The participants were determined to portray life as being the same as their peers and like every other young person their age. They did not want to be defined by their bronchiectasis and viewed their life as *'just normal'*. In this view of life, bronchiectasis was not the focus; instead, what was more important, was *'fitting in'* and being like their peers. These findings align with a growing body of research that acknowledges that young people with chronic illness see themselves first and

foremost as typical young people striving for a normal teenage life (Ferguson & Walker, 2014; Higham et al., 2013; Horky et al., 2017). Participants used several strategies to achieve what they perceived to be normality, and this was an individual and personal perception. For some, it was participating in shared interests and activities with peers; for example, sports, camp, general socialising and attending church groups that gave them a sense of normality. Other participants used social comparison to enhance their own view of life normal. They did this by comparing themselves to healthy peers and describing how capable or *more* capable they were at things such as sports. Other studies have found this to be a common strategy used by young people, both those with chronic illness (Morse, Wilson, & Penrod, 2000) and without, as a normal part of adolescent development (Ragelienė, 2016). It is usual and expected that during adolescence young people will self-compare with peers as they try to figure out who they are and with whom they fit (N. Hill, Bromell, Tyson, & Flint, 2007). It is a normal part of growing up. Participants wanted to talk about this experience, their friendships, school achievements, family and their goals and aspirations for the future. When participants presented this view of their life, it was clear that they were journeying through adolescence in much the same way as their healthy peers. They had little interest in revealing their bronchiectasis and did not see it as central to their identity or to their day to day life. This fits with studies of young people with cystic fibrosis which similarly found that young people did not view themselves as sick or handicapped but, in fact, viewed their life as ordinary, despite the expectations of those around them that their disease would be more central to their self-image (Admi, 1996; Horky et al., 2017). One of the possible explanations given for this was related to the lifelong nature of cystic fibrosis and the suggestion that because participants had grown up knowing no other life, it was, therefore, viewed as ordinary. In the current study, the same explanation could be relevant because most of the young people had never known a life without bronchiectasis. It is likely they saw it as a natural part of their life and had grown accustomed to the ebbs and flows in its visibility. This was not necessarily because they had normalised or denied it, but because at that moment bronchiectasis was simply not visible in their view of themselves and their life. It was only when they experienced symptoms, interruptions and self-management responsibilities that they

acknowledged the disease's presence. Such findings are comparable to how Morse et al. (2000) described children with disabilities and their families as inhabiting two distinct and unique 'worlds' that they could move back and forth between. The young people in this study had access to both the 'everyday-as-normal' world and the 'disabled- as-normal world' and moved between these depending on how visible bronchiectasis was at the time. Their ability to navigate these two separate views of life supported both their normative adolescent identity development (i.e., their ability to feel '*just normal*'), as well as their capacity to integrate and normalise life in the context of having bronchiectasis.

### **Normalisation. Normal to me, symptoms and interruptions**

Despite the participants initial assertion that their life was '*just normal*', participants reluctantly, but eventually, admitted a second view of life in which symptoms, self-management responsibilities and the interruptions of bronchiectasis imposed a modification to this view. Each participant, in their own way, used normalisation to reconcile this new view of life and employed strategies that enabled them to integrate it. Normalisation is a cognitive and behavioural process where an individual uses coping strategies and techniques to minimise the impact of illness, accepts there is a deviation from health and strives to live as usual despite the limitations (Deatrick, Knafl, & Murphy-Moore, 1999; Knafl & Deatrick, 1986; Morse et al., 2000). The participants in this study utilised both behavioural and cognitive tactics to normalise life with bronchiectasis but the tactics used were unique to the person.

The physical symptoms of cough, soreness and tiredness were one aspect of bronchiectasis that sometimes made it difficult to feel like a typical young person. Most participants described how they did not even think about bronchiectasis unless they experienced symptoms. Over the course of the interviews, it became clear that although coughing was normalised by some participants, the majority agreed that when symptoms increased it was harder to feel normal and this changed their view, forcing them to accommodate bronchiectasis into their life. These findings, in keeping with previous research, highlight how young people learn to normalise symptoms as a common coping strategy in chronic illness (Admi & Shaham, 2007; Badlan, 2006; Bailey et al., 2018; Kirk & Hinton, 2019; Matthie, Hamilton, Wells, & Jenerette, 2016). The current study differs somewhat from these other studies in

that it acknowledges an individualism to the normalisation process. The participants in this study all developed their own individual subjective definition of what 'normal' was and what 'doing well' looked like for them and, therefore, normalised symptoms in different ways. For example, *Coughing in the morning*, was described by Blud as normal for him; whereas others, such as Leigh, described how coughing was only present when he was sick. The symptoms of soreness and fatigue were also experienced in different ways by different participants. Helena, for example, who had more severe disease, experienced these symptoms as part of her daily life; whereas for others, those symptoms were only associated with getting or being sick. Participants were on their own personal journey of normalisation of bronchiectasis symptoms, learning how to integrate them while trying to live as normal life as possible. *'I feel like I am the same as everyone else. Just like everyone'* (JohnBoy, 15).

The desire for normalcy is important to anyone with chronic illness but particularly so for young people who are amidst a period in life where the influence of peers and the social pressures related to this developmental stage strongly influence the young person's desire to maintain a typical life. The data from this study support the notion that being with friends, going to school and being able to participate in sports was an important way that the young people minimised the social impact of bronchiectasis and contributed to their ability to cope and feel less overwhelmed by their illness. Participants often used words like *'it's no big deal'* or *'you get used to it'* which signified how they downplayed the impact of bronchiectasis. Knafl and Deatrack (1986) described this as a cognitive strategy that minimises the struggles and adjustment that having a chronic illness requires, by viewing it as inconsequential within their life. The young people in this study used normalisation as a strategy to accept the reality of living with bronchiectasis while not allowing it to dominate their life.

Interestingly, the desire for normalcy was common across all the participant ages and there was no evidence in the interview data that indicated a period of rebellion or desire to assert normality by deliberate non-adherence to treatment. Previous studies have indicated that young people in early adolescence do not always show this determination for normality and that by middle adolescence the desire for normality becomes more evident and, thus, sometimes leads to rejection of

treatment plans (Taylor, Gibson, & Franck, 2008). In addition, Protudjer, Kozyrskyj, Becker, and Marchessault (2009) found that this strong desire to be like peers has potential to negatively influence disease management and impact on adherence. However, this was not the case in the current study. Instead, results indicated that participants used normalisation strategies from early adolescence through to early adulthood; and rather than consciously rejecting prescribed treatment as way of reaching desired normalcy, they adapted and modified it in order to fit with their day to day life.

Normalisation is often written about in relation to families, and in particular parents and caregivers and how they adapt behaviours to create normal family life within the context of having a child with a chronic condition or severe physical disability (Emiliani, Bertocchi, Potì, & Palareti, 2011; Gantt, 2002; Knafl, Darney, Gallo, & Angst, 2010; Morse et al., 2000; Rehm & Bradley, 2005). These papers acknowledge how parents play an integral role in teaching their children how to cope, adapt and learn to normalise their condition. The results of this study concur with this notion and the participants described the active role that parents played in supporting them to fit self-management practices into daily routine and learn to look after themselves. By creating routines surrounding bronchiectasis in family life, participants came to know and understand these as part of daily life and, therefore, they became normal.

The interruptions of bronchiectasis challenged normalcy. This was especially relevant in relation to school absenteeism. When participants missed school because of symptoms, clinic appointments or hospitalisation, it interfered with their view of normal life. Missing school resulted in negative feelings, social challenges with peers and negatively impacted on educational goals. These findings are well supported by other papers that have found a close connection between missing school and decreased quality of life, negative social well-being including difficulties with fitting in and poorer academic achievement (Santos et al., 2016; Shaw & McCabe, 2008; Taras & Potts-Datema, 2005). Being able to attend, to do well and to achieve what they wanted to in school helped participants to feel normal. Participants described how parents, teachers and friends helped them to catch up, involved them in regular class education while in hospital and thus helped them to cope with the interruptions to

school. The use of support from family and friends has previously been highlighted as an important strategy that helps young people balance the challenges associated with school/education and living with chronic illness (Atkin & Ahmad, 2001; Ferguson & Walker, 2014; Secor-Turner et al., 2011).

One of the other key strategies highlighted and used by the participants to combat the negative effects of missing school was attendance at NHS. Several young people described the positive impact this school had on their ability to keep up and maintain a sense of normality in their life during times when they were not able to attend their regular school. The NHS in New Zealand is a Ministry of Education funded programme, established in 2000, that supports students who have high health needs and are unable to attend their regular school. There are a variety of options for how this support is provided such as in hospital teacher support, visiting the student at home or students can attend a community support centre (Education Review Office, 2019). The participants had accessed these options at different times and for different reasons; for example, some talked about having the teachers visit while they were in hospital whereas other described how they had utilised the service when they were in recovery from an exacerbation and needed to ease back into regular school hours. They clearly articulated how much value they placed on the service and appreciated the ability to select the option that best suited their circumstances at a given time. Although the desire to return to normal school was ever present, the NHS helped make the transition back to regular school easier. There was little, if any, evidence in the literature, or description of an equivalent school, that supported young people with chronic illness in this way. One system described from the United States, called Homebound Instruction, assists in the transition of children and young people with chronic illnesses from hospital to school but a number of issues were highlighted that pose significant barriers to this system's effectiveness and it was vastly different system to what operates in New Zealand (Macciomei & Ruben, 1989; Shaw & McCabe, 2008). Although there was no evidence in the New Zealand literature that evaluated the NHS programme and/or outlined how it developed, this study provided strong evidence that it was well appreciated and needed by the young people who use it.

The notion of ‘fitting in’—being normal—and the adaptive process of normalisation while living with chronic illness is particularly salient for young people because of the influence of peers, the social pressures related to this developmental stage and the young person’s desire to maintain a typical life. This study adds detailed descriptions of this experience from the perspective of young people with bronchiectasis.

### **A life interrupted**

Participants described four key areas of life that were frequently interrupted by having bronchiectasis: school, social interactions, sport and family. The previous section discussed how participants coped with some of these interruptions by using the process of normalisation. Participants also emphasised how interruptions to school and family life resulted in both feelings of guilt and frustration.

