

**Supporting Chronic Cardiac Illness Self-management in Young People: How can we Optimise
Health Information Delivery in the Paediatric Cardiology Outpatient
Department**

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A thesis submitted to Auckland University of Technology in partial fulfilment of the requirements for
the degree of Master of Health Practice (MHPac)

Faculty of Health and Environmental Sciences

Auckland University of Technology

2022

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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 (except where explicitly defined in the acknowledgements), nor 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: 12th April 2022

Acknowledgements

I would like to acknowledge the following people for their substantial help and support during this project:

Julie Blamires for her support as my supervisor

Starship Foundation for awarding The Heather Forss Nurse Scholarship that enabled me to complete this project

Paediatric Cardiac and Congenital team for supporting and agreeing to be part of this project

Suzanne Hardy – The Wordarchitect for final editing of the document.

Abstract

Congenital heart disease is estimated to be the second most common chronic illness globally. In New Zealand it affects almost 500 babies every year. In addition, rates of acquired heart disease such as rheumatic heart disease are also high, predominately affecting Māori and Pacific Island populations, and those living in low socioeconomic areas of the North Island. Advances in surgical intervention and wrap around care has meant there is a growing population of young people and adults living with congenital and acquired heart disease. To ensure these individuals develop the ability to self-manage their chronic illness as they move through their cardiac journey, they must be provided with the knowledge and skills to do so. The aim of this project was to explore how healthcare providers from a paediatric cardiology outpatient department, prepare children and young people for self-management of their chronic illness.

Rosswurm and Larrabee's (2009) model of evidence-based practice change provided the framework for this project. Through observing healthcare professionals in the clinical setting and reviewing best evidence literature there were six key areas of cardiac health information that were identified and should be discussed at an outpatient clinic. They were recognised as being important in maximising health and well-being and supporting self-management in paediatric cardiology. The delivery of these should be multimodal, delivered in a developmentally appropriate manner and time, ensuring that the child, young person, and their family have understood and can build on the information delivered to them.

The project allowed the opportunity to reflect on our current practice of delivering health information to support self-management. Key recommendations were identified which included having a nurse specialist present in the outpatient clinic, consistent use of multimodal cardiac and health information strategies and the development of an interactive app or passport for cardiac children and families that incorporates the many facets of their cardiac journey.

It also highlighted potential research for the future that would explore the experiences of health education among children, young people with congenital and acquired heart disease and their families, as well as their perceptions of preparedness for self-management.

Chapter 1 – Introduction and Background

Congenital and acquired heart disease affects a growing number of children and young people both in New Zealand and globally. This practice project has been utilised to explore the topic: “Supporting chronic cardiac illness self-management in young people: how can we optimise health information delivery in the Paediatric Cardiology Department?” This chapter will provide background into the prevalence of congenital and acquired heart disease and highlight what clinicians need to consider to optimise long-term outcomes for this population. How the outpatient clinical setting provides a key area for addressing self-management skills and acknowledging health literacy, as an important aspect of how we can continue to improve health for children and young people with congenital and acquired heart disease in the longer term.

Paediatric Congenital Heart Disease globally and in New Zealand

Congenital Heart Disease (CHD) is estimated to be the second most prevalent chronic illness globally, with approximately 8 in every 1000 babies born with a heart or circulatory condition. Worldwide the incidence of CHD continues to increase and is described as the most common birth defect (Lotto et al., 2019; Lykkeberg et al., 2020; National Institute for Cardiovascular Outcomes Research, n.d.; Raissadati et al., 2020). In New Zealand, there are approximately 500 babies born per year with a cardiac diagnosis (Stats New Zealand, n.d.). Acquired heart disease such as Rheumatic Heart Disease (RHD), have the highest rates amongst indigenous and Pacific Island populations in both Australia and New Zealand. Other global areas that see a high incidence are Oceania, South Asia, and central Sub-Saharan Africa, however it is rarely seen in high income countries. In New Zealand RHD almost exclusively affects Māori and Pacific Island populations living in low socioeconomic areas in the North Island (Bennett et al., 2021).

Up until the mid-1950’s the chance of survival was low, depending on the severity of CHD. Significant advances in surgical approaches, anaesthesia and the ongoing care of the infant has increased survival not only through infancy but into childhood and beyond, with the majority reaching adulthood (Eagleson et al., 2020; Wu et al., 2020). Increases in incidence can be attributed to improved prenatal screening where identification of CHD ensures appropriate plans are put in place; for example, place of delivery, treatment options and appropriate interventions performed in a timely fashion (Larsen et al., 2017; Raissadati et al., 2020). Despite development in these areas, we have made little improvement in the prevention of

CHD. Wu et al. (2020), state that only 15% of infants born with a CHD have an identified known cause that has attributed to its development whilst in utero.

It is now estimated that 90% of children who undergo open heart surgery in the first year of life will be expected to live into adulthood (Lykkeberg et al., 2020; Moons et al., 2009). Subsequently, there has been a notable shift in attention being directed to long term holistic care of this population to ensure that all aspects of health and wellbeing are being met. Internationally it is recognised that lifelong specialised care that addresses quality of life, neurodevelopmental issues and psychosocial aspects is required (Diller et al., 2015; Eagleson et al., 2020; P Moons et al., 2021).

Congenital and Acquired Heart Disease – chronic illness

Internationally we are seeing an increase in the number of young people living with a chronic condition or with special needs (Gallo et al., 2021; Henry & Schor, 2015; Modi et al., 2012; Sattoe et al., 2015; Saxby et al., 2020; Williams-Reade et al., 2020). Chronic illness defined by Brown et al. (2007) is “a disease state that has symptoms with a protracted course and involvement of one or more body systems and may impair health status or psychological functioning that lasts longer than three months” (p. 3-4). There has been an increase in the prevalence of chronic conditions among children and young people over the last 20 years, with the United States of America having a 5% increase per year of children with medical complexity (Gallo et al., 2021). Often the medical complexity is accompanied by one or more other co-morbidities, such as developmental delay or intellectual disability (Williams-Reade et al., 2020). Chronic illness and the associated day-to-day management can have a profound effect on family functioning. The demands this poses for children and their families is complicated, time consuming and burdensome. The parent can feel a heightened sense of responsibility and protectiveness (Gallo et al., 2021; Williams-Reade et al., 2020). The child may perceive their illness as a threat and therefore downplay the severity so as not to be seen as a burden to the family. There is the need for emotional adjustment from both parents, siblings and the child affected. How the parent reacts to the illness can have a considerable impact on how the child does, affecting adherence behaviours and illness outcomes (Williams-Reade et al., 2020). If a family displays cohesiveness, adaptability, and supportiveness there is seen to be better adherence behaviours, and with a collaborative approach parents and children can experience a more seamless transition to self-management of their chronic illness (Brown et al., 2007; Modi et al., 2012; Williams-Reade et al., 2020).

CHD is one of the most common single organ malformations, with improved detection and overall management long term survival is good, however there is a risk of late morbidity (Erikssen et al., 2015; Larsen et al., 2017; Raissadati et al., 2020). CHD covers a broad spectrum of diagnoses that can be categorised into simple or complex: Table 1 demonstrates the differentiation of these heart conditions as identified by Erikssen et al. (2015). However, even within each of these categories there needs to be acknowledgement that there can be a range of severity. Regardless of whether the diagnosis is simple or complex, infants, children and young people should have lifelong cardiology follow-up. Assessing and monitoring exercise tolerance and capacity, symptoms, weight, and growth trajectory, as well as neurodevelopment, is vital for maintaining health and wellbeing (Boyle et al., 2015; Lykkeberg et al., 2020; Wernovsky et al., 2017). There are known associated risks of late morbidity after congenital heart surgery in infancy. These co-morbidities include valvular disease, myocardial dysfunction, arrhythmias and, coronary artery disease (Diller et al., 2015; Erikssen et al., 2015; Fernandes et al., 2011; Lykkeberg et al., 2020; Moons et al., 2009; Wernovsky et al., 2017). The frequency of follow-up for children and adolescents with CHD will vary depending on the type of CHD they have. The complexity of the heart defect will also determine who would ideally be the lead clinician: paediatrician or specialist cardiologist (Diller et al., 2015; Lykkeberg et al., 2020; Moons et al., 2009). The Cardiac Society of Australia and New Zealand – Standards of Practice Position Statement provides guidance for clinicians who do not have the expertise to care for infants and children with heart problems (The Cardiac Society of Australia and New Zealand, 2016). In New Zealand, most children with congenital and acquired heart disease will be followed by a Paediatric Cardiologist and the guidelines for frequency and standard investigations have been outlined in the Starship Clinical Guideline – Follow-up after cardiac surgery (Stirling, 2019).

TABLE 1. Criteria of heart condition - diagnosis hierarchy

COMPLEX	
1	Univentricular hearts (UVH)
2	Truncus arteriosus communis (TAC)
3	Interrupted or hypoplastic aortic arch (I/HAA)
4	Transposition of the great arteries (TGA)
5	Atrioventricular septal defect (AVSD)
6	Total anomalous pulmonary venous drainage (TAPVD)
7	Pulmonary atresia (PA)
8	Tetralogy of Fallot (TOF)
SIMPLE	
9	Ventricular septal defect (VSD)
10	Coarctation of the aorta (COA)
11	Aortic stenosis (AS)
12	Pulmonary stenosis (PS)
13	Mitral valve defect (MV)
14	Partial anomalous pulmonary venous drainage (PAPVD)
15	Atrial septal defect (ASD)
16	Patent ductus arteriosus (PDA)
17	Other (MISC)

(Referenced and adapted from Erikssen et al.,2015)

Self-Management

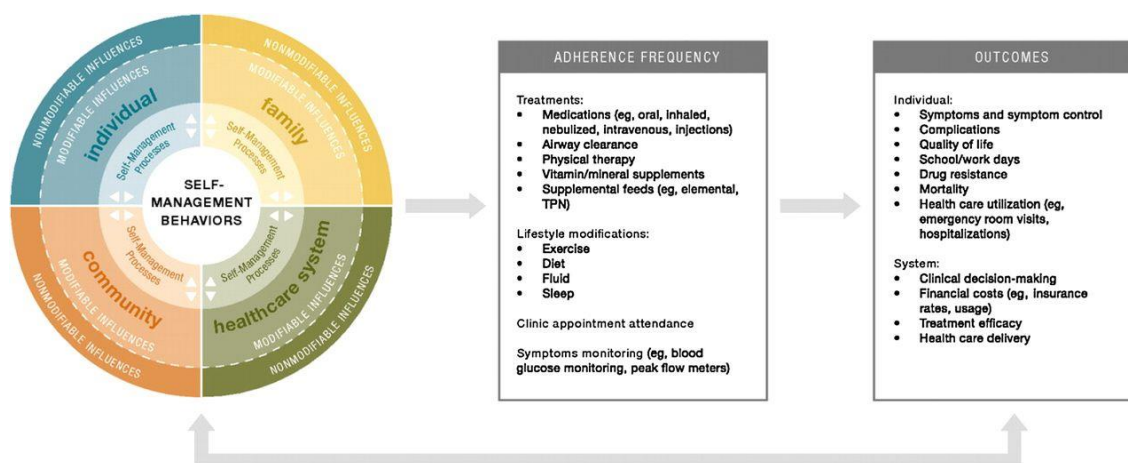
With the increasing number of young people living with chronic illness the focus is beginning to shift from short term outcomes to long term clinical and quality of life outcomes (Basken & Acosta, 2021). With this shift, families, children and young people are all increasingly becoming responsible for these outcomes in the community in partnership with health care providers (Basken & Acosta, 2021). As a result, the role of the physician is not only of diagnosing and treating acute illness but also working collaboratively with patients and their families to manage chronic illnesses and optimise quality of life and health outcomes (Lorig & Holman 2003).

According to Lorig & Holman (2003), self-management, as a recognised conceptual care model, was first described in the 1960's by the author, Thomas Creer, in his book, "Rehabilitation of chronically ill children." The issue of self-management was raised as being notably important for those with chronic disease, where the person alone was responsible for his or her day-to-day care over the length of the illness. For those with chronic conditions, self-management is a lifetime task aiming to keep wellness in the foreground. Supporting the development of self-management behaviours for an individual with a chronic illness, such as adherence to treatment plans, attending appointments and building their capacity to navigate challenges and solve problems will improve health outcomes (Lozano & Houtrow, 2018). Adopting good

self-management behaviours will reduce hospitalisation and utilisation of healthcare, thus reducing costs (Henry & Schor, 2015; Marcus, 2014; Modi et al., 2012). Sattoe et al. (2015), defined self-management as “The individual’s ability to manage the symptoms and consequences of living with a chronic condition, including treatment, physical, social and lifestyle changes. In conjunction with family, community, and health professionals” (p. 705).

According to Henry and Schor (2015), models used in adult self-management have been around for several years, though they tended to be more generic in nature, addressing a wide range of conditions. The focus of these models is on learning management skills for their disease, as well as focusing on goal setting, action planning and symptom management. Research has shown these models to be effective in optimising health outcomes, however they are not so easily transferable to paediatrics (Bodenheimer et al., 2002; Henry & Schor, 2015; Modi et al., 2012). There are however, certain areas that overlap and can be applied to paediatric care; these include aspects of daily life such as medical, role and emotional management. This supporting knowledge and skill acquisition helps develop confidence to be involved in their own health care. Recognising and incorporating the important role of the parent/caregiver and the development stages of youth overtime, are key to ensuring optimal health outcomes for children and young people (Henry & Schor, 2015; Lozano & Houtrow, 2018; Sattoe et al., 2015).

Figure 1 – Paediatric self-management model – Modi et al. (2012)



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Self-management concepts in paediatrics' – “The significance of promoting self-management and understanding its impact on health and wellbeing is becoming increasingly important in paediatrics'.” Modi et al. (2012) acknowledged that self-managing paediatric chronic conditions can be challenging for all involved, and research in paediatric conditions

shows a high occurrence of poor self-management and non-adherence. They noted that there was a lack of self-management models for children integrated into the health system. They set out to design a model that recognises what is unique in the paediatric population and adapt what works well in the adult models. They created a conceptual framework for paediatric self-management (see Figure 1) with four main identified domains: individual, family, community, and the health care system. Within each of these domains there are areas that are non-modifiable, for example, age, gender, family structure, cognitive functioning, neighbourhood and access to health care. However, there are also modifiable tasks that the individual, the parent, or health professional may be able to make to enhance self-management skills. Examples of these may include disease treatment and knowledge, health beliefs and perceptions, family functioning and coping styles, social networks and patient-provider communication (Modi et al., 2012).