Many described how missing school was the most stressful thing about having bronchiectasis. Lengthy and multiple appointments, as well as hospitalisations for either acute exacerbations or chest ‘tune ups’<sup>12</sup>, were the most commonly cited reasons for school absence. The previous section highlighted how interruptions to school challenged the participants’ view of normal life. Missing school was described as socially disruptive and having a negative impact on academic goals and achievements. These findings fit with previous studies that have found the same (Geist, Grdisa, & Otley, 2003; Kaffenberger, 2006; Shaw & McCabe, 2008; Sturge, Garralda, Boissin, Doré, & Woo, 1997). In the current study, it was clear that disruptions to school, especially absences, became increasingly significant as participants progressed through higher school years. Participants described the increased pressure and stress associated with the academic expectations in secondary school. Although the participants in this study did not talk about choosing to miss appointments because of school, previous studies have found this to be the case with more missed appointments occurring in older adolescents and young adults (Chariatte, Michaud, Berchtold, Akre, & Suris, 2007; Neal et al., 2001). The participants who were of school age expressed frustration over missing events that occurred at school but there was no evidence they missed appointments because of

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<sup>12</sup> ‘Tune up’ is a colloquialism for the regular and intermittent use of antibiotic therapy (typically intravenous ) in stable patients (Maguire, 2012).



school commitments. Other studies have found that 'interference with school' was the most common reason for missing appointments among adolescents (Chariatte et al., 2007; Irwin, Millstein, & Ellen, 1993; Skaret, Raadal, Kvale, & Berg, 2000). The differences in the current study might relate to the fact that most participants were of an age where parental influence on attendance at clinic was strong and many participants were not old enough to choose the event over the appointment. The key message from the findings of this study is that young people do not want to miss school; they are a reminder about being responsive and considerate of the needs of adolescent patients.

The findings describe the impact and interruption that bronchiectasis has on the young person and family and, in addition, suggests that young people are concerned about this impact. Participants expressed concern and a sense of responsibility about the interruptions to family life as well as guilt over the financial and employment disruptions their bronchiectasis caused for family members. Although the literature is filled with articles that describe the various ways that chronic illness impacts on young people and their families (Flynn, Kliems, Saoji, Svenson, & Cox, 2018; Golics, Basra, Finlay, & Salek, 2013; Sawyer et al., 2007; Shardonofsky, 2019; Yeo & Sawyer, 2005), there is a paucity of studies that address young people's own feelings of concern over the interruption their illness causes their families. Cappelli et al's (1989) study of young people with cystic fibrosis and type 1 diabetes reported concern and guilt from the young participants about how much their parents had to sacrifice. In the adult literature, a review by Demain et al. (2015) reported how patients felt guilt in relation to the physical workload and the financial costs of treatment experienced by their families. But this has not appeared as a strong finding in studies of young people with chronic disease. In this study it was initially believed there would be a cultural influence, given the importance placed on family and family relationships, within both Māori and Pacific cultures. After reviewing the data and in consultation with cultural advisors, there did not appear to be obvious ethnic differences between the participant reports. New Zealand European, Pacific and Māori young people all expressed similar concerns about how their disease impacted on family life.

The findings from this study indicate that young people experienced interruptions in their day-to-day life due to bronchiectasis and that these interruptions were often related to health system-imposed obligations. These findings expand our understanding about some of the challenges of living with bronchiectasis and highlight young people's notion of self-perceived burden on their families.

### Symptoms. Sore and tired

"Symptoms become known, only by the report of the people experiencing them" (Armstrong, 2003, p. 601). Although this study never intended to focus on the symptoms of bronchiectasis, when asked to talk about their day-to-day life, participants disclosed a great deal about symptoms. The results pointed to significant variability in the physical symptom patterns as well as in the emotional impact among the participants. The results further indicated a potential prodrome to an exacerbation of bronchiectasis and that participants had a strong ability to perceive symptoms. Although it may not be surprising that tiredness may be expected when feeling unwell, the prominence of this as one of the most significant symptoms, the degree of fatigue and its universality was surprising.

**Individual symptom patterns.** The findings demonstrated that young people experienced their own unique and individual pattern of symptoms leading up to and during an exacerbation. Participants described and clearly articulated understanding between typical day to day symptom variation (*'normal sick'*) and symptoms that indicated they were *'getting sick'*. Getting sick was a description used by participants and interpreted as referring to a pulmonary exacerbation of bronchiectasis. Participants reported a variety of symptoms or symptom changes that indicated to them that they were getting sick. Increase in coughing, coughing up sputum, changes to the colour of sputum, along with sore heads, throats and chests were identified as symptoms that preceded an acute exacerbation. The variation in symptom pattern has been demonstrated in adult studies of bronchiectasis but, as of yet, not described in children and/or adolescents (Dudgeon et al., 2018; Wei-jie et al., 2019).

The study's findings also found that in addition to having good symptom perception, the participants experienced an awareness of an illness prodrome prior to the onset of exacerbation of bronchiectasis. Fatigue was one of the first warning

signs. Participants described how tiredness and lack of energy preceded 'getting sick' and acted as a red flag to both participants and their parents. Many described how they noticed this symptom on their own, whereas others required some support from parents to help them recognise this as an early warning symptom. Prodromal symptoms are defined as subtle symptoms that present before the onset of an illness, and are often ignored (Seemungal et al., 2000). A study in cystic fibrosis patients found increase in cough and fatigue symptoms occurred two weeks prior to a exacerbation in a group of adult patients (Sarfaraz, Sund, & Jarad, 2010) and past studies have noted prodromal symptoms in patients with asthma (Beer, Laver, Karpuch, Chabut, & Aladjem, 1987; Edmondstone, 2000; Newton et al., 2013). To date, no studies in which patient awareness of prodromal symptoms that precede exacerbation of bronchiectasis have been found.

As well as describing variation in symptom pattern, participants also demonstrated good awareness to perceive and interpret symptoms. This is considered in the literature to be an important first step towards self-management (Babler & Strickland, 2015; Karlsson, Arman, & Wikblad, 2008; Schofield & Horobin, 2014) and a positive influence on adherence to therapy (Schofield & Horobin, 2014). The ability to perceive symptoms also decreases the risk of delays in treatment (Mammen et al., 2017). Although there are no studies among young people with bronchiectasis, studies in children and adolescents with asthma have linked an inability to accurately perceive symptoms with greater functional impairment and asthma related morbidity, a greater risk for hospitalisation, more emergency department visits and more missed days at school (Baker et al., 2000; Banzett, Dempsey, O'Donnell, & Wamboldt, 2000; Mammen et al., 2017; McQuaid et al., 2007; Hyekyun Rhee, Belyea, & Halterman, 2011). Given the relationship between repeated infections and worsening bronchiectasis, it is a positive sign that participants in this study had good symptom perception.

Symptoms presented challenges physically and emotionally for the participants. Participants experienced limitations in their activities, due to the physical constraints and/or symptoms of their illness. Descriptions of frustration over not being able to participate in activities, such as cross-country or camp, and the strategies employed such as squeezing in chest physiotherapy and rest to proactively

manage symptoms were some of the ways participants described minimising impact. Having activities limited or being prevented from taking part in activities due to physical symptoms has been found to put younger people at greater risk for mental health issues (Adams, Chien, & Wisk, 2019), as well as having the potential to impact on educational achievements, increase social stigma and diminish well-being (Lambert & Keogh, 2015; Wisk & Weitzman, 2017a, 2017b).

Of all the symptoms described by the participants, cough and sputum production held the most potential for social embarrassment and induced feelings of inadequacy. Several examples of this were given, such as not being able to complete a game or event (JohnBoy) or feeling concerned about coughing in front of friends at school for fear of social repercussion (Liz). Suppression of cough was, therefore, utilised as a mechanism for protecting against the social embarrassment participants felt about coughing up phlegm. Along with feeling embarrassed about cough and phlegm, it also induced feeling of personal disgust and discomfort. These symptoms invoked negative feelings towards bronchiectasis and are in line with other studies that have reported social embarrassment and concealment over cough in adults with bronchiectasis (Dudgeon et al., 2018; McCullough et al., 2015; Wei-jie et al., 2019), primary ciliary dyskinesia (Schofield & Horobin, 2014; Whalley & McManus, 2006) and cystic fibrosis (Jamieson et al., 2014). This is the first study, however, to report these findings in young people with bronchiectasis.

**Sore and tired.** In addition to describing cough and sputum, participants emphasised two additional symptoms. Several referred to chest pain, specifically noting location and sensation during an exacerbation, and every participant described fatigue as a common experience of bronchiectasis. These findings are not well described in the literature or recognised as common in the clinical setting and offer new insight into the symptom experience of young people with bronchiectasis.

Chest pain was described by several participants and they used a variety of words including *'fullness'*, *'tightness'* and most commonly the word *'sore'*. For the participants that experienced this symptom, the intensity of the pain was significant and most often related to a chest infection/exacerbation. Some of the participants associated the location of pain with the location of their bronchiectasis. Chest pain is minimally described in the adult literature on bronchiectasis (Dudgeon et al., 2018;

King et al., 2012); however, interestingly, chest pain did not meet the threshold of the Delphi process to be considered one of the key symptoms described in the consensus definition of exacerbation in bronchiectasis (A. T. Hill et al., 2017). King et al.'s (2012) study analysed chest pain and found that non-pleuritic chest pain occurred commonly and was predominantly associated with an exacerbation. However, there were no clear features that differentiated those who had pain and those who did not. In another study, conducted by the same researchers, they were able to show association between a similar type chest pain and left lower lobe collapse with pain resolving once the collapse resolved (King, 2009a). The novel findings from this study describe chest pain as a relatively common symptom among young people with bronchiectasis during an exacerbation.

Every participant in this study talked about tiredness. They described it as 'low energy', 'feeling weak' and as an 'all over body tiredness'. They recognised and acknowledged how the tiredness they felt with bronchiectasis was different from everyday tiredness and how their peer group experienced tiredness. There was also a link between worsening disease and an increase in tiredness. For these reasons, I interpreted these descriptions of tiredness as fatigue. The word fatigue comes from the Latin word *fatigare* which means 'tire out' (Stevenson, 2010). This makes the differentiation between just plain old tired and fatigue challenging. In health and illness, fatigue is often defined as an overall feeling of extreme tiredness or lack of energy from mental or physical exertion or illness (Marino, 2019). Fatigue is recognised as a common symptom in a variety of chronic illness in children and young people (Crichton, Knight, Oakley, Babl, & Anderson, 2015; Nap-van der Vlist et al., 2019), as a symptom that impacts on QoL (Eddy & Cruz, 2007) and has been shown to be an important and debilitating symptom of bronchiectasis in adult patients (Hester et al., 2012; King et al., 2006).

The participants in this study described tiredness as a prodromal symptom prior to exacerbation and a key symptom during an acute illness. Along with being highly prevalent, lack of energy and fatigue impacted on physical, cognitive and psychosocial functioning. The findings of this study complement previous research addressing fatigue in other chronic conditions in young people, such as cancer, where it is described as having an impact on routines such as school and making interactions

with friends and family much harder (Corey, Haase, Azzouz, & O' Monahan, 2008); and congenital cardiac disease where the symptoms of breathlessness, fatigue, dizziness and chest pain are described as frustrating and encumbering (Cornett & Simms, 2013). Additionally, fatigue has been reported in patients with cystic fibrosis in a study by Goss, Edwards, Ramsey, Aitken and Patrick (2009) where participants reported the most common symptoms as cough, fatigue, chest congestion, difficulty breathing/shortness of breath and wheeze. Despite the frequency with which participants mentioned fatigue (second most mentioned symptom behind cough) very little attention or emphasis was placed on this symptom in the discussion or in the analysis of the symptom tool developed (Goss, Edwards, Ramsey, Aitken, & Patrick, 2009).

Interestingly, in patient information and websites that describe the symptoms of bronchiectasis, chest pain (and less commonly fatigue) is found. For example kids health (<https://www.kidshealth.org.nz/bronchiectasis>), the bronchiectasis toolbox (<https://bronchiectasis.com.au/>), the bronchiectasis foundation (<https://www.bronchiectasisfoundation.org.nz/>), Health Navigator New Zealand (<https://www.healthnavigator.org.nz/>) and bpac (bpac <sup>nz</sup>, 2012). Yet clinicians, including myself and the clinical supervisor for this project, rarely ask about these symptoms in practice; nor do these symptoms appear in the Thoracic Society of Australia and New Zealand guidelines for chronic suppurative lung disease and bronchiectasis in children and adults (Chang et al., 2010). The findings from this study regarding fatigue and chest pain have not previously been reported in the literature in children and young people and provide new insight into the patients' experience of symptoms in bronchiectasis.

## Transition to self-management

*Self-management is the individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic illness. (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178)*

The findings described how young people were on their own individual journey towards self-care independence and were learning to look after themselves as a young person with bronchiectasis. Despite the challenges associated with

transitioning to self-management, while going through normal adolescence, young people with bronchiectasis show resiliency as well as the capability to adapt and integrate bronchiectasis self-management into their *pretty normal* life. Two key overarching findings that relate to self-management transition will be discussed in the following section.

First, the findings of this study indicate that young people, across a variety of ages, demonstrate self-management capability. All the participants described in various ways how they monitored and were aware of their symptoms and understood the need for and necessity of treatments such as taking antibiotics or doing chest physiotherapy. These findings fit with the work of Richard and Shea (2011) who reviewed the literature on self-care and self-management concepts. They described how self-management includes both self-monitoring and symptom management and, importantly, the management of functional, emotional and psychosocial consequences of having a chronic health condition (Richard & Shea, 2011). The majority also had knowledge about their illness and recognised changes and when to seek help. They described the various strategies they used to keep themselves safe from infections such as avoiding cold, and/or other people who were sick. Knowledge about their bronchiectasis, as well as knowledge about risks and symptoms, translated to positive action in relation to self-management. These findings fit with and expand on what is known about the facilitators to self-management in adolescence and suggest that young people have this capability across a range of ages not only in later adolescence (Lindsay, Kingsnorth, & Hamdani, 2011). It may be relevant that most of the participants in this study had been diagnosed at a young age and, therefore, had more experience with self-management of bronchiectasis over time. As Sawyer (2005) eloquently pointed out “young people do not magically develop the capacity for self-management on their 18<sup>th</sup> or 21<sup>st</sup> birthday” (Rutishauser, Sawyer, & Bowes, 1998, p. 406). This study supports the notion that young people variably develop self-management skills and knowledge over time but that they can, and do, show self-management capability.

Second, the transition to self-management is an individual journey supported by parental involvement and willingness to share management. In this study, although participants did self-monitor and manage symptoms, they were still reliant

on family members for support in doing so. The literature highlights how having supportive parents, strong family relationships and high levels of family functioning encourage young people to engage in self-management (Modi et al., 2012). One of the common barriers to self-management transition discussed in the literature concerns parents relinquishing control. In this study, participants were of different ages and stages of transitioning to self-management and thus parents were also at different stages of relinquishing control. This was evident with the younger participants who looked to their parents for support with answering questions during the interviews and by the progression among older participants who were starting to share decision making about their bronchiectasis management. Furthermore, there was minimal evidence of conflict surrounding the relationship between parents and young people and the transition to self-management. Some participants recalled how parents would remind them about their physiotherapy or remind them about having supplements, but this appeared to be only mildly irritating and did not result in rebellion or have a detrimental effect as reported in other studies (Babler & Strickland, 2015; Dashiff, Vance, Abdullatif, & Wallander, 2009). Similar to other studies in self-management, the findings of the current study did not find any common personal characteristics that either hindered or supported this transition among participants; instead, it was good balance of individual actions and parental support and encouragement that contributed to self-management development (Karlsson et al., 2008; Young, Rew, & Monge, 2019).

### **Resilience and a pretty normal life**

The final important finding from this study is that young people with bronchiectasis show resiliency in their descriptions of day-to-day life with bronchiectasis. In many ways, this notion of resiliency has been illustrated in all the previous sections of the current chapter, as well as across all key themes and elements. Resilience is the ability, regardless of age, to have adaptive responses to adversity such as in chronic illness, and the situations known to be generators of stress associated with the condition (Cal, Sá, Glustak, & Santiago, 2015). The findings illustrate that young people with bronchiectasis demonstrated key features of resilience described in the literature including positive coping, self-esteem and positive future expectations



(Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013; Compas et al., 2012; Ferguson & Walker, 2014; Jaser & White, 2011).

In the beginning of this chapter, normalisation was described as a key coping strategy used by the study participants and revealed how young people, despite the interruption and frustrations of symptoms and self-management tasks, learned to integrate and adapt. At the same time, they endeavoured to live as normal a life as possible. Ferguson and Walker (2014) described how resilience for young people with chronic illness is about effectively negotiating adolescence while showing a willingness and capability to strive for a 'normal' life despite the unpredictability of their situations. The findings from this study clearly fit with this description and, additionally, highlight how they were developing other coping strategies such as primary and secondary control coping (Lennon, Psihogios, Murray, Holbein, & Holmbeck, 2016).

Primary coping was demonstrated in several examples where participants problem solved and attempted to change the source of stress such as doing physiotherapy before school or before attending a sleepover so as not to feel abnormal because of coughing. This was also seen in the participants' emotional reaction to bronchiectasis. Participants felt frustrated and annoyed at times by the interruptions but did not feel these problems were insurmountable; for example, *'it's no big deal'*, *'it's a pain but you get used to it'*. Participants also continually reminded me about all the things they loved to do and did well, displaying good self-esteem and hope for the future as outlined in the findings chapter a pretty normal life.

The influence, importance and support of peers, was another strong finding in this thesis. Friendships and social supports have been found to positively influence young people's ability to self-manage healthcare tasks and the findings of this study expand and further our knowledge (Helgeson, Lopez, & Kamarck, 2009; La Greca, 1990).

### Implications and recommendations for practice

This is the first study in New Zealand that asked young people with bronchiectasis to describe their day-to-day experiences and it provides opportunity for clinical reflection. This study has shown that young people do not always view bronchiectasis as the most important thing in their world. It is important that healthcare

professionals working with these young people are aware of their wider concerns and interests beyond the diagnosis and treatment of bronchiectasis. In order to engage successfully with young people, interventions should focus on healthcare challenges alongside individual and social needs (Cartwright et al., 2015; Secor-Turner et al., 2011).

Young people as consumers of healthcare have specific needs and requirements. The findings from this study have highlighted how several of the interruptions to day-to-day life were a result of healthcare-imposed obligations such as attending clinic appointments or prolonged hospitalisations. The reality for young people with a chronic illness, like bronchiectasis, is if they require assessment and/or intervention, they are obliged to attend appointments away from school and during school hours. The findings from this study reveal this is a significant source of frustration and disruption to the lives of young people. Consideration should be given to how healthcare services are delivered and how well they meet the needs of young people and their families. The World Health Organization's (1999) five criteria (accessibility, acceptability, appropriateness, effectiveness, and equity) for assessing the adequacy and quality of health services for adolescents could provide a useful starting framework or platform for evaluation of current and future services.

Participants described unique and individual experiences and have highlighted the very personal nature of the condition. This reminds healthcare professionals of the need to be mindful of these differences and act and plan care collaboratively with the young person and their family. There is not a one size fits all approach. This is of particular importance in the face of supporting the development of self-management skills prior to transitioning to adult services. Communicating with and uncovering the needs of each young person provides a challenge for health professionals often due to workload, time restraints and funding limitations. However, early planning and a transition process that occurs over time in collaboration with the young person and their family, means a successful and individualised transition process should be possible (Dickinson & Blamires, 2013).

The findings have shown that self-monitoring of symptoms is subjective and individualised in bronchiectasis. Given that preventing and treating pulmonary exacerbations promptly are a key goal of bronchiectasis management, the findings

that participants identified prodromal symptoms provide opportunity for greater appreciation of the varied and personal symptom experience of people with bronchiectasis. Asking about and assessing these symptoms will give greater understanding of the disease. Early identification of these symptoms has the potential to improve outcomes if management plans included when to start escalating treatment and reducing delays in seeking medical intervention to prevent an exacerbation.

This study provides insights into the capability of young people to self-manage and has important implications for practice. Assessment of self-management skills of young people with bronchiectasis is crucial for supporting the successful transition to adult care and adulthood (Lindsay et al., 2011). In addition, these findings have highlighted the role of parents in the transition toward shared management. A young person's confidence to manage their condition is increased by parental support (Lindsay et al., 2011) but there is a fine balance that must be achieved between "supporting parental involvement while promoting the engagement of young people with self-management" (Sawyer & Aroni, 2005, p. 406). Health professionals have a critical role to play in supporting parents and young people to learn how to share and develop the young person's skills in care management. Strategies such as education with families about how and when to commence this shift of responsibility as well as advocating shared decision-making as soon as developmentally appropriate, appear to be well supported by the young people in this study.

### **Recommendations for further research**

This qualitative study has provided some insight into the day-to-day life of young people with bronchiectasis; however, further research is needed to increase knowledge and expand understanding of some of the findings from this study. Such research could include:

- 1) Research to assesses and describe the features of both fatigue and chest pain in young people with bronchiectasis.
- 2) A comparative study to compare the experience of fatigue in young people with cystic fibrosis and bronchiectasis.

- 3) Investigation of the process of how and what attributes in young people and their family's ability to take ownership and fully transition to self-management.
- 4) Examination of the experience of parents of young people with bronchiectasis in New Zealand.
- 5) Examination of instituting management plans when prodromal symptoms occur to see if this improves outcomes such as reducing exacerbations, school absenteeism and even hospitalisations.

Whatever form or direction future research projects take it is imperative that not only the young person's voices is heard but that the research contributes to addressing systemic change in order to realise equitable health outcomes, particularly for Maori and Pacific young people.

### Limitations of this research

**Generalisability:** This study provides insights into the experience of 15 young people with bronchiectasis in New Zealand. The findings are specific to their experience and, therefore, cannot be generalised to other young people with bronchiectasis.

However, it is possible there are some commonalities and shared experiences among other young people with bronchiectasis, especially given the commonalities of experiences within this study population.

**New Zealand born sample:** One of the limitations of this study is related to the sample, including only participants who were New Zealand born and educated. Young people born in the Pacific might have shown greater cultural difference in their experiences of bronchiectasis. Despite this limitation, the sampling technique in this study was effective and purposive, and the sample represented good variation in age, gender, geographical distribution and ethnicity; overall, meaning the population of young people with bronchiectasis in New Zealand was well represented.

**Long term disease:** Most participants had been living with bronchiectasis since childhood. Potentially the experience may have been different for young people newly diagnosed or who had acquired the condition in late childhood.