Lozano and Houtrow (2018) viewed self-management differently describing them in the paediatric setting to be more one of shared management. This is reflective of the role that a parent or caregiver has in the ongoing care of a child and young person with a chronic illness. They acknowledged key differences between adults and paediatrics; firstly the child and young person is dependent on another individual for some if not all their care, where as an adult is autonomous and independent. Cognitive, motor, language, social and emotional development comes in different stages and times for children and young people, and therefore paediatric models need to consider this fluidity and be adaptable for it. Lastly, the vast diversity of diagnoses in children mean that often they are cared for by a specialist team in tertiary centres. Adapting self-management support to reflect the development trajectory of the child and family from child to young person and thereafter into adolescence is also vital. Henry and Schor (2015) described there being at least 3 participants to consider when supporting self-management, they are: the health provider, the parent, and the child. They found that the provision of self-management anecdotally had been a one-off event, and they strongly suggested that in fact it should be an ongoing process that evolves through the course of the child and family's journey, utilising multimodal approaches.

Responsibilities of developing and supporting skill acquisition for self-management is spread across a multi-disciplinary team, which includes nursing. Working in partnership with parents and incorporating the child and young person's view of health and illness gives scope for greater participation in the development of self-management, leading to better engagement in ensuring their own health needs are met (Basken & Acosta, 2021; Henry & Schor, 2015; Lima

et al., 2017; Lorig & Holman, 2003; Lozano & Houtrow, 2018; Marcus, 2014; Modi et al., 2012; Sattoe et al., 2015).

Health Literacy

To optimise health outcomes and improve quality of life for young people and their families who have a chronic illness, clinicians need to understand the effect of health literacy, including how to identify health literacy in their patients, and how to promote/develop it for them (Estacio et al., 2020; Lambert & Keogh, 2014a). Health literacy, according to Meyers et al. (2019) is “the degree to which individuals have the capacity to obtain, process and understand health information and services needed to make appropriate health decisions” (p. 24). In addition to the above definition, Estacio et al. (2020) discuss the importance of skills, abilities and resources that people need to access to make informed decisions about their health and well-being.

Health literacy encompasses more than just the ability to read and write. Understanding numeracy, developing critical thinking and problem-solving skills as well as the ability to make decisions, seek information and effectively communicate with healthcare providers, are skills that parents, caregivers and children need to foster to improve quality of life and enhance their health outcomes (Lambert & Keogh, 2014a). As health care professionals we should view health literacy as something to be developed, rather than looking at it as something lacking. Modifying how we interact with families and children, we can promote health literacy and build families’ capacities, so they can effectively build trusting relationships, enabling them to seek timely and reliable health information (Estacio et al., 2020; Lambert & Keogh, 2014a).

Lambert and Keogh (2014a), claim that health literacy is not just a minority problem; in Europe it is estimated that every second person is affected by poor health literacy in some way. It is not isolated to race, gender, income, or education level. Even the most literate of people can be challenged when having to read and understand medical information and make decisions to improve the health of their child or young person (Marcus, 2014). It is important not to isolate or shield children from healthcare but support them to achieve independence with their chronic healthcare needs, scaffolding toward self-management. It is vital then, that as nurses, we recognise what level of health literacy parents have. Low health literacy is often synonymous with poor parenting behaviours, where medication errors are more likely to occur, and preventative health care is less likely to be undertaken (Lima et al., 2017; Sanders et al., 2009). Encouraging children to be active and present early in their health journey can have

positive outcomes, with them being more engaged with their health. They are more likely to have developed meaningful relationships with healthcare professionals and have the skills to make sound decisions that will improve their health outcomes (Henry & Schor, 2015; Lambert & Keogh, 2014a; Modi et al., 2012).

Many factors can influence how much a child is involved in healthcare discussions and decision-making opportunities. The developmental stage of the child, level of maturity, attitudes and beliefs of both parents and health care providers can affect how we interact with children in the health care setting (Boyle et al., 2015; Koller, 2016; Saxby et al., 2020). As nurses working with children with chronic illness, such as congenital and acquired heart disease, we can empower them to work in partnership with their parents and other clinicians to use and build on their current knowledge, and also acquire the skills to become more active in their care and management. Not imposing an age limit of when nurses and healthcare professionals should actively involve children will offer opportunities to enhance their understanding and competency (Koller, 2016; Lambert & Keogh, 2014b).

Assessing health knowledge and literacy – The challenge that nurses and other health clinicians face is how do we know that a parent or child has understood what has been explained to them. It is easy for us to assume that we have described it in a way they are able to comprehend and therefore make informed decisions about their health. There are tools to assess health literacy, but these are infrequently used in the clinical setting; often used more in the realm of research (Lambert & Keogh, 2014b). However, there are two recognised methods that we could adopt in our daily practice to check in and ensure what we have taught has been understood. The teach back method or the Ask Me 3™ are two such initiatives that have been adopted in New Zealand by the Health Quality and Safety Commission New Zealand. The teach back method uses open ended questions that encourage parents and young people to reframe what has been said to show understanding in a non-judgemental way (Sawin et al., 2017). It is recognised that parents and young people often feel shame and stigma when suffering from a chronic illness, so when coupled with inadequate health literacy, this can present a barrier to accessing healthcare in a timely manner when faced with a crisis (Manganello et al., 2015). The Ask Me 3™ method was developed by the Institute for Healthcare Improvement, Boston. They focus on safety and quality, striving to advance and sustain better outcomes in the health setting. The three questions for which the programme gets its name, are designed to promote effective communication between healthcare providers and patients. The three questions are: what is my main problem? What do I need to do? Why is it important for me to do this? (Institute for Health Care Improvement, n.d.; Lambert & Keogh, 2014b). The patient should be

encouraged to ask questions and the clinicians should ensure that they are answered and understood by the patient (Health Quality and Safety Commission New Zealand, n.d.; Institute for Health Care Improvement, n.d.; Marcus, 2014).

Acknowledging the importance of health literacy and the role it has in self-management ensures that we promote it more consciously when interacting with parents and young people. Nurses play a critical role in both providing opportunities to improve health literacy and teaching aspects of self-management of chronic illness and we should take each health encounter as an opportunity (Estacio et al., 2020; Lambert & Keogh, 2014b). Recognising that during an acute presentation or crisis the ability for a parent or young person to be receptive and retain information is limited. However, outpatient clinics could provide an ideal setting for assessing health literacy skills, exposing, and educating them to self-management, and to get feedback from the parents and young person on their level of understanding (Bruce et al., 2014; Henry & Schor, 2015; Lozano & Houtrow, 2018). Having this embedded in outpatient practice allows for consistent exposure to health care information, as the young person moves through their journey to transition. They will have a good understanding of their health condition, established preventative measures and sound relationships with healthcare providers that will optimise their health outcomes.

Paediatric Cardiac and Congenital Service – Starship Children’s Hospital

The Paediatric Cardiac and Congenital Service (PCCS) provides cardiology and cardiac care for New Zealand and parts of the Pacific Basin. It encompasses the infant, child or young person and their family, from cardiac fetal life to adolescent transition, as well as Adult Congenital (those born with a cardiac defect who have reached adulthood). The service cares for congenital and acquired heart disease and the team is made up of multiple health professionals. Together we are striving to provide quality care to this growing population both as inpatients and outpatients. The outpatient department is physically near the children’s heart ward and is focused on providing ongoing assessment and follow-up. As a national service, outpatient clinics are provided regionally, where the cardiologist travels and works in collaboration with local paediatricians to provide care for our children and young people (Starship Child Health, n.d.).

My role in the PCCS team as a cardiac nurse specialist (CNS) is to work collaboratively with families and the wider multidisciplinary team to optimise quality of life and mitigate life threatening events; this provides an overview and coordination of care, education and

management of variances from expected cardiac pathways. Working alongside the family helps them to navigate their child's journey through the PCCS service. One of the areas that our team of nurse specialists have a crucial role in is the outpatient department (PCCS Nurse Specialist, 2019).

PCCS Outpatient Department – The outpatient department provides a platform for parents, caregivers, and young people to interact with clinicians about their cardiac condition, current state, and what ongoing investigations are required to monitor their child. It is also the perfect opportunity to provide education to young people and their families, preparing them for what the future may look like. Offering accurate and timely education and information will support parents from early in the child's journey to make informed decisions, foster sharing of information with the child and enable them to work in partnership with health care providers to promote self-management (Marcus, 2014; Wernovsky et al., 2006).

Why this practice question?

Children and young people with congenital or acquired heart disease are living longer and as healthcare professionals we need to set them up to succeed in being able to manage their condition as independently as possible. All the while, ensuring that we optimise health outcomes and improve their well-being. Understanding the skills required to self-manage their chronic illness and how we can collaboratively work with them from an early age to acquire these is imperative. Given the importance of developing and ensuring self-management capacity among children and young people with congenital and acquired heart disease, the cardiac service aims to provide an environment where they can acquire the skills in a safe and supportive location, with the right people.

Currently we do not know if we are providing the best level of education and support for children and young people to develop self-management of their congenital or acquired heart disease. Rosswurm and Larrabee's framework (2009), will be used to guide a research-based approach to addressing this question (Melnik & Fineout-Overholt, 2015). The project aims to explore how healthcare providers currently prepare young persons for self-management of their chronic illness, within the paediatric cardiology outpatient department. Several questions underpin this proposed project; observation of how health information is given, what is the information that is shared and does the age of the child influence how healthcare providers engage with them. The outcomes of this evidence-based approach could attribute to better health outcomes for New Zealand's cardiac children.

Chapter 2 – Methodology/Framework

This chapter will explore how my role as a Cardiac Nurse Specialist (CNS) led me to want to understand how and what information was shared in the outpatient setting and if it was meeting the needs of our children and young people to develop skills for self-management of their chronic cardiac illness. I will discuss the rationale for selecting Rosswurm and Larrabee's (2009), (Melnyk & Fineout-Overholt, 2015) model of evidence-based practice change, outlining the steps undertaken as part of this project.

Personal position statement and identifying the project

A role that I have with in the PCCS wider team is as a member of the outpatient quality hub. A responsibility of the outpatient quality hub is to routinely review how the outpatient department is working, and what can we do better. This is based on feedback from the clinicians involved and surveying families on a yearly basis. The quality team also reflects on key performance indicators and presents on a yearly basis at the quarterly PCCS Quality and Improvement meetings. Additionally, in the last 2 years the cardiac nurse specialist team undertook a review of the role of the nurse specialist within PCCS; an aspect of this is our contribution to the outpatient department. We found that there was potential to widen our scope of practice and have a more active presence in clinic appointments to improve aspects of health outcomes for our children and young people. While reflecting on the notion of expanding our practice role I begun to question: are we providing excellent care in this space, is the health information that we give helping to set our children and young people up to succeed in self-management of their chronic illness, or can we do better?

Initially, I discussed my project idea with the nurse unit manager (NUM) and the outpatient department quality hub senior medical officer (SMO), exploring different iterations of the focus question, eventually settling with: "How and what is the best way to deliver health information to children, young people, parents and caregivers in the PCCS outpatient setting, to support developing self-management of their chronic illness." Within the clinical team and based on anecdotal evidence there was a belief that clinicians were providing information to children and their families all the time during clinic appointments, but to my knowledge this had never been formally reviewed. We didn't really know as a team what and how we were providing, in terms of information and education, and nor whether this was meeting the needs of our population, ensuring health equity, enhancing health literacy, and ultimately improving health outcomes through the life span.

Project framework

The model utilised for this project was the Rosswurm and Larrabee's (2009), revised version; 'A model of evidence-based practice change' (Melnik & Fineout-Overholt, 2015). This model fits with the aims of the project, which seeks to explore the possible need for change in how and what health care information we deliver and seeks to answer the following questions: Are we meeting the needs of our population to support self-management of chronic illness? Does current practice reflect existing research or is there a need to change? The model presents an opportunity to compare what is currently known, design a practice change, or enhance practice delivery by following the six key steps methodically:

1. Step 1: Assess the need for change
2. Step 2: Locate the best evidence
3. Step 3: Critically analyse the evidence
4. Step 4: Design practice change
5. Step 5: Implement and evaluate change in practice
6. Step 6: Integrate and maintain change in practice

(Rosswurm & Larrabee 2009, revised Model of evidence-based practice change, Melnik & Fineout-Overholt, 2015. p.286)

Although there are six steps within this model, only the first three were undertaken as part of this project. In the following section I outline the steps in the framework and what I planned to do within each of those steps. Chapter 3 will present the results of those steps.

Step 1 – Assess the Need for Change in Practice

This step entails assessing the need for change or identifying an opportunity for practice improvement. This involves engaging with stakeholders, collecting internal data about current practice, and gathering external data.

Stakeholders – For this activity I planned to identify the key stakeholders that would be integral to the practice project. Engaging with them and sharing the aims of the project, their involvement and what the likely benefits would be was necessary to establish buy-in. Involving stakeholders from the outset of any change process is vital in ensuring that any change is embraced and embedded into practice. Establishing relationships early in the process facilitates active engagement and willingness to share and explore potential practice change

(Campbell, 2020). I did this in a variety of ways, through stakeholder meetings, email correspondence and presentations. This will be described in further detail in Chapter 3.

Collecting internal data – To help identify if a practice change was needed, it was necessary for me to gather internal data that was pertinent to the project question, “What and how does the PCCS health care team deliver health information in the paediatric outpatient to support the development of self-management skills for children and young people with cardiac disease?” To obtain this information, I recognised that one useful and practical way to gather this data would be to observe clinicians in the outpatient clinic, engaging with children, young people, and families during their usual appointment. Observational methods to collect data are considered useful for understanding what people do, including their roles, actions, and behaviour in a natural setting (Fetters & Rubinstein, 2019; Walshe et al., 2012). In this case, observation of clinic interactions was thought to be a valuable way for me to observe educational moments in action within the clinic consultation. In addition to observing clinic interactions, I planned to include an environmental audit where I would explore the outpatients’ physical space to observe where sharing health information occurred.