**Health stability at time of interview.** At the time of the interviews, all the participants (except for one) were well. They were not experiencing an exacerbation

of their bronchiectasis and were overall stable which could have influenced the participants' responses in the interviews. If the same interviews were done during a period of instability or following a recently experienced exacerbation, their experiences and perceptions may have been different.

**Parental presence at interview:** Most of the interviews took place with the young person on their own with no parents or caregivers present. This ensured that the participant was uninfluenced by parental expectations or interference during the interview and the data collected were the participants experiences, uncorrupted by parents' perceptions. In addition, it gave opportunity for me to be sure that the young people were participating in the study because they wanted to, not because their parents wanted them to. In three cases, parents were present during the interviews. I recognise this was a limitation as the opinions of the young person may have been different if they had been alone. In addition, there were times when parents attempted to shape the interview by reminding the young person to talk about something that was important to *them*. I am mindful that this may have not been what was important to the young person but at times this was helpful as it elicited more detail from the young person. One participant, Richie, was severely developmental delayed; therefore, his parents had to support and encourage him to answer the questions. This impacted negatively on the quality of the data from this interview where most was gathered came from the parents rather than the young person.

Finally, it is important to acknowledge that data collection, interpretation and analysis will have been influenced by my position as an expert clinician, novice researcher and by my ethnicity. Having worked for so many years as a nurse specialist interviewing and assessing young people as part of clinical practice, I assumed that skills would be transferable. This belief that these were transferrable skills clouded and inhibited the gathering of data in the first few interviews I conducted. Following the first two interviews, I sought help from my supervisor. I arranged a meeting time where we sat and looked at the interview transcriptions. My supervisor pointed out that I had moved too quickly to asking about bronchiectasis and that it would have been better to begin with more general questions and encouragement of the participant to talk about what they wanted to.

She reminded me to think back to my research question. I could see once this was pointed out to me that I was indeed 'leading the witness' (Hutchinson & Wilson, 1994). Through discussions with my supervisor and detailed journal writing, I acknowledged and reflected critically on how past interview experience as a nurse was sometimes helpful but also a hindrance in the data collection phase (Hunt, 2009). I utilised Sally Thorne's (2016) chapter on '*Entering the field*' as the framework for reflexive practice which allowed me to see where I could change and develop as a researcher. With each interview, I improved and developed my skills in the iterative process of ID; but, it should be acknowledged that a more experienced researcher may have gathered deeper understanding from the data, producing different findings and knowledge about the young people's experience of day to day life bronchiectasis.

Finally, it should also be acknowledged that my ethnicity as a NZ European researcher may have limited or hindered the young participants comfort with openly revealing cultural needs and/or differences during data collection. It is possible that utilising different researchers or research assistants from varied ethnic backgrounds, (matching to those of the participants) would have revealed more and/or different data surrounding the influence of ethnicity and culture on day to day life with bronchiectasis.

## Conclusion

This research has shown how young people with bronchiectasis experience day-to-day life as *pretty normal* and reveals how they balanced the normative developmental tasks of adolescence while adapting and coping with the demands of bronchiectasis through using behavioural and cognitive strategies of normalisation. They achieved a pretty normal life by having two separate views; one in which they were normal and living the same life as their peers, '*just normal*', and a second view, '*normal to me*', which required them to cope with the interruptions of bronchiectasis and was influenced and impacted by symptoms, interruptions and self-management responsibilities. These findings regarding normalisation in chronic illness are not new but do offer expanded understanding on the experience as relates to young people in New Zealand with bronchiectasis.

This study described how young people experience interruptions in their day-to-day life due to bronchiectasis and that these interruptions are often related to health system-imposed obligations. These findings expand understandings about some of the challenges of living with bronchiectasis and highlight how young people perceive themselves to be a burden on their families. In the face of managing a chronic illness with significant symptoms, interruptions and self-management responsibilities, young people with bronchiectasis, across a variety of ages, demonstrate self-management capability and resilience. The study described how transition to self-management is an individual journey supported by parental involvement and willingness to share management.

This is the first study to report on the symptom experience of young people with bronchiectasis and describe how they experienced their own unique and individual pattern of symptoms leading up to and during an exacerbation and demonstrate good awareness and ability to perceive and interpret symptoms. The findings from this study regarding fatigue and chest pain have not previously been reported in the literature in children and young people and provide new insight into the patients' experience of symptoms in bronchiectasis.

### Final Remarks

At the heart of this study was a desire to understand how young people with bronchiectasis experienced day to day life. The goal to come to know what mattered most to them, to learn if and how bronchiectasis affected their lives and to give voice to each of their personal, subjective narratives. The fifteen young participants who took part in this study revealed important insights about themselves, about the importance of living a normal life and about the position that bronchiectasis held in that life. To my knowledge this is the first study that has enabled young people with bronchiectasis to tell their story. This study has shown the importance of thinking beyond a medical view and towards a more holistic view where the young person's subjective personal experiences are considered and valued to be as much a part of their care plan as any other aspect of treatment and management. The findings also provide an important reminder to health professionals that first and foremost young people value being normal. They have the same concerns and stresses about school, friends and family as any other young person and these are the things that matter

most. Having a chronic illness such as bronchiectasis undoubtedly challenges these important matters, but it is only a small part of how young people view their life.



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## Appendices

## Appendix A: First 2 interviews critique and analysis with supervisor

Interview ①

1. Let's just start with easy stuff. How old are you?
2. 13
3. And what year of school are you in?
4. Year 9.
5. Year 9 okay. And so how is year 9 gone? First year of high school... how has that gone.
6. I like it.
7. What do you like about it?
8. I like.. Well it's a lot...it's a bit more challenging but I kinda like how its streamed as well. How it goes from the top classes to the lower classes and in the order of how whangerei is spelt. I kinda like it like that I have never done that before.
9. What about that do you like? Why is it that you like it?
10. It means that everyone in our class is more less the same learning so we are all at a similar area and we can all be taught the same things.
11. So what is your favourite subject?
12. Well I like PE, Social studies and horticulture, which I did at the start of the year. We had our own gardens pretty much. If it was a sunny day we got to do weeding and stuff and all the produce we got to keep. We did a little bit of book work on the days it was raining and if we had an assessment we did book work before that as well. So pretty much just gardening though
13. Do you garden stuff around the house here?
14. Yep.. Yeah we just planted gardens here and will have a veggie patch.
15. What other subjects do you like at school?
16. I...I'm good at science but I don't really like it but um I like the plants and animals part of science that we did.
17. What about friends and stuff what do you like to do?
18. It's a lot different at boys high because it was...At my old school we used to go out on the field and play football on the courts and stuff but no one.. there's like no goals on the field and stuff so we cant do that. I play handball sometimes Or six square, its kinda like football handball but you kick it.
19. What other things do you like to do for fun? I know you like to play football. Is that your favourite?
20. Yeah And fishing... yeah I am not sure just like football and fishing. Just football and fishing.
21. (Mum). Any form of football Indoor football outside, twilight
22. So how much football do you play a week?
23. Um.. Wednesday training, Tuesday futsal, Thursday I have twilight and on Sunday I have futsal again. Oh yoy Futsal is on a Tuesday Training on a Friday and on Sunday
24. That's a lot of football. Okay let's talk about your bronchiectasis. Start with when you were diagnosed with Bx.
25. I was seven. I think is that right?
26. (Mum whispers)... yeah I think so yeah

Give more time for Messi to talk in General

Tell me more?

This transition is not great. Too quick to jump to Bx.

Interviewing like a Nurse instead of a researcher



## Appendix A: First 2 interviews critique and analysis with supervisor

Interview (2)

Here should have given participant a bit more time before jumping into this

33. What is the hardest thing about having bronchiectasis?	Missing school is a challenge
34. Probably if you have been sick for a while and haven't really been back to school its really hard to go back to school, especially if you are a teenager because its like a lot happens within like 2 weeks or something that your re away. And in high school you've got a bunch of different teachers, you don't have the same teacher for every subject so its harder to keep up with all of the subjects and fitting back in because everything's changed and like friendships changed that kind of stuff. Kinda hard to get used to that. Change all the time.	Different as a teenager  Hard to keep up when you miss school because of illness  Missing school is hard Friendships change and this is hard
35. How do you deal with that? What do you do?	
36. UMMM I am normally nervous for the first day back and I go in and say 'hi guys' and they go "Kitten!" and just run up to me and hug me. So once that's done then I kind of get used to it.	Returning to school after being away is nerve wracking
37. What else is hard or challenging?	<i>Focusing on Negative</i>
38. Probably homework can be a bit hard. Especially when you first go into hospital when you're still quite sick because you are always really tired and you can't do your homework because you're too tired. You can't really have friends over in the hospital because they are normally usually busy, and they have school as you don't, so sometimes you might feel like calling them in the middle of the day and they might be in class so you can't really call them or talk to them much. I guess I just um just kind of deal with it.	Keeping up with school is hard when tired and sick  Hospital isolates you from friends  Just get on with it. Coping dealing with it.
39. How do you 'deal with it'?	
40. I feel a bit sad after a while being in hospital not seeing them but I don't know I just...	Sadness and missing friends
41. The hardest things for you are being away from friends, being away from school. Have I got that right? What about being at home?	
42. To be honest its probably easier at home. You've got your own bed, you've got your own places in the house that you like to sit. You can make your own food, have nice food, homemade food. Nice. Its with family. Easier for friends, cuz they don't have to travel all the way into whangarei.	Being sick at home is easier- own space- familiar comfortable places Easier to have contact with friends- less isolation
43. You said you have two brothers. How do you get along?	
44. Ummm. Not really. Don't get along. Yeah. Charlie the crazy one is 6. Brayden gets angry and he is 12. Annnnnndddd... Charlie is too hypo and he's very annoying and mean to me but Brayden he's normally. he's not really home much. He's always out scootering with his mates. he's usually out scootering with him mates or out scootering out there or going down to the skate park or down to the schools and	Siblings are annoying Siblings busy with own life

*Lost flow in this interview*

*than jumped back to family*

Once again moving rapidly to questions about bronchiectasis → Need to allow more space to talk about "life" not

## Appendix B: Health and Disability Ethics Committee ethics approval letter



Health and Disability Ethics Committees  
Ministry of Health  
133 Molesworth Street  
PO Box 5013  
Wellington  
6011

0800 4 ETHICS  
hdec@mh.govt.nz

18 September 2017

Mrs Julie Blamires  
10 ~~Ranleigh~~ Road  
Mt Albert  
10 ~~Ranleigh~~ Road, Mt Albert  
Auckland 1025

Dear Mrs Blamires

Re:	Ethics ref:	17/NTA/163
	Study title:	Young people's day to day life experience living with bronchiectasis. What matters most?

I am pleased to advise that this application has been approved by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern A Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at any locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a given locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

- Please make it clear in the Participant Information Sheet whether a participant's GP will be informed/not of their participation in the study. (This should be an optional statement in the Consent Form).
- The Consent forms should only have yes/no options next to the statements that are truly optional, that is, if answered no, a participant can still take part in the study.