Collecting external data – For this sub-activity within step 1, I planned to compare PCCS to other external clinical areas that were similar, to help identify the need for practice change. To do this I identified other areas within paediatrics where children and young people had similar chronic health conditions that required lifelong care. Although there were many clinical areas to choose from it was decided that diabetes and cystic fibrosis clinics were the most appropriate, given the lifelong and complex nature of these conditions. I planned to observe the clinicians in their outpatient setting, gather information on how they engaged with children, young people and their families to deliver health information. The intention of this step was to draw comparisons between current practice in PCCS and these other areas to determine if there were different and/or better ways in which we could deliver health information.

I also planned to gather information via email from three overseas paediatric cardiac centres to ascertain information about their outpatient clinic practices regarding health information sharing, including how they utilise the role of the CNS.

Identifying the problem and linking the problem, intervention, and outcome – This sub-activity of identifying the problem and linking to an intervention and outcome is the most challenging part of this framework for my practice project. This activity is when the team

identify a practice problem or opportunity to improve; this is based on the stakeholder engagement and the collection of internal and external data already undertaken in step 1 (Melnik & Fineout-Overholt, 2015). Although I was unable to identify the problem and intervention at this stage, once I had undertaken steps 2 and 3 of the model, by locating best evidence and critically analysing the data, I was able to identify areas for improvement. In Chapter 6, I will provide key recommendations in detail, including future directions for potential research to gather qualitative data about the experiences of children, young people and families with congenital heart disease and the clinicians that care for them.

Step 2 and 3 – Locating and critically analysing the best evidence

These steps of the revised Rosswurm and Larrabee model (2009) (Melnik & Fineout-Overholt, 2015) are utilised to locate the best evidence related to the project question. For this I planned to utilise data-bases such as Cinhal Complete (via EBSCO), Joanna Briggs Institute EBP (OVID), Ovid database and Google Scholar to perform a comprehensive review of the literature pertinent to the question identified. Once collated, reviewed, and appraised I planned to synthesise the literature and identify key themes related to the question. Chapter 4 will present the literature review and the themes developed that were relevant to this practice project.

Step 4, 5 and 6 – Design practice, implementation, and integration

Given the importance and key goal of this project to understand what and how information was delivered by health care professionals in the outpatients setting and due to the complexity and time requirements to collate this internal and external data, steps 4, 5 and 6 were not undertaken as part of this project. However, I did identify three key recommendations that with time can be further developed and implemented to make positive change. I was also able to identify potential research projects that could provide valuable insight into the experiences of children, young people and their families with congenital and acquired heart disease and also the healthcare workers that provide the care - these will be presented in Chapter 6.

Ethics consideration

The Paediatric Cardiac and Congenital service undertakes quality improvement projects routinely. PCCS outpatients, is a quality hub that presents outcomes yearly at a Quality Forum. Although this practice project is not currently part of this review it is necessary to evaluate

how and what information clinicians provide in the setting of outpatients to ensure it fits with evidence-based practice and is attributing to better health outcomes for our children and young people, therefore ethics approval was not required.

Approval from the lead clinician of the Outpatient Quality Hub, clinical director of PCCS and the nurse unit manager, was sought to ensure that the practice project aligned with the strategic plan of PCCS. Approval was sought from the appropriate senior leadership teams of the areas outside of PCCS that was observed as part of the project.

Clinicians in the outpatient departments were given an information pack about the proposed review and permission was sought from those involved in the observations. Families whose clinic appointment was identified as an observation opportunity were also provided with information and given the opportunity to decline. There was no collection of personal health data, or collection of human tissue, therefore there was no requirement for HCED review. Additionally, no personal staff data was included, and no HRC funding was required, an AUTC review is therefore not required.

Chapter 3 Results

Step 1 of Rosswurm and Larrabee's model 2009, is to assess the need for practice change (Melnik & Fineout-Overholt, 2015). I utilised this step to explore if a practice change or opportunity for improvement on "how and what health information we deliver to children and young people in the outpatient setting to support developing self-management of their chronic illness." This chapter will present the results of the activities undertaken in this step, with a particular focus on the collecting of internal data to identify if there were opportunities where a practice change could improve well-being and health outcomes for the population.

Step 1 - Assessing the need for change in practice

The first step in the model consists of a series of points that assess the need for practice change:

- Include/engage stakeholders
- Collect internal data about current practice
- Compare external with internal data
- Identify the problem
- Link the problem, interventions, and outcomes

The outcomes and details of these activities will be described as they form the basis for this project and inform the recommendations and proposed practice change.

[Include stakeholders/engage stakeholders](#) – As discussed in the previous chapter, I initially talked with my direct manager the NUM and the quality lead for outpatients to help develop and outline the question. I engaged with the wider senior leadership team of PCCS by firstly introducing my practice project idea to our clinical director, NUM, quality hub lead SMO and the Director of Nursing, Starship Children's Hospital. Once there was consensus that the project aligned with service quality improvement objectives, I needed to get buy-in from the wider PCCS clinical team who would be involved in clinic appointments. Their understanding of the rationale and the support that they would provide was crucial to the project's success. To do this, I initially utilised the opportunity to attend the SMO biweekly meeting and present the project idea. I then presented at the outpatient quality hub presentation at the Quality Forum in March 2021 to outline my project, what I was hoping to achieve and what their role was in the collecting of information, which involved the wider clinical and non-clinical team. Those that were present were: Fellows, Registrars, Nurse Practitioners, Nurse Specialists, Nursing

staff and administrative support staff, including the receptionist/scheduler for the outpatient clinic.

I formally invited them to participate in being observed during a consultation with our children and families in our cardiology outpatient department. I explained that I was looking at how we deliver health information and the different modalities we use to provide this. I explained that in addition to focusing on *how* we deliver information, I was also going to be listening for *what* information is shared during the consultation. The intention was not to focus on one particular group of clinicians but to observe different clinicians whom may be involved in the clinic setting. I spent time reassuring the staff and explaining that I anticipated the project would have little, to no impact on their daily work, and that the observations would be incorporated into the daily running of a normal outpatient clinic. I was clear that there would be no personal identifiable information included in the final presentation of the project, ensuring I maintained their privacy and the privacy of the patients and families. In addition, I clearly articulated that participating in this project (and thus being observed in practice) was entirely voluntary and that if they did not wish to participate this was entirely their choice and right.

I recognised that by identifying stakeholders and presenting the purpose of the study to them, what the benefits are and how they may be involved would facilitate more buy-in. Involving key stakeholders from the outset of a project is important, especially if a need for change is identified, then their support and commitment to implementation is stronger. Establishing the relationships early in the process helps to facilitate active engagement, a willingness to share and explore potential practice changes (Campbell, 2020)

[Collecting internal data about current practice](#) – The intention of this activity is to collect internal data about the current practice that is pertinent to the clinical problem/question. I was interested in finding out how and what information and/or education is provided in the outpatient setting to support children and young people to develop skills for self-management of their chronic illness. As this is an area that hasn't been explored before in PCCS it was to be the most important and detailed part of this project. Three activities were undertaken to gather the data to describe current practice:

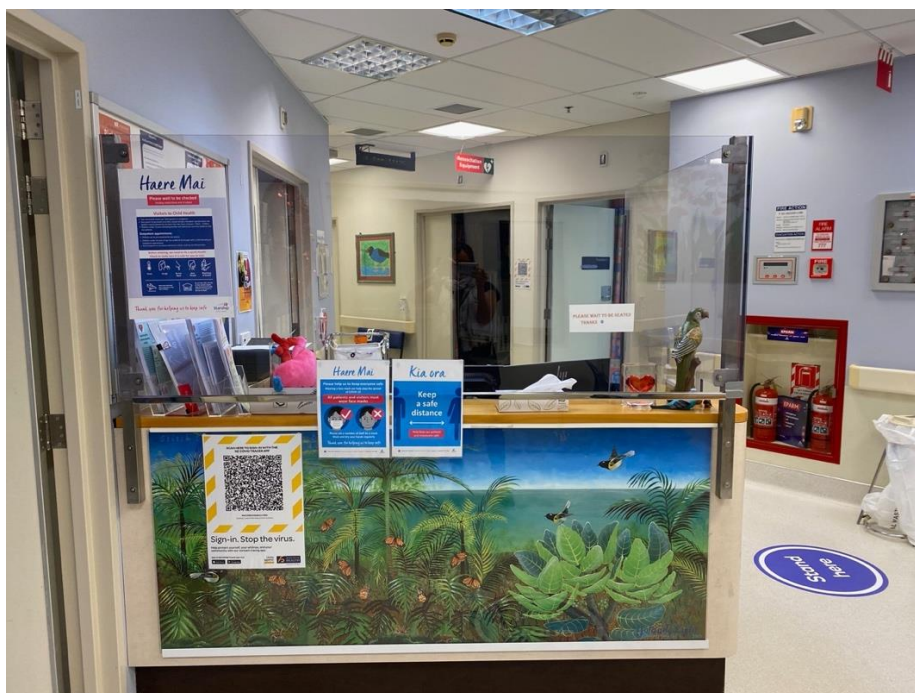
1. Taking in the scene – observing the environment
2. Observing current practice in the PCCS outpatient clinic
3. Observing current practice in at least one other chronic care outpatient setting

Each of these planned activities will be described

Activity 1 – Taking in the scene, painting a picture of the PCCS outpatient area and its function

Spaces and places – Firstly, I started by observing the department and tried to envision it through the eyes of a child and visiting families. The intention of taking in the scene, was to provide detail about the context of the journey that they undertake each time they come into clinic. As I observed the clinical spaces, I kept asking myself if there were identifiable opportunities to provide additional educational strategies or materials that could enhance a child's prospect to attain more knowledge about their condition.

The children's outpatient clinic is an area attached to the main children's heart ward at Starship Children's Hospital, Auckland, New Zealand. It is comprised of a waiting area for children and families, served by a main reception area with one receptionist. Prior to Covid-19 the outpatient department had a play area for young children, books for reading and distraction, and toys to play with which was therapeutic for them. These have since been removed, creating a space that is not as child-friendly. However, there are still televisions in both the main reception and in the echocardiogram rooms to keep them distracted. The reception desk, as you can see in the photo (picture 1), has a plastic screen in place to protect our clinic administrator, which has created a barrier between the staff and families, children and young people. When observing our administration person when families arrive, she warmly greets them making them feel welcome despite the plastic barrier. There are pictures at child height and also on the walls that do keep child-friendly aspects going.



Picture 1 - Main reception of PCCS outpatient clinic – where the receptionist will greet children, young people and their families



Picture 2 - Main waiting area of the PCCS outpatient clinic

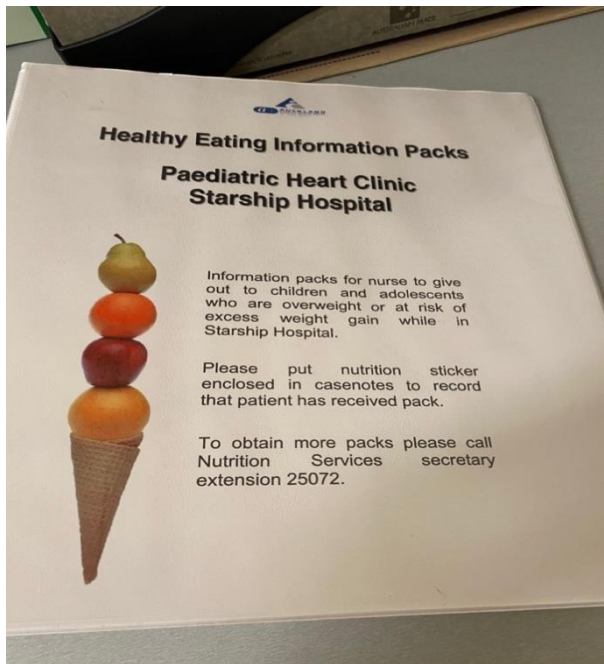
There are 3 main clinic rooms where consultations take place: a clinic room for the designated clinic nurse to perform observations, height and weight, a designated room for the electrophysiologist to do electrocardiograms (ECG) and three further echocardiogram rooms, where children have their heart scans.

On the wall at the entrance to the clinic there is a pamphlet stand which contains “Welcome to Auckland District Health Board – Your Rights,” in six different languages. Also, “Health and Disability – Consumer Rights,” as well as Heart Kids Information pamphlets about the role of the charity that provides support to families and children during their heart journey. There are also pamphlets on childhood immunisations and a small selection of commonly used medication for heart children, which are only available in English (picture 3).

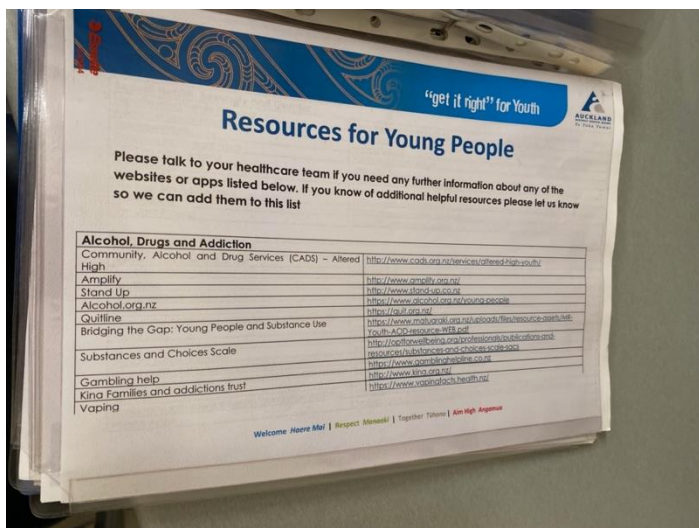


Picture 3 – pamphlets available at the main reception

Each consultation room has a computer, which gives the clinician access to the child's health record. There is a folder of heart diagrams, information on healthy eating, mental health for adolescents and young adults, as well as other supportive material for adolescents for guiding the transition to adult services. When exploring the value of these materials I found the heart pictures were all from the same reputable source, which is accessible from heartpassport.com subscription but there wasn't consistency with what was available. Additionally, information about some very common heart defects was missing. The Healthy Eating folder which is supplied by the Nutrition Department at Auckland District Health Board has not been updated since 2008 (picture 4). It does include generic pamphlets on making good food choices, but not specific to age or ethnicity. A folder for our young people and older adolescents (picture 5) on caring for their mental health has good resources to help clinicians support them if there are concerns identified about their mental health during the consultation. The information in this folder also provides supportive material for older adolescents in their transition to adult services, this has been developed by the Youth Health Hub (Auckland District Health Board, n.d.).