## Appendix C: Auckland University of Technology Ethics Committee approval letter



**AUTEC Secretariat**

Auckland University of Technology  
D-88, WU406 Level 4 WU Building City Campus  
T: +64 9 921 9999 ext. 8316  
E: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)  
[www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

24 November 2017

Annette Dickinson  
Faculty of Health and Environmental Sciences

Dear Annette

Ethics Application: 17/434 Young people's day to day life experience living with bronchiectasis. What matters most?

I wish to advise you that a subcommittee of the Auckland University of Technology Ethics Committee (AUTEC) has approved your ethics application.

This approval is for three years, expiring 22 November 2020.

**Standard Conditions of Approval**

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)

Yours sincerely,



Kate O'Connor  
Executive Manager  
Auckland University of Technology Ethics Committee

Cc: [julie.blamires@aut.ac.nz](mailto:julie.blamires@aut.ac.nz); [elshadan.tautolo@aut.ac.nz](mailto:elshadan.tautolo@aut.ac.nz)

## Appendix D: Auckland District Health Board Research Committee (locality agreement)



6 October 2017

Julie Blamires

AUT University  
90 Akoranga Dr  
Northcote  
0627

Dear Julie,

**Re: Research project A+7736 (Ethics 17/NTA/163) Young people's day to day life experience living with bronchiectasis. What matters most?**

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee  
Dr Mary-Anne Woodnorth  
Manager, Research Office

c.c. Carla Jacobson Cass Brynes

.../continued next page

Research Office  
Level 14, Support Bldg  
Auckland City Hospital  
PB 92024, Grafton, Auckland  
Phone: 64 9 307 4949 Extn. 23854  
Email: [mwoodnorth@adhb.govt.nz](mailto:mwoodnorth@adhb.govt.nz)  
Website: [www.adhb.health.nz/health-professionals/research/](http://www.adhb.health.nz/health-professionals/research/)

**Institutional Approval**



## Appendix E: Counties Manukau District Health Board Research Committee (locality agreement)

**From:** [researchoffice@middlemore.co.nz](mailto:researchoffice@middlemore.co.nz) [mailto:[researchoffice@middlemore.co.nz](mailto:researchoffice@middlemore.co.nz)]

**Sent:** Tuesday, 31 October 2017 11:24 a.m.

**To:** [julie.blamires@aut.ac.nz](mailto:julie.blamires@aut.ac.nz); Sarah Mooney (Physiotherapist) (CMDHB)

**Subject:** Research application number 445 has been approved

Dear Julie Blamires,

---

Application Registration Number: 445

Ethics Reference Number (if applicable): N/A

Application Title: Young people's day to day life experience living with bronchiectasis. What matters most?...

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I am pleased to inform you that the CM Health Research Office has approved this project with you as the CM Health Co-ordinating Investigator.

Your project is approved until 14 Sep 2019 or as specified on your ethics approval letter. For amendments or extensions please contact the Research Office.

In addition to this approval, the CMDHB Maaori Research Review Committee has appreciated the opportunity to engage with you regarding the relevance of this research for Maaori.

The committee is able to approve your research project to be conducted in the auspices of CMDHB.

Our Committee would also like to offer our support regarding any further culturally responsive practice and guidance you may seek advice on.

For research, you are required to complete and upload a final report template. Please note your final report will be available to all CMDHB employees.

If you wish to view your application please click on the following link:

[Click to view application](#)

We wish you well in your project.

Yours Sincerely

Dr Dominic Madell



**Research Manager**

Counties Manukau Health

*Under delegated authority from CM Health Research Committee and Director of Hospital Services*

This e-mail message and any accompanying attachments may contain information that is confidential and subject to legal privilege. If you are not the intended recipient, do not read, use, disseminate, distribute or copy this message or attachments. If you have received this message in error, please notify the sender immediately and delete this message. Visit [www.kiwihealthjobs.com](http://www.kiwihealthjobs.com), New Zealand's largest employment site for jobs in the public health sector. 100% owned and supported nationally by the District Health Boards (DHBs) and the New Zealand Blood Service (NZBS). If you are looking for medical jobs in New Zealand, your career in health starts with us.

## Appendix F: Participant information and consent for participant >16 years of age

### Participant Information Sheet

Study title:

**Young people's day to day life experience living with Bronchiectasis. What matters most?**

Locality:	#7736	Ethics committee ref.:	17/NTA/163
Lead investigator:	Julie Blamires	Contact phone number:	09 921 9999 ext7979

You are invited to take part in a research study aimed at exploring your experience of living with Bronchiectasis. This study will contribute to a Doctor of Health Science qualification that the principal researcher is undertaking at AUT University. The nurse, physiotherapist and/or doctor will talk to you about the study and answer any questions you have. You can take a copy of this information sheet to think about it or talk about with your family or friends before you decide.

Once you understand what the research is about and if you agree you would like to take part in it, you will be asked to sign a consent form. You will be given a copy of this information sheet and the consent form to keep.

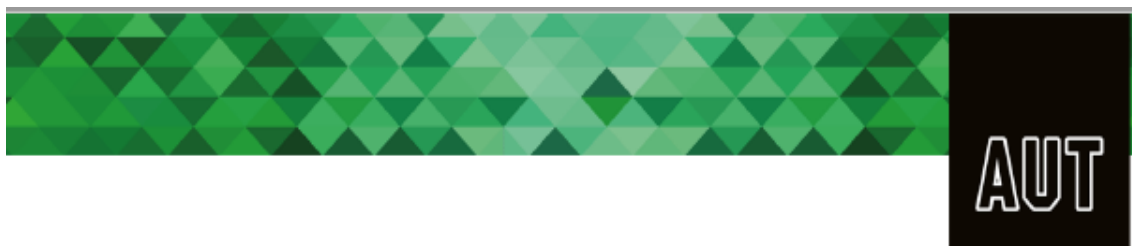
This document is 4 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

#### **WHY ARE WE DOING THIS STUDY?**

Many young people in New Zealand live with Bronchiectasis. We know a fair amount about how to diagnose and treat bronchiectasis but we know less about the psychological, emotional and social challenges for the young person growing up with this disease. We want to know how young people describe their everyday life experience living with bronchiectasis and understand what matters most to them. We hope that the information gained from the study will help us to plan care that better meets patients' needs and that young patients will feel more actively engaged in management of their bronchiectasis.

#### **WHAT WILL I HAVE TO DO IF I AM PART OF THIS STUDY?**

You have been identified as a young person between the ages of 12-24 with a diagnosis of bronchiectasis. If you choose to participate, you will take part in an interview with a researcher where you will be asked to describe your experiences and views of living with bronchiectasis. The interview will take about 60-90 minutes. The interview will be recorded and a transcription summary of the interview will be made available if you request. The stories and comments from all the interviews will be used to find themes and patterns. You may or may not be asked for a second interview in order for the researcher to check that the themes developed fit with your experience. You do not have to agree to a second interview.



### **WHAT ARE THE BENEFITS OF THE STUDY?**

The benefits to you personally will stem from having the opportunity to tell stories and to relay your experiences in a way that suits you. The benefits to the wider Bronchiectasis community are that health providers will better understand the patient experience and this will feed back directly into care.

### **WHAT ARE THE DISCOMFORTS OR RISKS? HOW WILL THESE BE ALLEVIATED?**

Living with a chronic disease such as bronchiectasis can be challenging. There is a possibility that you may feel uncomfortable talking about some of your experiences. It is entirely up to you what experiences and stories you wish to discuss. You have the right to have a support person with you. If any health or other issues are identified during the interview, consent from yourself will be sought prior to referral back to the health care team. If you request a cultural support person, one can be provided for you or you can select a person yourself. Should you feel uncomfortable or distressed at any stage during the interview you have the right to stop the interview process. You do not have to give a reason.

### **WHAT ARE THE COSTS OF PARTICIPATING IN THIS RESEARCH?**

There will be no cost to you but we ask that you give your time. If you choose to take part, you will take part in a 60-90 minute interview with a researcher. The researcher will meet you at a place convenient for you.

### **HOW DO I AGREE TO PARTICIPATE IN THIS RESEARCH?**

You will need to complete a consent form to take part in this research. This might happen two ways:

- 1) The nurse, physiotherapist or doctor in clinic will go over the information provided and answer your questions. If you agree to participate, they will contact the researcher on your behalf and provide your contact details. The researcher will then ring you to arrange an interview.
- 2) You will be given the patient information sheet by the nurse, physiotherapist or doctor and will take it away to think about. You will contact the researcher directly if you wish to participate. The consent will then be signed at the arranged time of the interview.

### **WILL I RECEIVE FEEDBACK ON THE RESULTS OF THE RESEARCH?**

You can choose to receive a summary of the findings of this research. Once these are available, you can choose to have them sent to you at an address you provide, or attend an information meeting given by the research team. You will get details of these options once the study has been completed which will be about 18 months after the interview.

### VOLUNTARY AGREEMENT

Your participation in this project is voluntary (your choice). You can withdraw from the study at any time prior to the completion of data collection.

### CONFIDENTIALITY

Should you decide to participate in this research study your participation would be confidential. Interview recordings and transcripts will only be available to the research team. All identifiable details will be held securely and no information identifying you as a participant will be included in any of the project reports or publications. Your GP will not be aware of your participation in this study.

### WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

**Julie Blamires**  
Registered Nurse, Lecturer  
Auckland University of Technology  
Email: [julie.blamires@aut.ac.nz](mailto:julie.blamires@aut.ac.nz)  
Telephone number: 921-9999 extension 7979

Thank you for your consideration in participating in this important study.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
Fax: 0800 2 SUPPORT (0800 2787 7678)  
Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

If you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.

If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868920 ext 3204.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS      Email: [hdec@moh.govt.nz](mailto:hdec@moh.govt.nz)



## Participant Consent Form

*Young people's day to day life experience living with Bronchiectasis. What matters most?*

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	<input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	<input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	<input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	<input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	<input type="checkbox"/>
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	<input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	<input type="checkbox"/>
I understand my responsibilities as a study participant.	<input type="checkbox"/>

I wish to receive a summary of the results from the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
--	------------------------------	-----------------------------

### Declaration by participant:

I hereby consent to take part in this study.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

### Declaration by member of research or healthcare team:



I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_



## Appendix G: Participant information and assent for participant <16 years of age

### Child participant Information Sheet

Study title: **Young people's day to day life experience living with Bronchiectasis. What matters most?**

Locality:	#7738	Ethics committee ref.:	17/NTA/183
Lead investigator:	Julie Blamires	Contact phone number:	08 821 8888 ext7878

#### **YOUR ASSENT (AGREEMENT)**

We are asking you to be part of a research study. This study will contribute to a Doctor of Health Science qualification that the principal researcher is undertaking at AUT University. The bronchiectasis nurse, physiotherapist and/or doctor will talk to you about the study and answer any questions you have. You can think about it or talk about it with your family or friends before you decide.

#### **WHY ARE WE DOING THIS STUDY?**

Many children and young people in New Zealand live with Bronchiectasis. We know a fair amount about how to diagnose and treat bronchiectasis but we know less about what it is like every day to live with bronchiectasis from a patient's view. We want to know how young people describe their everyday life experience and understand what matters most to them. We hope that the information gained from the study will help us to plan care and better meet the needs of patients.