Picture 4 - Healthy Eating folders provided by the Nutrition Department at Auckland District Health Board



Picture 5 - One of the pages in the Youth Health Information folder in the clinic room, Youth Health Hub

The designated clinical room (picture 6) for the nurse to perform height and weight, observations and other procedures does not have visible health information for families. It presents as a very clinical room with only a small selection of child friendly posters on the wall to help with distraction.



Picture 6 – Designated clinic room for clinical observations, height and weight

Structure and timing of clinics – PCCS outpatient clinics run Monday to Friday; each SMO has a designated clinic day and rotates through a day stay clinic on Monday and Friday morning. On average there would be 77 clinic slots per week, not including the day stay. SMO's have between 11 and 14 patients per clinic, with approximately two new patient referrals and nine follow up appointments. Paediatric clinics are run in the afternoon, with the first clinic appointment at 11:30am. Each appointment would be between 2-3 hours in duration; families are warned about this in their clinic letter. The reason for the length of the appointment is that it depends on the tests required, as they are all performed at the same time. As a minimum, a child or young person will have the following tests: observations – heart rate, blood pressure, oxygen saturation, respiratory rate and, temperature. They will be weighed, their height measured, and an ECG done. Most will have an echocardiogram, which can take between 20-30 minutes and performed by one of our technicians. The child and young person will then be reviewed by either our designated paediatric registrar or cardiology fellow, who will consult with the designated SMO. The SMO may or may not see the child or young person; this is a clinical decision made at the time of the consultation.

Activity 2 – Observing current practice in PCCS outpatients

Methodology – To get an understanding of what health information was shared in the setting of our cardiology outpatient clinics I planned to observe interactions between various clinicians and children and their families attending the outpatient clinic. As a nurse specialist I had spent time intermittently in consultations with families and had an inclination of what was typically discussed. For the most part these interactions would be focussed on symptom and diagnosis, as well as occasionally preventative health information, for example, endocarditis prevention. I wanted to become more immersed in the consultation, to hear what was discussed and then compare 'our' practice to what the literature described as best practice, in relation to how and what information is best shared to support self-management skills.

Observing clinical practice and/or patient clinician observations as a methodology, is thought to provide the researcher with accurate, thorough, and factual descriptions of what is observed in the natural setting (Salmon, 2015). The benefits of observing these encounters in a natural setting are that they give important insight and provide opportunities to understand and capture information in the context of the interaction first-hand (Fetters & Rubinstein, 2019). The intention of observing the interactions directly was to enable me to see things that may have been missed, if I were to use other methodologies such as interviews or review of a written clinic letter. It also had the advantage of seeing what was happening in real time, hearing the verbal and watching the non-verbal interactions between clinicians, children and families, rather than relying on self-reporting (Casey, 2004; Fetters & Rubinstein, 2019; Salmon, 2015).

As a nurse specialist in the PCCS team I already have a role within the outpatient department, providing a consistent point of contact for families and a seamless link back to the community. However, for the purpose of this project I became the complete observer. By allowing myself to step back completely from my current role and take an observer role I was able to give myself the opportunity to be completely immersed, the benefit of which has been addressed in the previous paragraph. It does come with drawbacks too, Coker et al. (2013) and Fetters & Rubinstein (2019), discuss the 'observer effect,' or observational bias where healthcare workers may alter their behaviour when they are aware of the presence of the observer. I needed to consider how this may impact on the findings, which will be discussed in more detail later in the chapter. I also needed to be mindful of situations that would be deemed unsafe and how my code of professional conduct would influence my need to intervene (Casey, 2004; Coker et al., 2013).

Participant consent – Participants for this observational study were clinicians and included: registrars, cardiology fellows, nurse specialists, nurse practitioners, registered nurses and senior medical officers. Information about the project was provided to the clinical and clerical team members within the service in meetings, as outlined in the engaging with stakeholders' section. In addition, I offered a specific detailed information sheet for clinicians who were to be involved, and thus observed in clinics during the observation periods. This letter provided details of the project, what their role was and a space to sign consent, they were also made aware that I may be present at any of their subsequent clinics. All clinicians, including those that were assigned to cover the cardiac clinic were willing to participate and they all signed consent forms (See Appendix 1).

Families were not being actively observed or interviewed as part of this project; however, I would introduce myself, my role and what the purpose of the project was. An information sheet for families that provided further details about the project was provided (See Appendix 2). As part of this information, it was important that I advised both the clinician and/or family that they were in no way obligated to participate in the observation and if they chose not to it would not affect their outpatient appointment or experience.

Method – I planned to take an unstructured approach to gathering data from the observation moments. Being unstructured allowed me, the researcher, to have more creativity and to consider the complexity of each situation on its individual merits. One of the greatest strengths of an unstructured approach is that there is an open-endedness of the observations (Fetters & Rubinstein, 2019), where there is minimal control, and the researcher can capture any data, not necessarily looking to fit it into a pre-defined category. This way of collecting the data has the potential for revealing insights about the way health care workers and the institution interact at a given time and place (Fetters & Rubinstein, 2019).

I started my observations in May, and quickly came across some issues which required review and modification on how I was undertaking observations these in the clinic. In essence the first few observations became a mini-pilot that enabled me to identify issues and challenges and thus modify my unstructured observation approach. Three issues were identified during this mini-pilot:

1. Patient selection – diagnosis and age
2. Timing of the observation

3. The tool for noting the observation needed refining

To address the issues identified above I met with my supervisor on 24th May 2021, to discuss different strategies that could be used to deal with them.

1. Patient Selection

Firstly, we acknowledged that to find the answers I sought, I would need to be more selective of the patient population that I chose. Each clinic has a proportion of new patients and follow-ups, and it was clear that not all patients would fit the criteria of chronic illness or have the complexity associated with self-management. My supervisor and I looked at more detail of the types of patients that would be better suited to the project, thus developing a criterion that I could use to preselect for each clinic.

This allowed me to pre-screen each clinic by accessing our regional care portal (RCP) for each outpatient clinic that I was available to attend. I could identify those patients that fitted the criteria of complexity of chronic cardiac conditions that are outlined in Table 1 of Chapter 1. The inclusion of patients with acquired heart disease, such as rheumatic heart disease (RHD) was discussed, as these patients are under surveillance for either valve repair or replacement. Given the significant chronicity with this condition they were deemed an important group to include. The age of the child was taken into consideration and it was decided I would only include patients who were 4 years and over. The literature supports the provision of opportunities to learn self-management of their illness during childhood, and it was identified that school age is a beneficial time to begin to engage with them (Boyle et al., 2015; Lambert & Keogh, 2014a; Williams-Read et al., 2020). Implementing this change meant I had moved toward a more purposive sampling of the population, ensuring that what I was going to be observing met the perspective of the project question (Melnik & Fineout-Overholt, 2015).

2. Timing of observation

There were a number of challenges identified around the timing of when patients would be going in to see clinicians. During the 'pilot study' there was a lot of time spent waiting for the child, young person and family to be seen or there were clashes where I would already be with another family. It was initially thought that by following a family through their clinic journey it would help identify where key patient education points would be undertaken. However, there were often long periods of time where children and young people were waiting after tests had been completed and when the clinician was ready to

see them, thus a lot of downtime where education was not happening. Part of following through with a patient was to provide myself with as many opportunities to observe when education could be taking place. The outpatients' clinic has a designated nurse for every appointment. After observing a number of times it was felt that the value added from continuing to record them was limited, the role was deemed to be more task-orientated in nature. They were very welcoming of the child, young person and family in to the room, they put them at ease so that they could perform the clinical observations, measuring weight and height but the provision of health education was limited.

Changing my approach to preselecting children and young people for each of the clinics helped with the timing issue. I could enlist the help of the clinic receptionist, fellow and registrar who was on for that day. I would inform them who I was going to see in the clinic and asked if they could ring or text me when they were taking the patient and a family in. Acknowledging that I didn't want to impact on the smooth running of the clinic, there was an understanding that if I couldn't be present or I was delayed the clinicians would go ahead and start, minimising delay to the family as well. This process did help some of the time but due to the busy nature of the clinic it was not always fool proof and there were occasions that I missed opportunities to be present.

3. Tool development for notation

Initially, I developed a simple tool to utilise to note during the observation sessions. The tool had four main domains for me to annotate information as I observed in the clinic. This was to help with identifying more detailed themes when interpreting the collated data. However, after the initial review with my supervisor it was evident that further development of the tool was required to improve capturing information during the sessions. Each observed session was likely to have two clinicians involved; the original tool didn't allow me to make differentiated notes when more than one was involved. I wanted the ability to separate who was asking what but not wanting to segregate out the "one" session. For examples of the first and second tool, see Appendix 3a and 3b. The final iteration was used reasonably successfully, although in the future if I was wanting to replicate this study it would need more robust scrutiny and potentially further development to guarantee the same information is recorded regardless of the researcher, strengthening the validity of the study (Melnik & Fineout-Overholt, 2015). Ensuring that in the future, when a practice change has been implemented, we can re-evaluate, confirming the change has been adopted and that the desired outcomes are achieved.

Having addressed the issues raised in the initial observations I started collecting data with a more structured approach to recruiting patients.

How the data was analysed – My literature review provided an opportunity to explore the key education concepts and themes that ideally should be covered during a clinic interaction, providing me the key areas and topic headings I wished to highlight within the observation template. They included four topic headings: what was the purpose of the visit today, healthy lifestyle coaching, psychosocial and how the information was delivered (Boyle et al., 2015; Henry & Schor, 2015; Knowles et al., 2016; Koller, 2016; Lambert & Keogh, 2014a; Manganello et al., 2015; Modi et al., 2012). Under each of these themes there were sub-themes that I was listening for, based on what I had read in the literature, about what areas should be focused on for developing self-management skills (Henry & Schor, 2015; Lozano & Houtrow, 2018; Modi et al., 2012). Acknowledging that I had these pre-conceived ideas, I attempted not to be biased to the observed interaction so that I didn't miss other key important questions or information sharing. Fetters and Rubinstein (2019), acknowledged that personal bias should not be seen as a flaw but as an important aspect of the data collection. However, they note that the researcher should undertake a personal inventory prior to entering the field and reflect on preconceptions.

Having collected the data as described, I then transcribed the handwritten notes into a table using the headings above, putting under each of them what was heard during the clinic interaction (See Appendix 4). I went through each interaction and looked for trends of topics that were discussed; in the first read through I noted down twelve sub-themes. I read over the results several times and through this process came up with what I felt was a more thorough representation of what was discussed in clinic. The final total of sub-themes that were discussed was fifteen. The increase came from firstly separating out exercise; there were times that exercise was mentioned to elicit symptoms that the young person might be experiencing. Other times it was discussing the importance of exercise, what to avoid and what could be done. Another area that I picked up on during the repeated reading was the clinicians asking and checking in on how the family was doing. The final sub-theme was clinicians asking about smoking in the home.

With the more comprehensive list of sub-themes, I re-read the templates multiple times looking for the number of instances a clinician discussed them with the family and child. On some occasions, it would be covered by both a registrar or fellow, as well as the SMO. In this circumstance It would get marked down twice in that sub-theme. Once I felt that I had

thoroughly read through the interactions, had identified the sub-themes, and marked down the number of times it was discussed, I collated the number of times each sub-theme was discussed by the different clinician. Doing this enabled me to have a visual of sub-themes that clinicians covered, although a very rudimentary way of looking at the data, it still allowed for identifying areas that were well-covered during the observed interactions, which areas were covered moderately well and which areas were not well-covered. Coker et al. (2013) addresses the use of a recognised published approach to analysing the data collected, which would strengthen the rigour of the study. If this study was to be replicated after a practice change was implemented, the use of such an approach would only strengthen the study findings (Coker et al., 2013; Melnyk & Fineout-Overholt, 2015).

Results of the observational study

Timeframe – Observations were undertaken from 14th May 2021 until 17th August 2021; the end date will be explained later in this chapter. The total number of observations was fourteen.

Patient demographics – For the fourteen encounters the diagnosis for all but one of them was congenital heart disease, the other was rheumatic heart disease. There was an age range of 4 years and 3 months to 15 years and 6 months. Five of the children were New Zealand European, 6 were Māori, 2 Tongan and 1 identified as 'other.' They were all accompanied by one parent or both and one was with a grandparent.

For the purpose of this review, our data intelligence team pulled data about the number of children who would typically be seen during a 2 monthly period. This was to give me an idea of how many children and young people could be seen who fitted the identified criteria for this review. I filtered the data by first removing any new referrals or new patients. Then using the criteria for diagnosis, ensured it fitted with the complex condition outlined in Table 1, Chapter 1, as well as acquired heart disease and then age. I excluded patients who were from overseas and any who were not brought/did not attend. Over that two-month period there were a total of 54 who would have been eligible to be observed, however I observed fourteen.

Table 2 – Summary of patients observed in the outpatient clinic

	Gender	Age	Ethnicity	Diagnosis	Who attended	Clinician observed
1	M	6y 11mth	Māori	Pulmonary atresia/Intact ventricular septum. s/p Fontan	Mother	Registrar Consultant
2	M	4y 5mth	NZ European	Transposition of the great arteries /hypoplastic aortic arch. s/p arterial switch operation and arch repair	Legal guardian - Grandmother	Registrar Consultant
3	M	7y 10mth	NZ European	Supravalvar aortic stenosis, elastin disorder. s/p repair	Father	Registrar Consultant Nurse
4	F	6y	South East Asian	Interrupted aortic arch. s/p repair	Father	Consultant
5	M	14y 7mth	NZ European	Double inlet left ventricle (single ventricle). s/p Fontan	Mother Father	Fellow Consultant
6	M	11y 7mth	Tongan	Rheumatic heart disease	Mother	Fellow Consultant
7	F	5y 3mth	NZ European	Tetralogy of Fallot. s/p repair	Mother	Fellow Consultant
8	F	9y 11mth	Māori	Congenitally corrected transposition of the great arteries. s/p PA band	Mother	Consultant
9	M	8y 10mth	Pacific	Transposition of the great arteries. s/p arterial switch operation	Father and siblings	Registrar Consultant
10	F	4y 3mth	Māori	Tetralogy of Fallot. s/p repair	Mother	Registrar Consultant
11	M	8y	Māori	Ventricular septal defect, coronary cusp prolapse. s/p right ventricular muscle resection and subaortic membrane resection	Mother	Registrar Consultant
12	F	12y	Māori	Tetralogy of Fallot. s/p repair	Mother	Registrar Consultant
13	M	11y	NZ European	Transposition of the great arteries. s/p arterial switch operation	Mother Father	Registrar Consultant
14	F	15y	Māori	Tetralogy of Fallot. s/p RV-PA conduit	Mother	Adolescent Nurse Specialist Consultant

Clinicians observed – For the encounters included in the small review the SMO was involved in two by themselves, the rest they saw in conjunction with another clinician. Eight with the

cardiology registrar, two with one of the cardiology fellows and one with the adolescent nurse specialist. All patients were seen by the clinic nurse who did the height, weight and vital signs observations.