#### **WHAT WILL I HAVE TO DO IF I AM PART OF THIS STUDY?**

If you choose to take part in the study you will be asked to answer some questions about what it is like for you to have bronchiectasis. This will take about 1 hour. Your answers to the questions will be grouped into patterns and compared with other patient's answers to see what is the same and what is different. Your answers will be confidential and no one will be able to identify them as your answers. Your GP will not be informed about your participation in this study. You might be asked for a second interview but you do not have to do it if you do not want to.

#### **WHAT ARE THE BENEFITS OF THE STUDY?**

It should be fun to have a chance to tell someone about what it is like to have bronchiectasis. It will be helpful for doctors, nurses and physiotherapists to know what matters the most to you. This will make sure they are looking after you and others with bronchiectasis in the best way possible.



#### WHAT ARE THE DISCOMFORTS OR RISKS?

We do not expect any bad effects or risks. It is entirely up to you what you wish to discuss.

#### VOLUNTARY AGREEMENT

You are free to decide if you want to be part of this study or not. If you choose not to take part you will still be treated at the hospital as usual. If you decide to join the study then change your mind you will still be treated at the hospital as usual.

Sign the form when you have had a chance to ask all questions and you feel happy about being in the study.

Contact:

**Julie Blamires**  
**Registered Nurse, Lecturer**  
**Auckland University of Technology**  
**Email: [julie.blamires@aut.ac.nz](mailto:julie.blamires@aut.ac.nz)**  
**Telephone number: 921-9999 extension 7979**

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
 Fax: 0800 2 SUPPORT (0800 2787 7678)  
 Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

If you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.

*If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868020 ext 3204.*

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
 Email: [hdec@moh.govt.nz](mailto:hdec@moh.govt.nz)



## Experience of Bronchiectasis Agreement Form

Child (12-16)

*Young people's day to day life experience living with Bronchiectasis. What matters most?*

**Participant's Name**

\_\_\_\_\_

**Please tick to indicate you assent (agree) to the following**

I understand I am taking part in a research study	<input type="checkbox"/>
I will be asked questions about my Bronchiectasis, and invited to tell my story.	<input type="checkbox"/>
I understand that taking part in this study is my choice and that I may change my mind at any time	<input type="checkbox"/>
I understand that everything I say is confidential.	<input type="checkbox"/>
I know who I, or my family can contact if I have any questions about the study in general.	<input type="checkbox"/>

I have read and I understand the information sheet about the study. I have had the opportunity to discuss this study. I am happy with the answers I have been given.

**Print Name (Child):** \_\_\_\_\_

**Signed:** \_\_\_\_\_ **Date** \_\_\_\_\_

Parental Consent Form signed as well **YES**

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant (child) and their caregivers, and have answered the child and caregivers questions about it. I believe the participant and their caregivers understand the study and have given informed consent to participate.

**Signed:** \_\_\_\_\_ **Date** \_\_\_\_\_

Principal Investigator or Healthcare Team (nurse, physiotherapist, doctor)



## Appendix H: Parent information and consent for participant <16 years of age



### Parent Information Sheet

Study title:

Young people's day to day life experience living with Bronchiectasis. What matters most?

Locality: #7738

Ethics committee ref.:

17/NTA/163

Lead investigator:

Julie Blamires

Contact phone number:

09 921 9999 ext7979

Your child has been invited to take part in a research study aimed at exploring their experience of living with Bronchiectasis. This study will contribute to a Doctor of Health Science qualification that the principal researcher is undertaking at AUT University. The nurse, physiotherapist and/or doctor will talk to you about the study and answer any questions you have. You can take a copy of this information sheet to think about it or talk about with your family or friends before you decide.

Once you understand what the research is about and if you agree that your child should take part in it, you will be asked to sign a Consent form. You will be given a copy of this information sheet and the consent form to keep.

This document is 4 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

#### WHY ARE WE DOING THIS STUDY?

Many young people in New Zealand live with Bronchiectasis. We know a fair amount about how to diagnose and treat bronchiectasis but we know less about the psychological, emotional and social challenges for the young person growing up with this disease. We want to know how young people describe their everyday life experience living with bronchiectasis and understand what matters most to them. We hope that the information gained from the study will help us to plan care that better meets patients' needs and that young patients will feel more actively engaged in management of their bronchiectasis.

#### WHAT WILL I HAVE TO DO IF I AM PART OF THIS STUDY?

Your child has been identified as a young person with a diagnosis of bronchiectasis. If you agree for your child to be part of the study, they will take part in an interview with a researcher where they will be asked to describe their experiences and views of living with bronchiectasis. The interview will take about 60-90 minutes. The interview will be recorded and a transcription summary of the interview will be made available to you (and them) if you request. The stories and comments from all the interviews will be used to find themes and patterns. Your child may or may not be asked for a second interview in order for the researcher to check that the themes developed fit with their experience. You/they do not have to agree to a second interview.



#### **WHAT ARE THE BENEFITS OF THE STUDY?**

The benefits to your child will stem from having the opportunity to tell stories and to relay their experiences in a way that suits them. The benefits to the wider Bronchiectasis community are that health providers will better understand the patient experience and this will feed back directly into care.

#### **WHAT ARE THE DISCOMFORTS OR RISKS? HOW WILL THESE BE ALLEVIATED?**

Living with a chronic disease such as bronchiectasis can be challenging. There is a possibility that they may feel uncomfortable talking about some of their experiences. It is entirely up to them what experiences and stories they wish to discuss. They have the right to have a support person with them during the interview. If any health or other issues are identified during the interview, consent from yourself and your child will be sought prior to referral back to the health care team. If you request a cultural support person, one can be provided. If you decide to join the study and then change your mind, the interview will be stopped and you do not have to give a reason.

#### **WHAT ARE THE COSTS OF PARTICIPATING IN THIS RESEARCH?**

There will be no cost to you but we ask that you give your time. If you choose to take part, your child will take part in a 60-90 minute interview with a researcher. The researcher will meet you and your child at a place convenient for you.

#### **HOW DO I AGREE TO PARTICIPATE IN THIS RESEARCH?**

You will need to complete a consent form to take part in this research. This might happen two ways:

1) The nurse, physiotherapist or doctor in clinic will go over the information provided and answer your questions. If you agree to participate, they will contact the researcher on your behalf and provide your contact details. The researcher will then ring you to arrange an interview.

2) You will be given the patient information sheet by the nurse, physiotherapist or doctor and will take it away to think about. You will contact the researcher directly if you wish to participate. The consent will be then be signed at the arranged time of the interview.

#### **WILL I RECEIVE FEEDBACK ON THE RESULTS OF THE RESEARCH?**

You can choose to receive a summary of the findings of this research.

Once these are available, you can choose to have them sent to you at an address you provide, or attend an information meeting given by the research team. You will get details of these options once the study has been completed which will be about 18 months after the interview.

### VOLUNTARY AGREEMENT

You and your child's participation in this project is voluntary (your choice). You (or they) can withdraw from the study at any time prior to the completion of data collection and it will not affect the care you receive.

### CONFIDENTIALITY

Should you consent for your child to participate in this research study participation would be confidential. Interview recordings and transcripts will only be available to the research team. All identifiable details will be held securely and no information identifying you as a participant will be included in any of the project reports or publications. This will be kept until the children are 10 years beyond 16 years in case they want it returned. It will then be destroyed in a confidential manner. Your GP will not be informed about your participation in this study.

### WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Julie Blamires  
Registered Nurse, Lecturer  
Auckland University of Technology  
Email: [julie.blamires@aut.ac.nz](mailto:julie.blamires@aut.ac.nz)  
Telephone number: 921-9999 extension 7979

Thank you for your consideration in participating in this important study.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

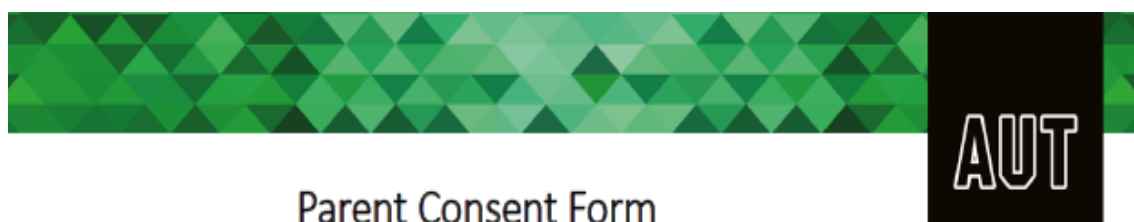
Phone: 0800 555 050  
Fax: 0800 2 SUPPORT (0800 2787 7678)  
Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

If you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.

If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868920 ext 3204

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
Email: [hdec@moh.govt.nz](mailto:hdec@moh.govt.nz)



## Parent Consent Form

*Young people's day to day life experience living with Bronchiectasis. What matters most?*  
Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	<input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	<input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	<input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	<input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw my child from the study at any time without this affecting my medical care.	<input type="checkbox"/>
I understand that my child's participation in this study is confidential and that no material, which could identify my child personally, will be used in any reports on this study.	<input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	<input type="checkbox"/>
I understand my child's responsibilities as a study participant.	<input type="checkbox"/>

I wish to receive a summary of the results from the study. Yes ☐ No ☐

### Declaration by participant:

I hereby consent for my child to take part in this study.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

### Declaration by member of research or healthcare team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant's caregiver/parent understands the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix I: Counties Manukau District Health Board Māori Research Review Committee



29 September 2017

Ms Julie Blamires  
Auckland University of Technology  
90 Akoranga Drive  
Northcote  
Auckland 627

[julie.blamires@aut.ac.nz](mailto:julie.blamires@aut.ac.nz)

Teenaa koe Julie

**RE: Maaori Research Review Approval for *Young people's day to day life experience living with bronchiectasis. What matters most?***

The Maaori Research Review Committee (the Committee) has reviewed your application and we are pleased to provide our endorsement for your proposed research proposal. The Committee wishes you every success in research.

We would welcome any progress reports throughout your research approach, and a copy of your published findings.

Naaku noa, naa

Leigh-James Henderson  
Maaori Research Review Committee

## Appendix J: Auckland District Health Board Māori review letter

**From:** Kim Southey (WDHB)  
**To:** [Julie Blamires](#)  
**Subject:** Maori Research Ethics Review: RRC 7736, living with bronchiectasis  
**Date:** Thursday, 14 September 2017 2:21:40 PM

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Tena koe Julie,

I have completed a preliminary Maori research ethics review of a study you are either leading or coordinating.

There are no concerns with the study. The only requested amendment is to add the standard Maori Health Team and Maori Health Research contacts to any participant information sheets. These contact details are as follows:

*"If you require Maori cultural support talk to your whanau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Maori Health Team) by telephoning 09 486 8324 ext 2324.*

*If you have any questions or complaints about the study you may contact the Auckland and Waitemata District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868920 ext 3204."*

**Once I have cited the amended participant information sheet I will send an approval letter to the ADHB Research Office.**

Please feel free to contact me if you have any questions in the meantime.

Nga mihi

Kim Southey  
**Kaupapa Maori Analyst**  
**Waitemata and Auckland District Health Boards**

[Legal Disclaimer](#)



## Appendix K: Interview topic guide

### Topic Interview guide for Semi-Structured Interviews

This research study employs an interpretative descriptive methodology and hence relies on the stories and experiences that participants bring to the interview.

It is not the intention of the researcher to enter the interview with prearranged questions.

I am very keen to allow the participants to shape the interview however the participants may need a beginning point to start from then I could employ any of the following prompts:

*Warm up questions.*

Tell me about the kinds of things you enjoy doing? (*prompts Sports/afterschool activities/babysitting/being with friends*).

Do you go to school/work? What do you enjoy most about work/school?

*Then move to study related prompts:*

Tell me your story of being diagnosed with bronchiectasis?

What is a typical day like for you right now?

Do you think there are any things that you have to do differently from your friends/peers/colleagues?

Do you think this is related to your bronchiectasis? Tell me how? [*Probe: ? Restrictions: Diet /activity/meds*]

What has it been like growing up with Bronchiectasis? [*Probes: People growing up with a chronic disease (like bronchiectasis) have been described as having a life that is "not ordinary." How would you respond to that description? What does an ordinary life look like to you?*]

What support and resources have been helpful to you? (who are the people that are most important in your life?)

What has been the best thing about growing up with Bronchiectasis?

What has been the worst/hardest thing about growing up with Bronchiectasis?

What are the most important areas of your life?

Anything else you would like to tell me about growing up with Bronchiectasis?

Additional prompts which may be used throughout the interview:

When you described... what did you mean

I'm really interested in what you just described....

Can you tell me a bit more about....

What did you understand by that... Why do you think that was like that...

## Appendix L: Excerpt from reflexive journal

### Journal and memos example 1.

#### November 22<sup>nd</sup>/2017

Trying to overcome my nervousness surrounding the first interview. I feel as if I am putting off doing the first interview and know that I really do need to just get on with it. Had a great conversation today with a colleague who reassured me that my feelings were normal and all part of the process. I thought about how as nurse we interview patients all of the time but there is something quite different about the process of interviewing as student as it is about my own learning. So in some ways I feel more vulnerable and in the position of less power than the participants. As a novice researcher I feel like my lack of expertise and knowledge on how to conduct a research interview is strongly influencing my fear.

#### December 5<sup>th</sup>/2017

##### 1<sup>st</sup> and 2<sup>nd</sup> Interview

These interviews took place back to back. Not ideal but the distance to travel was long.

##### Recording from the car drive up to Whangarei

Travelling north to conduct the first two interviews. It's a long drive with lots of time to think about how this is going to go. Oddly I feel nervous about doing this right, even though I know how to talk to patients and their families, it feels very different this time. They are not my patients and I am going in blind. It is an odd feeling to go into an interview without any background knowledge. Usually you know a little even if they are a new patient, you have some background information about how they got to you but this is, this is a totally different kettle of fish.

##### Post interview reflections-transcribed from voice recording

So reflecting on um interview with Messi. A thirteen year old boy who um requested that his mother be present during the interview, um, which was fine, um he mostly answered my questions. Mum did um mostly let Messi answer the questions himself. There were a few times where he mentioned things that he might want to tell me about. Lovely dry warm home in the country side. NZ European family. He was a good mood, had just come home from school. Was very receptive to the interview and seemed comfortable quickly after a bit of general chit chat and rapport building.

I found the second interview to be more challenging than the first. Again I think I am probably, I am aware I am probably asking too many questions, ah and not allowing the quiet. Um and I am struggling with that a bit. So that is something I need to work on. I did find it particularly challenging with Messi, to maintain the quiet as I was feeling a level of uncomfortableness with him answering the questions. Whether it was the fact that I was asking quite closed questions or whether he was only giving the amount of answer he/was prepared to give but it felt, felt like I had to press more to get more out of him. The two interviews, although I shouldn't have done them so close together. I am aware this is probably not the best approach so I am using this opportunity to reflect on both of them



together. As separate interviews but also as a contrast. The first participant has clearly had a much more challenging time with her bronchiectasis, um there have been many more hospitalisations, there continues to be more intensive treatment and challenges related to the bronchiectasis and I would say the second participant has more of get on with it kind of attitude. ~~He's~~ not going to let anything stand in the way of what he wants to do. And he. I get a sense that he is very frustrated with having this condition. It annoys him, it really ~~really~~ annoys him. He wants to be able to run and play sports and do cross country and does not want to be limited by his disease. And I found, I found... they were sharply in contrast to one another. In actual fact where participant 1 was yeah this is just the way it is, this is me this is my disease, I can't do certain things. Whereas the second participant was, I want this to be gone. He has aspirations for his disease, either he will grow out of his disease or he will have an operation to get rid of it. The first participant has moderate disease whereas the second likely mild. Yet Messi is much more annoyed and generally pissed off about it and how much it limits him when compared to the young person with more severe disease. Whether that's a boy girl thing, I don't know. So those are my first observations after the whirlwind trip and doing my first two interviews.

## Transcribing the first two interviews

Following the first interview I took time to reflect on the process before moving on to the second interview. I realised at the time that it was not ideal for me to be conducting the interviews back to back but had to do this for pragmatic reasons. At the time I considered that both interviews had gone reasonably well but once I began to transcribe the interviews I realised that there were a few improvements that could be made.

I transcribed interview 2 first and then moved on to the 1<sup>st</sup>. In the first interview I noted that I talked too much and tried to fill the quiet with more questions. This was likely a result of my nervousness but also could be related to the participants themselves or a combination of both. Both participants were almost 14. One had severe bronchiectasis and the other mild. They both had get on with it attitudes whereas the participant with the mild disease seemed to be much more frustrated and annoyed at his bronchiectasis whereas kitten had resigned herself to the fact that this was the way it was.

Some of the initial key things that came through for me were the fact that they did not really talk about cough or SOB as much I had anticipated they would. They talked about when they were getting sick and related this to being TIRED. Tired was a word that came up quite a lot when both participants were talking about being sick. Overwhelming tiredness. A body tiredness where they just had to be in bed. So tired they couldn't even be bothered answering questions. Both of these first two interviews were NZ European kids who came from middleclass homes that were warm and dry. They both talked a lot about their friends and the importance of them in their lives.

These first initial thoughts came out of the transcription process and are before familiarisation. I will return to these interviews at a later date to begin the thematic analysis process starting with familiarisation.

## Appendix M: Confidentiality agreement



Auckland University of Technology  
Private Bag 92006, Auckland 1142, NZ  
T: +64 9 921 9999  
www.aut.ac.nz

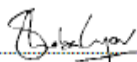
**AUT**

### Confidentiality Agreement for transcriptionist

*Project title:* Young People's day to day life experience living with bronchiectasis.  
*Project Supervisor:* Annette Dickinson  
*Researcher:* Julie Blamires

---

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:   
Transcriber's name: Shoba Nayar

Transcriber's Contact Details (if appropriate):

Email: [snayar10@gmail.com](mailto:snayar10@gmail.com)

.....

.....

.....

Date: 12 February 2018

Project Supervisor's Contact Details (if appropriate):

Annette Dickinson  
South Campus ME108  
09 921 9999 ext 7337

*Approved by the Auckland University of Technology Ethics Committee on type the date on which the final approval was granted AUTEK Reference number type the AUTEK reference number*

*Note: The Transcriber should retain a copy of this form.*

## Appendix N: Example of initial coding of an interview

1. Um. Um I think you can only have it like in one lung I think. Oh I have it only in my, um I think it's left. I think it's I only have it in my left lung. And um. Whenever I go to hospital I go for like two weeks. Um, and yeah.

2. *So what's that like?* *→ this feels like a lifetime!*

3. Um, it used to be fun but then like I, getting older and yeah like nothing to do. No one to yeah. The whole two weeks, so I'd be like, I come out like daily kind of, and go back at night yeah.

4. *Yeah so tell me more about being in hospital. So it used to be fun!*

5. Yeah.

6. *You said it used to be fun but now it's not. So tell me more about that.*

7. Well it's alright now but I haven't been in hospital since I think last year August yeah um. I see ah other people with bronchiectasis and yeah it's like um, oh. It's like I don't really like it because I get better like the first three days and then for the rest like one week and a half it's just, I feel normal. But I still have to stay in yeah. *dislike of hospital*

8. *Yeah so tell me more about that.* *Has to stay despite feeling normal* *— feel 'normal'*

9. Um. When I'm in there I do like three physiotherapy a day, sometimes four. Um I like sleep heaps in the hospital. And, like all the nurses know me yeah. oh like when I go in sick and they um like go on IV antibiotics and then I get better like first three days and then for the rest of the two weeks um I feel fine but I still have to stay in. Yeah. *Lots of physio in hospital*

10. *So how does that make you feel?* *— feels so tired hospital*

11. Yeah like annoyed kind of. Yeah.

12. *Yeah. Um, what is the worst thing about being in the hospital?*

13. Is like, no one my age and like the meals are like alright. And the best thing is ah, I get like time off school. Sometimes yeah. *Likes time of school*

14. *Yeah so tell me a bit about that. So what, what's that been like for you, when you have to miss school because of like being sick for example?*

15. Oh I don't really mind missing school yeah. Yeah it's just like my teachers they worry a bit yeah.

16. *What about keeping up with things and stuff, does that become a problem or?*

17. Um sometimes, not really no.

18. *Okay. So tell me about um, being sick. What does that mean? When you say you're sick so what does that, what does that mean?*

19. Oh like I can't like breathe properly sometimes. Or like I'm really hot or cold. And sometimes I can tell when I'm about to get sick. Like if I'm having a hot shower and it's cold but I'm cold, I'm sort of shivering yeah um. Or like if I'm really like tired, sleeping heaps. Like if someone touches me and it's like sore yeah, it's like sometimes symptoms, some symptoms yeah. *perfectly shivering - sore*

20. *Yeah so tell me more about those things.*

21. Yeah, and yeah like feel heaps of things, tired like dizzy and just sore everywhere. *Feels sore Dizzy*

22. *Sore everywhere.* *Feels sore Dizzy*

23. Yeah. Um, sometimes. It's mostly just sore in my chest. *Feels sore Chest sore*

24. *Right.*

25. Yeah.

26. *So talk about that, what's that soreness like in your chest? How would you describe it to someone who?*

27. Um like when I breathe in it hurts, yeah so. When I breathe out it's fine but it's just when I breathe in yeah it's sore. *Breathe in is sore*

28. *What about coughing? Do you cough a lot or?* *NO COUGHING?*

29. Um, not really no.

30. Sometimes yeah I cough a little bit more when I'm sick. But I cough at night, like when I'm during sleep. *But sometimes I cough*