[What information was delivered](#) – Next, I sought to analyse what information was delivered during the clinic visits. Key areas that most clinicians focused on were symptoms, schooling and, ongoing surveillance. Of the fourteen encounters all but two were asked about symptoms. Strategies to elicit symptom information were asking the child, young person and their parents directly about them, listing different symptoms commonly associated with heart disease and asking about how they felt when exercising or playing. Examples of the types of questions asked are below:

Registrar to 11 year old	“How do you feel you are at sport in comparison to others?”
Registrar to 12 year old	“Do you experience symptoms while playing sport?”
Registrar to 6 year 11 month old	“Do you have symptoms while walking?”
Fellow to 11 year 7 month old	To the child “Have you any symptoms, like shortness of breath?” To the parent “Are you worried about symptoms related to the heart or to his breathing?”
Consultant to 9 year 11 month old	“Have you experienced any palpitations – funny heart beats?”

Discussing ongoing surveillance was also covered in all but two sessions. This was discussed with families and children in context of the importance of ongoing follow-up and the rationale for why we do it in relation to their specific cardiac lesion. Also, for those that it was relevant for, was a discussion about what the ongoing surveillance may entail regarding specific tests and further imaging. Ongoing surveillance was mainly discussed by the consultant, the following are some examples:

Consultant to an 11 year old	"Imaging that we routinely do at this age would be a MRI and an exercise tolerance test" (The consultant went on to explain what that entails and why we do it)
Consultant to 6 year 11 month old	"We will be doing further imaging, including a liver ultrasound and bloods in the near future" (the consultant explained in detail why there will be a focus on the liver in the future)
Fellow to 5 year 3 month old	"The plan going forward will be to continue coming to clinic, we will do extra tests to look for..."
Consultant to 9 year 11 month old	"This is what we are going to do going forward and the tests I want you to undertake..."

Questioning about schooling and development was an area that was asked about in most of the observed sessions. This was used to elicit if there were concerns from families regarding their level of schooling or in comparison to peers if there were issues that were identified that needed to be considered and if any action needed to be taken.

Consultant to 9 year 11 month old	"Do you enjoy school? What are your favourite subjects?"
Registrar to 9 year 11 month old	"What are you good at, at school?" "What are your favourite things to do at school?"
Fellow to 11 year 7 month old	"What school are you at?" "What year are you in?"
Registrar to 9 year 4 month old	"Are the teachers happy where you are at with your school work?"

Areas that some clinicians addressed were exercise, healthy eating, how the family was doing in general and checking in at the end of the clinic appointment if there were questions or concerns that the family had. The context of looking at exercise was to see what was discussed specifically about exercise and its importance for keeping healthy, as opposed to the above section, where questions were asked about exercise as a way of finding out about how

symptomatic they were. SMOs were observed to more likely address this topic, followed by fellows, whereas registrars were less likely to review exercise for keeping healthy. Healthy eating was discussed in less than half of the observed clinic appointments, with both registrars and SMOs being the only ones to discuss this openly with the family. In two of the sessions this was addressed in context of growth parameters out of keeping with the age and stage of the child, stressing the importance of healthy eating, educating about good food choices, and exploring opportunities in the community to refer to for help. SMOs in five episodes were observed to engage with families by asking how they were are doing; registrars did this in two episodes and a fellow once. The SMOs were also more likely to do a final check-in at the end of the clinic appointment, asking the family if they had any further questions and enquiring about their understanding of what was going to happen next. However, registrars were most likely to be observed asking the families what they saw as the purpose of coming to their clinic appointment.

Consultant to 6 year 11 month old	“What do you understand about what happens going forward?”
Fellow to 5 year 3 month old	“How are you doing, mum?”
Registrar to 4 year 3 month old	To mother “Were there any questions that you wanted to bring to the clinic appointment today?”
Registrar to 9 year 4 month old	“Can you tell me why you have come to clinic today?”

Other areas that were sporadically mentioned or discussed by any of the clinicians observed were dental/oral hygiene, immunisations, smoking, housing and endocarditis prevention. Encouragingly, information was shared about current medications and appropriately discussed in five of the observed sessions, the remaining nine patients were not on regular medications and therefore it was not discussed. One of the interesting and somewhat disappointing finding was the lack of information sharing about endocarditis prophylaxis, given this is particularly important for ongoing protection for a number of specific cardiac lesions (The National Heart Foundation of New Zealand Advisory Group, 2008).

Dental or oral hygiene was discussed in only four observed interactions, of these two were from the registrar, one from a fellow and one from a SMO. This ranged from asking about teeth cleaning to more in-depth assessment of when the child or young person had last gone to the dentist. During the informal meeting with the clinic nurse, she mentioned that during

her interactions she does ask about dental, however there was limited or no documentation of these discussions. One registrar was holistic in his assessment of families, he not only asked about the cardiac health but also about the status of dental hygiene, smoking and housing. Immunisation was another area that was only discussed in two clinic appointments. This was in the context of younger children, ensuring vaccinations were up-to-date and checking if they had had their flu shot. Considering these observations were occurring as we approached the winter season, I would have expected more discussions around the importance of the flu vaccination and checking of other immunisation status of the patients.

How information was delivered – There were two main ways information was shared during the observed clinic appointments; these were verbally and visually. Under this heading I will discuss how verbal information was shared with family members but also specifically how clinicians engaged verbally with the children themselves.

1. Verbal

As expected, the most common way in which information was delivered was verbally. All fourteen encounters had information and results given verbally by all health practitioners involved in their visit to the outpatient clinic. The verbal information was predominately about the results of the tests, for example, ECG, echocardiogram, MRI (magnetic resonance imaging). These were either undertaken on the day or prior to the appointment. Clinicians compared them to previous results, acknowledging if they were stable or a cause for concern.

Eleven of the verbal interactions discussed what the future surveillance would look like, such as other imaging modalities (ultrasounds, CT, or MRI scans), non-invasive cardiac catheter procedure or specific blood tests. These are based on the standardised guideline for Follow-up post Cardiac Surgery Timeframes of when we would be considering certain tests and rationale for ongoing follow-up (Stirling, 2019, September 30). However, this was not backed up with any form of written information to help families remember what the future surveillance would look like or what the specific tests were. Each family does receive a copy of the clinic letter, which may be weeks after the appointment, by which time families may have forgotten what was discussed. Of the three that didn't have a discussion around surveillance follow-up, one did acknowledge that there would be ongoing injections every month but nothing specific about follow up for the cardiac condition. The other two didn't mention what the follow up or ongoing surveillance would be during the appointment.

Although this was not the specific purpose of this observation exercise, I was interested to see how, when and if the clinicians interacted or engaged in information sharing with the children and young people. It was encouraging to see that all the clinicians attempted to engage with the children and young people in the clinical setting. They did this through directing questions at them appropriately, and tried to get the child, or young person to engage — there was varying success of reciprocation despite the effort put in. Some examples of this:

Registrar and Consultant talking to a 6 year old	“How much running around do you do in the school yard? Are you able to keep up with your friends?”
Registrar talking to a 5 year old	“Do you enjoy school? What part of school do you like best?”
Fellow talking with a 14 year old	“Are you participating in any sports at school? Outside of school?”
Fellow talking with a 14 year old	“Can you remember the last time you were here we talked a bit about transition? Are there things you have thought about that we can work on for handing over to adults?”
Registrar talking with a 9 year old	“What year are you at school? Do you have a favourite subject? And are your teachers happy with you at school?”

2. Visual

The use of diagrams to describe the cardiac diagnosis and findings of the echocardiogram was used by one SMO; neither the registrars or fellows used diagrams. One SMO used the online growth chart to show the family the weight, as it tracked against the centile for the age group. This helped facilitate a conversation around the importance of healthy eating, exercise and managing weight for the importance of the child’s heart health. Using these visual tools can be useful for families. They give a better understanding as to why the hospital is so vigilant around maintaining healthy weight a healthy heart and thus reducing the risk of co-morbidities.

In one observation which was specifically for a transition clinic, a patient was given an information pack that contained material to support different aspects of transition, from

the paediatric to the adult team. The information pack is to support what is verbally discussed in the clinical setting and gives learning opportunities for the teenager going forward, to help prepare them as best we can.

Local external experience

In my initial proposal I had set out to other observe clinics whose clinical profile would be similar to paediatric cardiology. The intention was to observe how they provided health information to support self-management of a chronic illness. After gaining consent from the nurse unit manager and clinical lead to attend some of their medical speciality's clinics, two dates were scheduled. Unfortunately, the first date was not able to be attended due to a communication breakdown. The second date, although confirmed with the Diabetes team, was during the Respiratory Syncytial Virus (RSV) outbreak in Auckland and due to clinical need I was requested to be available to support nurses on the ward. Following this I arranged another date to observe but unfortunately Auckland went into level 4, followed by level 3 Covid-19 lockdown, which stayed in place until we moved to the traffic light framework in early December. This unfortunately impacted on my ability to draw comparisons between what I observed in our clinic and what happened in other similar areas.

International external experience

To help in comparing what we do with other centres I contacted colleagues in Melbourne, Brisbane and London working in paediatric cardiac outpatient areas via email. The reason for choosing these places was based on their similarity to New Zealand in terms of their publicly-funded healthcare systems and their centralised provision of paediatric cardiology care for large populations. I asked the following questions:

1. How is health information given?
 - a. Verbal
 - b. Written
 - c. Directed to websites, if so, which websites do you recommend for children and families?
2. Do you follow a set plan or pathway that you follow for the clinic appointments? Are there areas you always cover?
 - a. Recap diagnosis
 - b. Current state
 - c. Review of medications
 - d. Where to from here – short term
 - e. What the future journey may look like
 - f. Preventative care (i.e. dental, skin care, immunisations, healthy eating, exercise)

3. Who sees the patients?
 - a. Is it always the Registrar/Fellow and Consultant?
 - b. Do you run nurse led clinics for all patients or a specific group of patients?
 - c. Do the Nurse Specialists have a designated room and time slot in a clinic appointment to spend with families and children?
4. Do families have any electronic record that they keep with them or access to their child's cardiac health record?

I had the following feedback from Melbourne and Brisbane, (for a more in-depth synopsis see Appendix 5), but unfortunately did not receive a response from London:

1. How information was given?

Between the two centres they provided information both verbally, written and directed to websites. Brisbane has their own information sheets that they give out if they feel it is helpful. Melbourne will print out or refer to appropriate resources that reinforce elements of chronic health management.

2. Do you follow a set plan or pathway for clinic appointments?

Both Melbourne and Brisbane have nurses who will assess general health concerns, they will discuss diet, feeding, growth as well as exercise tolerance, symptoms and psychological concerns. In Brisbane they also perform observations, ECG and do height and weight measurements. The nurses will refer to allied health professionals as required. Consultants will recap the diagnosis, current state and further diagnostic testing if required. In Brisbane the nurses do a medication reconciliation and this is discussed and reviewed by the doctors. In Melbourne the Doctor reviews the medications and they report that dental care and immunisations are discussed at every visit. In Brisbane, the nurses also check all the preventative questions and reinforce the importance of them.

3. Who sees the patient?

In Brisbane it is always the nurse who sees the patient first and every appointment they are also reviewed by the consultant. Melbourne's regime is a little more complex as it depends on what sub-speciality is seeing the child. But in a general cardiology review clinic the child, young person and caregiver are seen by the nurse and fellow or consultant. Registrars are only in clinic one session per week for teaching purposes. In an aside, the nurses do also undertake a ward review clinic which is nurse led and the pre-admission clinic for cardiac catheter and surgery which is also nurse led. Melbourne has designated clinic space for their nurse as well as time during the clinic.

4. Do families have electronic records that they keep with them?

In Brisbane they don't, but acknowledged this would be a beneficial thing to have. Melbourne has a portal that parents sign up for and they can access their child's

medical record as well as look at appointments. They will get sent hard copies of their visit as well.

Summary

This chapter has provided an overview of the key work undertaken as part of Step 1 of Rosswurm and Larrabee's (2009) model (Melnik & Fineout-Overholt, 2015). I have included how I engaged with stakeholders in a variety of ways. The detailed account of the collection of internal data and what was demonstrated during the observations, which reflects our current practice and I have provided accounts of external data to draw comparisons.

Chapter 4 – Synthesising the Best Evidence

This chapter will describe the activities undertaken as part of the step 2 and three of Rosswurm and Larrabee's (2009) model of evidence-based practice change which involves critically analysing the evidence (Melnik & Fineout-Overholt, 2015). This involved locating the best evidence, assessing, and considering its strength. Also, it was important to ascertain if there is sufficient quantity and quality of evidence to support a change (Melnik & Fineout-Overholt, 2015). In this chapter I will discuss how I conducted the literature search and provide an overview of the key themes that support this project.

Research question

The first step in this review was to define a question or questions that would help refine the search and keep it focused; I designed the question carefully. By creating the leading questions, I was able to identify search terms that would guide the review, aiming to have a robust selection of evidence to compare. The final research questions that shaped this literature review were:

1. Why is self-management important for children who have a chronic condition?
2. How prepared are our children and young people at the transition phase?
3. What knowledge and health information do children, young people and their family/whānau require to support the development of self-managing congenital heart disease?
4. What is the best way to deliver that health information?

Search strategies

I conducted a search of the literature using electronic research databases: CINAHL Complete (via EBSCO), Joanna Briggs Institute EBP (OVID), Medline (via EBSCO), OVID and Google Scholar. When utilising these databases, limiters were set on the searches: English language and, date limitations to 2000-2021. Within these data bases I used the following key-words in various combinations:

- Paediatric/pediatric/children/child infant/young person
- Chronic disease
- Congenital heart disease
- Acquired heart disease
- Self-management/self-care/self-regulation/self-monitoring

- Health literacy/health education/health knowledge/health information/health understanding
- Chronic care model
- Transition
- Preparedness/readiness/preparation

Once the literature was identified and read, further articles of significance were identified through reviewing their reference lists. They were searched using the e-journal/eBook category of the AUT library and were included in the overall review.

Papers were excluded if they were:

- Citations, which were letters to the editor, comments, editorials, abstract only, or conference proceedings
- Studies that focused on chronic conditions other than heart conditions
- Studies that focused on adult patients

Utilising the articles that were found using the above search strategy I embarked on answering the questions I had identified to shape the literature review. This section is therefore divided by the three headings which address the why, how and what?

Why is self-management important with children and young people who have a chronic condition, for example congenital or acquired heart disease?

Adopting self-management in chronic care within paediatrics has the prospect of improving health outcomes, reducing health care utilisation and caregiver burden. It is engrained in the care of adults with chronic conditions and has been found to improve health outcomes and patient experience (Henry & Schor, 2015). Lozano and Houtrow (2018) identified three relevant key differences between adult and paediatric patients that may begin to explain why there is a lag in the uptake of establishing self-management in children. Firstly, there is almost always another person involved in the care of a child or young person whom they are dependent on to manage and provide care for their condition. By contrast, adults with chronic conditions tend to be more autonomous with their health care and daily lives. Secondly, there is a the diversity of paediatric chronic conditions, where children tend to be cared for by specialists, such as cardiologists in the case of congenital and acquired heart disease. This is in comparison to adult chronic conditions, which tend to have a smaller number of diagnoses and therefore, their primary teams, for example, general practitioners, have greater competence in managing them. This however, has the propensity to create siloed care within paediatrics as

the delivery of healthcare tends to be within the hospital system (Lozano & Houtrow, 2018). Thirdly, there is a different development trajectory across multiple domains of the child and young person including: cognitive, motor, language, social and emotional. This makes it difficult to target self-management at specific time points for the paediatric population; instead we should harness every opportunity to provide developmentally appropriate health education (Lozano & Houtrow, 2018; Modi et al., 2012; Saxby et al., 2020).

Self-management in paediatrics, was first described in the literature in the 1960s in Thomas Creer's *Rehabilitation of Chronically ill Children*, as cited in Lorig and Homan (2003), they described self-management as an important factor with those who had a chronic illness, where the individual has the responsibility of the day-to-day care for their lifetime. Modi et al. (2012) discuss that with the advances in paediatric medicine and effective management of a variety of conditions, it has meant that the medical care has become more complex, time consuming and requires careful navigation. They defined it as: "Self-management: The interaction of health behaviours and related processes that a patient and family engage in to care for a chronic condition" (p. e475). However, the iteration described in Henry and Schor (2015), gives the definition more depth, illustrating that it is what the individual will do to keep illness under control, as well as striving to minimise the impact of the chronic illness on functional and physical health and psychosocially.

Lorig and Holman (2003) identified three main tasks needed for self-management: medical management, role management and emotional management. There are six skills necessary to help ensure self-management is attainable: problem solving, decision-making, resource utilisation, action planning, patient provider partnership and self-tailoring (however I found it to be more adult focused). Lozano and Houtrow (2018) describe a set of common tasks that are directly related to healthcare but also incorporates social and lifestyle behaviours, such as attending school, participating in sports/exercise and other type activities to optimise health and well-being for a child or young person with a chronic condition, such as CHD. The authors suggest that working collaboratively and in partnership with wider groups is important when considering self-management in the paediatric population (Gallo et al., 2021; Henry & Schor, 2015; Lorig & Holman, 2003; Lozano & Houtrow, 2018; Modi et al., 2012).

It is clear from the literature that self-management is important for children and young people with chronic conditions and this should be incorporated in care delivery (Henry & Schor, 2015; Saxby et al., 2020; Williams-Reade et al., 2020). Developing good health behaviours such as knowledge, symptom management, and adherence to different treatment plans have shown

to improve health outcomes (Williams-Reade et al., 2020). Their ability to set goals, promote their own health and well-being as well as developing problem solving skills will provide them with a sense of self-efficacy and improve their quality of life (P Moons et al., 2021; Saxby et al., 2020). It is important to recognise the positive or negative influences of external domains such as communities and the health system. Also, what strategies can be implemented to ensure good outcomes and decrease the risk of disruption in care as they transition from paediatric to adult services (Henry & Schor, 2015; Lozano & Houtrow, 2018; Modi et al., 2012; Saxby et al., 2020).

Preparedness of young people for transition from paediatric services to adult care

As part of this review I wanted to also gain an understanding of how prepared young people are at the transition phase of their health journey. Were there identified gaps that could be addressed prior to this phase that would enhance and ensure successful transition, preventing lapses of care during this time (Lykkeberg et al., 2020). Transition is an important part of the journey in chronic illness, where the young person moves away from the paediatric world of care to the adult, having an increased responsibility for their own healthcare (Lykkeberg et al., 2020). Moons et al. (2009), undertook a qualitative study using semi-structured in-depth interviews to explore expectation and experiences of adolescents with CHD, who were being transferred to an adult CHD programme. They found that although the adolescents were ready for the transition and found that it was part of the normal process of growing up, they were not knowledgeable about their heart defect, still relying on their parents for guidance and information.

Similarly, Uzark et al. (2015), found that there were knowledge gaps for adolescents when transitioning to adult care. This included the heart condition, symptoms of deterioration and rationale for life-long follow-up. Young women also had little awareness about appropriate contraception, knowledge around pregnancy and hereditary concerns, if they did happen to get pregnant. The adolescents who undertook the study had low self-management scores, they alluded that this was most likely related to parents managing their child's care rather than encouraging self-management behaviours. Conversely, Burström et al. (2016) found that the cohort of adolescents in their study were quite knowledgeable about their heart defect but their understanding was incomplete. They also had gaps in knowledge around contraception, pregnancy and the hereditary nature of cardiac disease. They emphasised that caregivers should not take for granted that adolescents remember information that has been discussed

with them at a much earlier age. There was also acknowledgment that although adolescents were learning to communicate with healthcare professionals, conversations were still predominantly through the parent.

We can allude from the literature that adolescents have some knowledge but not necessarily be able to link it to what it means for them from a health perspective, the management of symptoms, and adherence to management plans. As healthcare professionals we could be doing more by actively engaging with children and young people in a developmentally appropriate way to educate them earlier. We can build on their knowledge so that by the time they are entering a transition programme they have received education that supports good health behaviours (Saxby et al., 2020).

What cardiac information is important for children, young people and their families to optimise self-management?

The literature review identified six key areas that were important for children and young people and their families to know about their cardiac condition, that would maximise health and well-being and support self-management of their chronic illness.

Cardiac health and knowledge – Hilton-Kamm and Haskill (2015), in their chapter contribution, “Communication Chaos in Pediatric and Congenital Cardiac Care,” - identified the first steps in setting good scaffolding of cardiac knowledge is for parents and caregivers to have a sound understanding of the cardiac diagnosis, what the initial treatment options are and what long-term outcomes are expected. By ensuring parents and caregivers have this solid foundation, they will have the ability to support their child and young person to achieve good health and well-being as they grow and develop. Confidence is strong when healthcare professionals provide consistent information that is easily understood; parents’ feelings of fear, anxiety and worry escalate when this is felt not to occur (Azhar et al., 2017; Bruce et al., 2014). Parental anxiety and apprehension can have a detrimental impact on their parenting ability and discipline style which over time can affect how children and young people manage their own behaviours (Boyle et al., 2015; Uzark et al., 2015; Williams-Reade et al., 2020)

Having a robust understanding of the cardiac diagnosis and treatment undertaken, facilitates knowledge about symptoms of a worsening cardiac state (Hilton-Kamm & Haskell, 2015; Uzark et al., 2015). The importance of recognising when health is compromised and escalating appropriately minimises the risks of having to undergo urgent medical treatment, where the

outcome may not be as good due to a delay in seeking medical attention (P Moons et al., 2021; Uzark et al., 2015). It was acknowledged through the literature that being able to link the symptoms to deterioration and knowing who to escalate to is vital in maintaining well-being (Moons et al., 2009; Uzark et al., 2015). Parents play an important role in early childhood but as children and young people become more independent and spend more time away from their main carer, the child also needs to be able to understand and recognise when to seek help (Boyle et al., 2015).

Azhar et al. (2017) found that although parents had been giving medications for some time, they had little understanding of what it was for and what the potential side effects were. Taking medication is another important part of maintaining cardiac health, but it is essential that the child, young person and their caregiver understand why they are taking it and what would be the consequences if they were to stop.

Healthy weight, healthy eating and physical exercise – A key area of self-management seen in the literature for those with a chronic illness is maintaining and promoting wellness and keeping this in the forefront to optimise health outcomes (Lorig & Holman, 2003; Lozano & Houtrow, 2018). According to the Ministry of Health New Zealand Health Survey 2019/20, one in ten children between the age of 2 and 14 years are obese, this increases to 1 in 3 adults over the age of 15 years (Ministry of Health, 2020). This is a worrying statistic and for children and young people with congenital and acquired heart disease the risk of obesity increases morbidity and mortality (Longmuir et al., 2013; Tamayo et al., 2015). Promoting and helping patients and their families to maintain healthy weight and eat nutritionally is an important role for any health care professional and discussing measures and strategies to help families with this should ideally occur at each clinic appointment (Boyle et al., 2015; Tamayo et al., 2015).

In infancy and early childhood, the impact of the cardiac diagnosis can affect the ability for them to grow appropriately. There is an increase in metabolic demand and thus an increase in calorie intake is required just to maintain adequate growth (Medoff-Cooper & Ravishankar, 2013). Nutrition and growth are important for healing after surgery, immune function, and neurodevelopment. However, this demand cannot always be met due to multiple reasons, such as feeding difficulties, or absorption issues and can be longstanding. Careful surveillance throughout childhood is required to ensure growth occurs along the expected trajectory for them (Boyle et al., 2015; Medoff-Cooper & Ravishankar, 2013; Ryeong Lee & Young Koo, 2020).

Physical activity is an essential part of not only cardiac health but improving self-efficacy for children and young people with congenital or acquired heart disease (O'Brien et al., 2013). The American Heart Association published guidelines in 2013, on promoting physical activity in children and adults with congenital heart disease. Participating in physical exercise not only helps to maintain healthy weight but also provides other significant health benefits such as: skeletal muscle function, improved immune system, vascular health, as well as improved psychological health (Longmuir et al., 2013). For children and young people, it can help to provide opportunities for normal physical development, participation in sports teams and lift self-esteem (Longmuir et al., 2013). Children who have heart disease, regardless of severity, strive to socially integrate, to be as normal as possible, finding ways to be physically active allows them to optimise social participation and normality, reducing negative impacts of their chronic illness on their daily life (Knowles et al., 2016). However, not every congenital or acquired heart disease is the same. It is important that exercise programmes are tailored around the complexity of the condition and what the cardiac limitations may be (Longmuir et al., 2013). Nurses skilled in caring for cardiac children are in a unique position to be able to help tailor individualised plans that incorporate healthy eating and exercise to meet these needs (Boyle et al., 2015; Longmuir et al., 2013; O'Brien et al., 2013; Scheffers et al., 2021).

Dental – Dental hygiene is an important aspect of overall health and well-being for any child and young person. In those that have congenital or acquired heart disease it is even more imperative that they maintain excellent dental hygiene, due to the risk of developing endocarditis; inflammation of the inner lining of the heart chambers and valves (The National Heart Foundation of New Zealand Advisory Group, 2008). Parents and caregivers should ensure that their child and young person has a dental check up every six months (Boyle et al., 2015). In New Zealand, children are enrolled in a free community based oral health service until the age of 18 years. It is imperative that at every clinic interaction that the question is asked to caregivers, children and young people when they last attended their dental review (Boyle et al., 2015). Also, we can assess hygiene practices by asking about teeth cleaning, type of drinks they consume and what their dietary intake is. Poor dietary choices, such as food and drinks that are high in sugar or acid content, lead to poor dentition (New Zealand Dental Association, 2013).

If children and young people with congenital or acquired heart disease develop endocarditis there is significant sequelae, such as damage to heart valves that require surgical intervention. The literature demonstrated that although parents had heard about endocarditis prophylaxis, it was concerning that it showed that only a small number of parents and young people could

adequately define it (Fernandes et al., 2011; Hilton-Kamm & Haskell, 2015). It is imperative that we not only discuss the importance of excellent dental practices and hygiene but also for a subset of cardiac conditions, where invasive dental or other minor procedures is required, endocarditis prophylaxis should be addressed. The Cardiac Society of Australia and New Zealand have clear guidelines for managing endocarditis prophylactically (The National Heart Foundation of New Zealand Advisory Group, 2008).

Immunisation – Proactive protection is recommended by immunising against childhood and seasonal illnesses that could have an impact on the health and well-being of the child or young person with a cardiac condition. Discussions should ensue at each clinic appointment around the importance of vaccinations and reassess that they are up-to-date, according to the National Immunisation Schedule. This will help minimise the risk of contracting a serious illness that may have long term implications to these children. Alongside the routine immunisation schedule, yearly reminders about the importance of getting the influenza vaccine should be undertaken; regardless of the time of year, this is funded for a subset of cardiac children (Boyle et al., 2015; Ministry of Health, n.d.)

Neurodevelopment – Children who have undergone bypass surgery as neonates are at higher risk of neurodevelopmental issues (Gaynor et al., 2015). These may be subtle learning difficulties, attention deficit disorder or more significant developmental concerns that impact significantly on the ability for the child or young person to participate to their fullest in daily life and schooling (O’Brien et al., 2013). Assessing to identify issues early, means that supports and plans can be put in place to ensure that developmental milestones are met (Boyle et al., 2015). Schooling is an important factor in self-efficacy and if not adequately supported the child can have negative experiences which can adversely affect their health (Knowles et al., 2016). According to Modi et al. (2009), development of school-based support for students with chronic illness can enhance self-management skill development and may even lead to symptom improvement. Working collaboratively across healthcare, communities, schools and in partnership with parents and caregivers can help to address these concerns (Henry & Schor, 2015).