*Looks like he's not*

*Breathless*

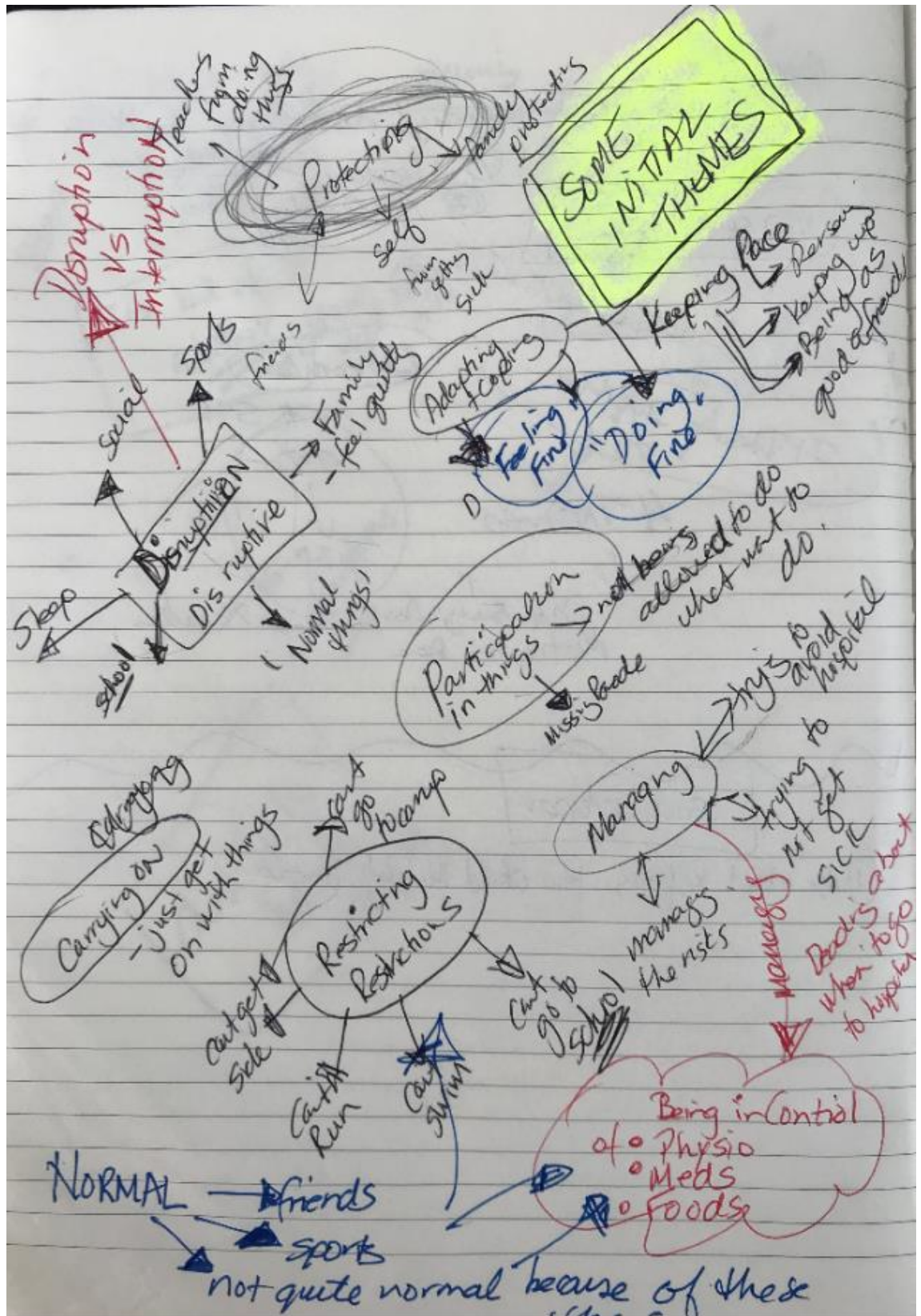
*I can feel when gets sick*

*Looks like he's not*

*So soreness tiredness dislike for hospital breathy* *— feels too old. sore myself. — physiotherapist when sick.*



Appendix O: Example of a mind map early in analysis phase



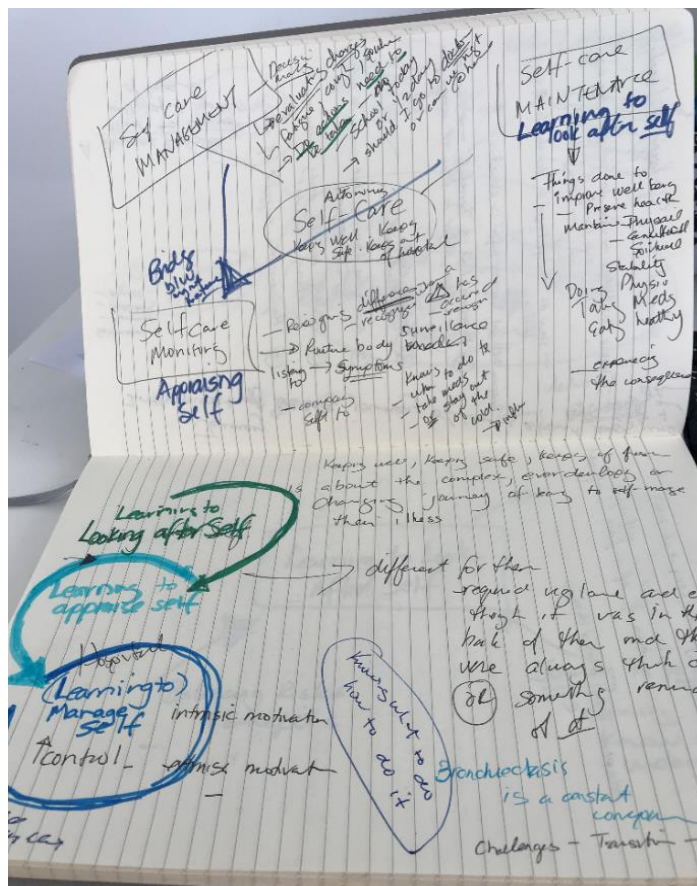
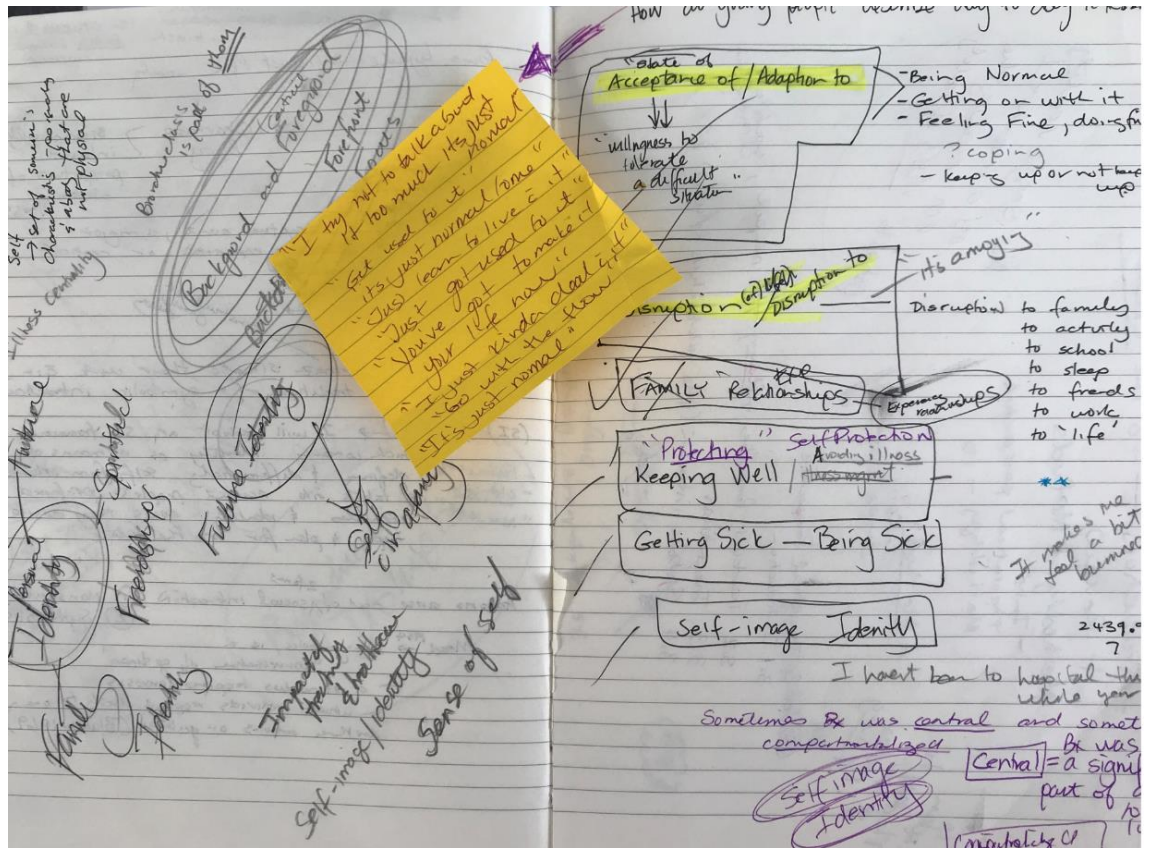
## Appendix P: Example of NVivo codes

**Nodes**

Name	Files	Refe
Acceptance of _Adaption to		1
Being 'normal'		7
Feeling fine. Doing fine		6
Getting on with it		6
Keeping up or not keeping up		3
Transition to adults		3
Disruption of _Disruption to		10
Disruption to family		2
Disruption to physical activity		10
Disruption to school		5
Disruption to sleep		3
Disruption to social & friends		7
Disruption to work		2
Missing out		11
Experiencing relationships		11
Future planning		1
Gettin sick _being sick		12
Chest Pain		2
Coughing		9
Diagnosis		4
Fatigue		14
Feeling 'sore'		4
Hospital experiences		10
Invisible illness		4
Knowing the signs		6
Sore Throat		5
Getting on with normal life		1
ITs annoying		1
Medications		5
Not knowing about bx		1
Physiotherapy		7
Quotable quotes		8
Self protection_ keeping well		12



## Appendix Q: Examples of theme development process.



# ① SORE & TIRED SYMPTOM EXPERIENCE

- i symptom of cough
  - it normal
  - trigger for dx
  - get sick
  - embarrassing
- ii symptom of soreness
- iii Noticing tiredness

How did participants come to know their symptoms & learn to interpret what those meant for them?

## FINDINGS - are these the actions taken along the journey?

### ② Pretty Normal An Almost Typical Life

- i It's just normal
- ii Close to normal
- iii It's just normal to me. Accepts

Coping  
- transition focus on  
iii needs to integrating into the context of individual life

Emotions Process  
Adjusting  
Integrating

Overlap's  
things  
develops strategies  
to be used

Integrates Bx into their day to day

### ③ Life Interrupted

- i School life interrupted
  - Daily tasks
  - Missing time
  - Coping strategies
- ii Social Life
- iii Sports & Leisure
- iv Family

### ④ Looking after Self

- ① how to keep well
- ② how to keep safe
- ③ how to know how to make choices help with