Lifelong follow up – Regardless of the complexity of the cardiac or acquired heart disease in children and young people, the literature tells us that they require lifelong follow up (P Moons et al., 2021; Raissadati et al., 2020; Wernovsky et al., 2017). This is to monitor for potential complications related to the defect and the surgical intervention that they have had during infancy and childhood; these complications can include heart failure, arrhythmias and

hypertension (Raissadati et al., 2020). It was therefore worrying that the literature demonstrated a lack of understanding by caregivers that their child and young person would require lifelong follow up, some reporting that they had not been told of the necessity for it (Azhar et al., 2017; Boyle et al., 2015; Hilton-Kamm et al., 2014). Although, anecdotally from my experience as a cardiac nurse specialist involved in counselling families from fetal diagnosis through the lifespan, parents are told at various points along the cardiac journey that this would be the case. However, because of the timing of when they are told, that is, in times of heightened stress and anxiety, families may not have been able to process and retain this information (Arya et al., 2013; Bruce et al., 2014). Some more simple defects that the initial surgical intervention renders them “cured” with little to no effect on day-to-day health, will still require long-term surveillance to ensure there is no long lasting sequelae, and families are told this (Raissadati et al., 2020; Wernovsky et al., 2017). Health care professionals caring for this population have a duty of care to ensure that families children, and young people are aware that as they move through their cardiac journey, they will always need follow-up (Boyle et al., 2015; Raissadati et al., 2020; Wernovsky et al., 2017). Explaining the rationale for why we do this and what we are watching for will help families understand and provide children with the reason why they need to keep coming to clinic.

Adherence to treatment, whether this be medication, nutrition, or exercise to maintain health and well-being are all important self-management tasks (Henry & Schor, 2015; Lozano & Houtrow, 2018; Modi et al., 2012). The ability for a child or young person to adhere to these common tasks, albeit the level of responsibility reflecting their developmental stage, is setting the foundation for good health behaviours that will be engrained in them through the lifespan to help minimise co-morbidities, improve health outcomes and decrease healthcare use (Henry & Schor, 2015; Lambert & Keogh, 2014a; Lozano & Houtrow, 2018; Marcus, 2014).

[How information should be given to support self-management skills of chronic conditions such as congenital and acquired heart disease?](#)

In this section I will describe what was shown in the literature about how information should be given to support self-management of congenital and acquired heart disease. Parents of these children are faced with an enormous task of understanding a lot of information, often all at once. For even the most well-educated person there is a sudden need for them to understand concepts and language that is completely foreign to them. Some caregivers may have had time to absorb and make sense of it, but for others they are trying to make sense of it during very stressful times (Arya et al., 2013; Bruce et al., 2014; Estacio et al., 2020). How information is delivered to children, young people and their families is crucial. While reviewing

the literature's three main themes it became apparent that how information should be given was acknowledged.

Multifaceted – One of the fundamental building blocks to successful engagement is effective communication between health care providers, patients and families including the provision of accurate information (Hilton-Kamm & Haskell, 2015; Koller, 2016). Within the literature it was evident that a variety of modalities are needed to educate children, young people, and their caregivers to ensure that it meets their learning needs. These include verbal, written, digital and illustrative, to name a few. Bruce et al. (2013) acknowledged that a lack of information was worrying for families and that providing it gradually throughout the journey, using a combination of written, illustrated and videotaped resources would provide reassurance to the ongoing care of their child. The use of technology to improve and facilitate communication has been described as one of the best methods to enhance data retention (Jacobs et al., 2016; Lambert & Keogh, 2014a, 2014b; Meyers et al., 2019). Tong et al. (2004), mooted the utilisation of a health passport that would hold pertinent information to support the transition of adolescents. More recently Lane et al. (2019) developed a clinician-parent home care education intervention, in consultation with healthcare and parents of cardiac children, which is a novel web-based educational technology. It is currently being tested to determine its feasibility. Regardless of what the modality is, communication should be clear and concise and the healthcare professional should devote time to share the information (Azhar et al., 2017; Bruce et al., 2014). Information should be provided in an individualised manner that considers the child's needs, so that they have an increased understanding of their cardiac condition and become greater participants in their health journey (Burström et al., 2016; Koller, 2016; Lambert & Keogh, 2014a)

Timing – What was strongly evident in the literature was not imposing an age limit on when health professionals should start involving children in the health information and education process (Boyle et al., 2015; Koller, 2016; Lambert & Keogh, 2014a; Williams-Reade et al., 2020). Health outcomes for children could improve if they were encouraged to participate, allowing for ebbs and flows of the level of involvement they wish to have. Information sharing should not be constrained to a specific age, giving patients and their carers opportunities to work alongside healthcare professionals, enhancing their understanding and competency (Boyle et al., 2015; Koller, 2016; Lambert & Keogh, 2014a; Saxby et al., 2020; Williams-Reade et al., 2020). Understanding their cardiac condition was considered an important marker of their involvement in health-related education and discussions (Koller, 2016; Lambert & Keogh, 2014a). Moons et al. (2009) describes transition as an educational process that ideally should

begin before children reach adolescence; school-aged children involved early in healthcare and education will improve their self-care and accountability (Saxby et al., 2020). As they become increasingly responsible for their own health, recognising their altered state, as maturity increases dependence on adult family members should correspondingly decrease (Boyle et al., 2015; Fan, 2008; Koller, 2016; Lambert & Keogh, 2014a; Williams-Reade et al., 2020)

Check-in – Healthcare professionals can address considerations of what the best way is to deliver information. We can engage with children and young people early to give them opportunities to participate in their healthcare but unless we have a process to determine whether they have understood, we can never be sure that what we are doing is correct. Medical terminology is complex and difficult to understand, and clinicians are often delivering information at highly stressful situations where the “shock” of the news creates an inability to digest and comprehend it, affecting their ability to make good decisions about their child’s healthcare (Bruce et al., 2014; Driessnack et al., 2014; Lambert & Keogh, 2014b). Healthcare providers need to ensure that the communication shared has been understood, Mangello et al. (2015) have suggested that health providers should use an approach called “teach back method” to ensure they understand the information provided. This method asks the clinician to validate the understanding by utilising open-ended questions to get the child or caregiver to reframe the information they have heard (Sawin et al., 2017). Lambert and Keogh (2014b) suggested not only using this teach back method, but another initiative called Ask Me 3™, developed in Boston, United States by the Institute of Healthcare Improvement and adopted by Health Quality and Safety Commission, New Zealand. This validated tool encourages caregivers, children and young people to ask of their providers three things that will help them gain better understanding of their health condition, what it is they need to do to stay healthy and why it is important (Health Quality and Safety Commission New Zealand, n.d.; Institute for Health Care Improvement, n.d.).

Summary

Undertaking an extensive literature review has uncovered possibilities for change. There have been aspects of self-management identified that can be incorporated into health interactions which can also address elements of health literacy. Early intervention with education across multiple modalities with opportunities to assess and reassess skill and knowledge acquisition will address adolescent transition preparedness and decrease the risk of lapses in care. Overall, the literature provided evidence that can be integrated to the care delivery by healthcare professionals in the clinic setting to optimise self-management to improve health outcomes.

Chapter 5 – Discussion

Exploring how and what information should be delivered in an outpatient setting, was achieved by observation and reviewing the literature. This has opened opportunities for change to support development of self-management skills of chronic cardiac illness. In the population of children and young people who have congenital and acquired heart disease, it is anticipated that survival is only going to continue to improve. Detection of disease, advances in surgical and interventional procedures, alongside improvements in medical care has meant that there will be a growing population who will reach adulthood. However, despite the advances in the totality of care, there continues to be a risk of morbidity and therefore managing to reduce the impact/risk is important to maintain quality of life and improve health outcomes.

Congenital and acquired heart disease – chronic illness

Worldwide there is 15-40% of people aged 0 to 20 years whose chronic condition affects their everyday life (Saxby et al., 2020). According to Brown et al (2007), a chronic illness is “a disease state that has symptoms with a protracted course and involves one or more body systems. It may impair their health status and/or physiological functioning” (p 3-4). Chronic illness creates formidable challenges for families and parents develop heightened levels of responsibility and protectiveness (Williams-Reade et al., 2020). There is disruption of the healthy siblings and the family relationship, with the need for emotional adjustment and management for all family members (Brown et al., 2007; Saxby et al., 2020; Williams-Reade et al., 2020). It is estimated that 90% of children who are born with congenital heart disease will reach adulthood (Eagleson et al., 2020; P Moons et al., 2021; Wu et al., 2020). Many will require lifelong care to manage chronic co-morbidities associated with their heart disease. Raissadati et al. (2020), undertook a population-based study in Finland, to look at the risk of late morbidity of paediatric patients who underwent surgery in infancy and found that regardless of the severity of their cardiac defect there was an increased risk of developing an associated late morbidity, that most likely would need treatment. This reinforces the significance of ongoing expert care to collaboratively work with young people and their families to manage their chronic illness alongside normal development trajectory (P Moons et al., 2021; Saxby et al., 2020).

Health literacy

Improving an individual's health literacy, even young school-aged children, should be paramount in the overall care delivery, particularly when they have a chronic illness like

congenital and acquired heart disease (Koller, 2016; Lambert & Keogh, 2014b). It is recognised that when a child, young person and their parents have adequate health literacy their health outcomes will improve; there is an increase in medication adherence, improved participation in shared decision-making and reduction in hospital admissions (Henry & Schor, 2015; Lambert & Keogh, 2014a; Lozano & Houtrow, 2018; Marcus, 2014). The need for developing health literacy in children is to ensure health-related knowledge, attitudes and behaviours is ingrained before problematic health attitudes and behaviours set in during adulthood (Driessnack et al., 2014; Keim-Malpass et al., 2015). Promoting children's involvement in education about their heart disease, aspects of maintaining health and health promotion will improve self-care and accountability (Lozano & Houtrow, 2018; Saxby et al., 2020). Managing this early in school-aged children will help facilitate them as adolescents to be more active in their healthcare; historically they have adopted passive roles, as the adolescent has relied on their parents. The reasons for this are multifaceted; it can stem from fear and anxiety from parents leading to overprotection and their own poor health literacy, which may affect their willingness to allow the child/young person to be more active. Social and cultural beliefs can also have an impact on the willingness to work in partnership with the young person and giving them a voice in their care (Estacio et al., 2020; Lambert & Keogh, 2014a; Meyers et al., 2019).

Keim-Malpass et al (2015), found that there was limited research regarding assessing young children and adolescents' health literacy in an outpatient and inpatient setting. There were few studies that included children with co-morbid conditions; most of the studies were with families whose children had asthma or diabetes. Estacio et al. (2020) discussed the significance of promoting and supporting parental health literacy skills, as they are tasked with making important health decisions that can have long-term impact on the health outcomes of their child with complex care needs. Developing supportive relationships between health professionals, the child and their families helps the young person to build trust and seek advice when needed (Burström et al., 2016).

Self-Management

Acknowledging the importance of health literacy, and the role it has in promoting health and well-being, it is also central to the development of self-management skills. Facilitating a child, young person and their family to obtain, process and understand even just basic health information and what health services will provide, is the first step to growing an individual's capacity for self-management (Lambert & Keogh, 2014a; Lozano & Houtrow, 2018). Effective self-management can lead to maximisation of health treatment, improved health outcomes

and reduction in unnecessary healthcare utilisation (Marcus, 2014; Modi et al., 2012; Saxby et al., 2020). Self-management builds the ability to undertake common tasks such as; adherence to medication and treatments, monitoring symptoms, attending clinic appointments, and keeping active, all of which contributes to optimising health and well-being (Henry & Schor, 2015; Lozano & Houtrow, 2018; Modi et al., 2012).

Modi et al. (2012) have developed a model of paediatric self-management that is not disease focused but able to be adapted across all paediatric chronic conditions. They set out self-management behaviours sitting centrally to four domains, that influence the ability for one to carry out these behaviours successfully: individual, family, community and healthcare system. Within each of these domains there are sub-categories, some of these are modifiable and some are not. For example, in the individual domain age, gender is non-modifiable but the persons understanding of their disease and treatment plan is modifiable. Their model also gives scope for the healthcare providers involved in the care of the individual to assess their level of maturity, ability to understand information and undertake certain tasks, therefore not limiting the timing of when to support skill acquisition for self-care. Introducing children and young people early encourages them to effectively interact with health professionals and the health system, offering opportunities for enhancing understanding of their condition and treatment plans. It gives them the prospect of developing skills such as understanding their cardiac condition, what their symptoms are that they should be aware of, when to ask for help and adherence to their medical treatment (Burström et al., 2016; Fan, 2008; Koller, 2016).

[PCCS Outpatients – linking observations and literature](#)

Undertaking this observational study in our cardiac outpatients provided me with a unique perspective of how and what information is delivered. I attempted to explore the role and function of what an outpatient appointment should be and whether there was any guidance as to what should be covered with children, young people, and their families. There was a dearth of literature linking outpatients directly to outcomes of improving self-management and health literacy and how clinicians can work to improve that. Although my study was small, it opens future opportunities to explore the function of outpatients and its role in supporting development of self-management skills from an early age, for children with cardiac disease. It would also be prudent to work collaboratively with families, children, and young people to explore what it is that they identify as their needs from an outpatient appointment, ensuring we meet their requirements as well. Despite being a small study there are interesting discussion points that can be drawn out and comparisons drawn to the other literature that was explored.

What information was shared – can we improve?

Cardiac health and knowledge – A positive finding during my observations was that most of the clinicians attempted to engage with children and young people, asking them health-related questions, to give them the opportunity to participate in their own appointment. This had varying degrees of success, ranging from minimal feedback, or just a few words, to the child and young person being able to provide information back to the clinician to support assessment of their current state. Regardless of whether there were meaningful responses or not, it was positive to observe that the clinicians were engaging with the child and young person, supporting the development of relationships with the healthcare provider and embarking on building trusting relationships (Boyle et al., 2015; Estacio et al., 2020).

It would have been more encouraging to have observed clinicians enquiring and engaging with the child or young person themselves about their own understanding of their heart condition and perhaps asking if they knew what symptoms would make them worried and who would they let know. Uzark et al. (2015) identified in their evaluation of adolescents' readiness for transition, that there were gaps in knowledge around their heart condition, gaps in understanding about symptoms that may indicate that there is deterioration in cardiac health and a lack of understanding about the importance of follow-up long term. Arya et al. (2013), identified in their study that parents of children with CHD wanted more information than a cardiologist provided, suggesting that healthcare workers need to consistently and constantly be sharing information. The cardiac outpatient setting is an ideal place where this can be undertaken.

Children, young people and their families need to have a sound understanding of what symptoms may be important that suggest that their health may be compromised (Uzark et al., 2015). It was reassuring to observe that all but two of the observed interactions, clinicians enquired about symptoms. In some cases, they directly listed what symptoms the child or young person may have experienced, and others listened to how the child, young person or parent explained how they managed day to day activities. Although I saw them asking about symptoms, few went on to discuss what symptoms would make the cardiac team worried, when help should be sought and from whom. Being able to recognise a worsening condition related to the cardiac condition is vital; early intervention to prevent development of co-morbidities will help with long-term outcomes (Knowles et al., 2016; Moons et al., 2009; Uzark et al., 2015). CNS' are not always present in the paediatric cardiology clinic to discuss symptom management with families; clinic letters may provide them as a point of contact. This is a

potential opportunity, where the CNS role could be utilised to provide the education and provide the conduit between community and hospital.

Parental knowledge and understanding of their child's cardiac condition is improved when health professionals spend more than ten minutes explaining and utilising multimodal approaches to providing information (Arya et al., 2013; Azhar et al., 2017; Hilton-Kamm et al., 2014). Integral to spending time and providing information is also assessing the family, child, and young person's understanding. We can provide education at every opportunity but without taking the time to ensure they have understood, we cannot assume that there is comprehension. From the study undertaken in the clinics it was observed that some clinicians, predominantly the SMO's would do a "check in" at the end of the clinic appointment. However, I did not observe if there was a particular structure to how they elicit that there was understanding. It would be encouraging to see clinicians utilising well-researched tools such as the Ask Me 3™ or the Teach Back method, which are two initiatives that the New Zealand Health Quality and Safety Commission (Health Quality and Safety Commission New Zealand, n.d.) have adopted to provide medical professionals with a framework to assess understanding and comprehension of information shared – this is discussed further in the chapter.

[Healthy weight, healthy eating and physical exercise](#) – Maintaining a healthy weight is particularly important for children and young people with heart disease. It is often assumed that because a child has a heart problem that there are physical limitations associated with it. Although it is important to tailor physical activity and sport participation to the specific cardiac diagnosis, regular exercise has multiple benefits for the child and young person. Not only does it help with maintaining healthy weight and development of gross motor skills, it also helps them to integrate into peer groups through sports, giving them a sense of normality and boosts self-esteem (Boyle et al., 2015; Scheffers et al., 2021). The American Heart Association released a scientific statement in 2013, supporting the health benefits of physical activity, they noted that there were very few cardiac diseases in children and adults that physical activity would not be recommended for and that there is an increased risk of developing co-morbidities such as hypertension, diabetes and depression with inactivity (Longmuir et al., 2013). It was observed in the clinical setting that although clinicians talked about exercise, it was more often associated with exploring whether the child or young person had symptoms of cardiac failure. In the future state a discussion about physical activity could be included, what we expect the child to do and suggestions of the types of exercise they can participate in, the healthcare staff providing an exercise plan that is safe. This could be coupled with an

explanation of the overall benefits of being physically active on heart health as well as on the child and young person's overall quality of life (Longmuir et al., 2013; O'Brien et al., 2013).

Encouraging physical activity should be complimented with education around healthy eating and making good food choices to help maintain healthy weight (Ryeong Lee & Young Koo, 2020; Tamayo et al., 2015). Healthy eating was discussed in less than half the interactions that were observed, however, all children and young people have their weight and height measured in the clinic and our electronic records allow for the plotting of these. It is a useful tool for clinicians to easily observe how well the child is growing and provides a visual for families to see exactly where their child is sitting on the growth chart. To ensure we are meeting the needs of our cardiac children and young people we need to integrate discussing and promoting both physical activity and healthy eating habits into every single clinic interaction. Not only are the electronic growth charts available to clinicians but there are folders provided by the nutrition department with supportive material to give to families. However, they do need to be updated and replenished regularly if they are to be of value in the outpatient department.

Dental – Poor dental hygiene in cardiac children can not only increase the risks of endocarditis but also impact on their overall health. It is therefore imperative that clinicians should be discussing with families, children, and young people at every outpatient clinic, when they were last seen by a dental team. In New Zealand children can be enrolled in publicly funded dental care until the age of 18 years (Ministry of Health, 2019). In the clinical setting it was observed there was only sporadic mention of dental hygiene practices and check-in's and when they had last been seen by a dental practitioner. Some of the questioning was cursory, for example, "Do you clean your teeth?", further detailed questioning was not undertaken.

Alongside ensuring that a child or young person is routinely having dental reviews, discussing if they require subacute bacterial endocarditis (SBE) prophylaxis for dental procedures is recommended. Clinicians should refer to the Guideline for Prevention of Infective Endocarditis associated with dental and other medical interventions (The Cardiac Society of Australia and New Zealand, 2008) when advising families if their child requires prevention. It should also be documented in their clinic letter for reference for not only parents but other health professionals that may be involved with the child and young person. It was disappointing that during the clinic appointments there was very limited discussion regarding dental/oral health and the promotion of dental hygiene and sharing of information around prevention of endocarditis.

Immunisations – Proactively managing a child and young person’s health when they have a cardiac condition is imperative. Interestingly and somewhat discouragingly was the finding that there was little discussion with families about immunisations. Clinicians were rarely observed asking if the child or young person was up-to-date with their childhood vaccines, nor did they enquire if they had their yearly flu vaccine. Considering the current climate of Covid-19, the respiratory syncytial virus (RSV) outbreak and that I was undertaking these observations in the early winter, I would have anticipated that there was more done to heighten awareness for these families. According to the New Zealand immunisation schedule, high-risk cardiac children are all eligible and funded for the yearly flu vaccine and there is funding for Palivizumab (prophylaxis for respiratory syncytial virus) for a small group of eligible children (Ministry of Health, n.d.). This is an important aspect of holistic care and there is good evidence that nurses and doctors should work collaboratively with families to educate them of immunisation schedules for their child, to help protect against childhood illness and promote their health and well-being (Azhar et al., 2017; Boyle et al., 2015).

Neurodevelopment – Where appropriate, healthcare professionals did ask the children and young people about their schooling, eliciting the classes they were in and what aspects of schooling they enjoyed. Asking class level is a subtle example of ensuring the child is working to the expected schooling level; a more in-depth discussion around development only occurred in one observation, which resulted in an appropriate referral. However, through an established neurodevelopmental programme within PCCS, an Ages and Stages Questionnaire is provided to the appropriate families to complete in the outpatient department. A recent review showed that this was a simple and efficient tool to assess for developmental delay in children and young people who had congenital heart disease (Lepine et al., 2021). Our team collect and collate them and give to the cardiac psychology team for follow-up. It is known that congenital heart disease, has been linked with educational challenges that continue along the age spectrum (Boyle et al., 2015; Knowles et al., 2016; Lepine et al., 2021; O’Brien et al., 2013). CNS are in a unique position to be able to educate families on areas that may cause concern, escalate appropriately and provide individualised health management plans.

Lifelong follow-up – Maintaining health and well-being for cardiac children and young people incorporates ongoing lifelong follow-up, monitoring the cardiac condition and assessing for possible complications from the interventions will help them to keep healthy. The literature suggests that even the simpler defects will also need lifelong follow-up (P Moons et al., 2021; Raissadati et al., 2020; Wernovsky et al., 2017). However, knowledge gaps about the

importance of lifelong follow-ups were still identified as a significant concern in the literature (Azhar et al., 2017; Fernandes et al., 2011; Uzark et al., 2015). In the PCCS outpatient clinic it was observed that healthcare professionals discussed ongoing surveillance needs. This implies ongoing follow-up but it was not explicitly stated in most of the appointments. In two observed sessions there were discussions with the adolescent around the need for transition, identified when their next appointment would be and described that it was going to be with the Adult Congenital Heart Disease team. They were also provided with written information (Transition Pack). Of these observed sessions the Adolescent Nurse Specialist was involved in one of them, it was noted that they had designated space and time to be able to explore what transition meant for them as an individual. This has been shown to be an important way to engage with young people who are amidst transition (Acuña Mora et al., 2020; P Moons et al., 2021)

How can information be delivered to support self-management and can we do better?

Utilising a multi-modal approach to delivery of health information – Unsurprisingly, the most common way in which clinicians shared information was verbally during the outpatient clinic visits. They discussed findings from tests undertaken and compared to previous results, explaining to the child and young person their current state. They would then discussed the next steps and what surveillance would be required going forward, for example, what next tests or procedures were required and likely timing. However, to ensure that the delivery of information is heard and understood it needs to be delivered in a multi-faceted way to provide families with the right information, so they can make informed decisions about their child's care (Lambert & Keogh, 2014a, 2014b; Marcus, 2014; Meyers et al., 2019). As the rates of survival increase for children with heart disease, there is a growing need for parents and caregivers as well as children and young people to have a good understanding of their diagnosis, what the risks are to the health of their child and the necessity for life-long follow-up. Hilton-Kamm and Haskell's (2015) chapter on Communication Chaos (Pediatric and Congenital Cardiac Care: Volume 1: Outcome Analysis) found that after reviewing multiple studies, there were gaps in parental knowledge. This ranged from inability to accurately describe the diagnosis, to a limited understanding of infective endocarditis, medications, symptoms or signs of deterioration or importance of life-long follow-up. This lack of knowledge can detrimentally affect the child and young person's long-term survival (Fernandes et al., 2011; Philip Moons et al., 2021). If we are seeing in studies that parents have limited knowledge and understanding, then the likelihood is that children and young people will have

limited knowledge as well (Lambert & Keogh, 2014a). To set children and young people up to succeed and develop the tools to self-manage their cardiac disease, clinicians need to be addressing how we can better deliver information to them.

Verbal conversations should be complimented with other modalities to ensure that information is understood and retained after the clinic appointment (Arya et al., 2013; Bruce et al., 2014; Lambert & Keogh, 2014b; Lane et al., 2019; Meyers et al., 2019). An obvious example is the utilisation of pamphlets or printed material that can be given to families at the time of the clinic appointments, these can be related to the cardiac diagnosis itself or information regarding tests that the team may want to undertake between clinic appointments, for example: cardiac MRI, CT scan or exercise tests. Having the information can help to alleviate anxiety about what is going to be coming up for the child and young person and can serve as a reminder that follow-up and surveillance is ongoing (Bruce et al., 2014). Directing families to reputable websites to add to their toolkit of knowledge is also good, however, there needs to be assessment of whether they firstly have access to the internet or computer and following up whether they have understood what they have read (Lambert & Keogh, 2014b; Meyers et al., 2019). The notion behind having multi-modal access to information, is that people all learn differently, and one size does not fit all. To support developing health literacy skills, the use of computer-based visual methods is one of the best for enhancing data retention (Jacobs et al., 2016; Meyers et al., 2019). Other complimentary technologies such as social media and online support groups can be pivotal in supporting developing knowledge and skills to manage the cardiac disease (Azhar et al., 2017; Henry & Schor, 2015; Lozano & Houtrow, 2018; Modi et al., 2012). Unfortunately, during the observations there was limited use of other modalities to provide and reinforce information to families, children and young people.

[Timing of engagement to share health information](#) – It was encouraging to see healthcare professionals actively trying to engage children and young people in their clinic visit, regardless of the feedback they got from them. Some of the children and young people were comfortable with talking with the clinicians, however the majority were reluctant to engage. Literature demonstrated that involving children, as young as school age, can foster good health behaviours that will support them to maintain good health and well-being (Boyle et al., 2015; Knowles et al., 2016; Saxby et al., 2020; Uzark et al., 2015). Consideration of their place along the developmental spectrum and accounting for their level of maturity has to be paramount; not all children are the same. As health care professionals we should not restrict our health education and information sharing to a specific age, instead assessing an individual for his or

her capability and adapting to their level will help to develop supportive and trusting relationships between clinicians and young people (Estacio et al., 2020; Koller, 2016; Lambert & Keogh, 2014a; Marcus, 2014; Saxby et al., 2020).

[Checking In: do our children, young people and families understand](#) – As mentioned earlier in this chapter there are two useful communication strategies that can be implemented by clinicians that can help validate the understanding of the child, young person and parent: Ask Me 3™ and utilisation of the Teach Back method. I didn't observe any of the healthcare professionals using a structured check-in approach. At the beginning of some of the clinics some of the clinicians asked families: "Why are you here today?" or questions to that effect. However, I didn't observe them asking: "Can you explain to me in your own words what your understanding of what I have discussed with you?" or "Can you tell me what the plan is going forward, so I know you have understood?" These are examples of the type of open-ended questions that the Teach Back method suggests, giving the young person and caregiver the opportunity to give feedback of their understanding and allow clinicians to correct any misinterpretations (Sawin et al., 2017). Ask Me 3™ is a method using 3 questions that encourages young people and caregivers to gain a better understanding of their health condition and what they and we can do to keep them well by asking; What is my main problem? What do I need to do? Why is it important for me to do this? (Health Quality and Safety Commission New Zealand, n.d.; Institute for Health Care Improvement, n.d.).

[Role of Nurse Specialist in the outpatient setting to promote self-management and health literacy](#)

There is a paucity of literature to support what is the gold standard of care delivery in the paediatric outpatient setting. What can be alluded to is that this space is untapped potential and the possibilities are vast. The clinical nurse specialist (CNS) could give an opportunity to provide expert clinical care to children, young people and their families, as well as provide education and support to staff. CNS' historically have been primarily associated with inpatient settings and more recently, in the community settings, where according to Kilpatrick et al (2014) the effectiveness of their role is shown to improve outcomes. They undertook a systematic review, assessing the cost effectiveness of CNS' in the outpatient care space as well. Although they described the evidence of low quality it did support the utilisation of the CNS in a complimentary role within outpatient settings. However, there needs to be consideration of how the role would fit with organisational goals, the needs of the population and what would be the overarching purpose would be. For example, in the provision of education focused on

health promotion, health maintenance and health prevention. Removing structural barriers within health systems to support the role of the CNS in providing holistic care to children and young people with complex and chronic conditions such as congenital and acquired heart disease, will enhance the overall population health, improve outcomes and reduce hospitalisations (Kilpatrick et al., 2014; Tracy et al., 2020).

In observing our clinic appointments, the CNS' do not have designated time or space in them to see the child, young person and families to be able to address health education and self-management skill. The Royal Children's Hospital, Melbourne, Australia describes a high level of CNS presence in the cardiology clinics. They have a designated clinic space and time with families to address general health concerns, what the diet and feeding regimes have been, assessing growth, exercise tolerance, as well as psychosocial concerns around schooling, family, and social interaction. The child, young person and family are then seen by the Consultant to discuss their current state, review medications, their plans going forward and review of the timeframe. Health prevention measures such as dental checks and immunisations are discussed at every clinic appointment. CNS' also lead a ward review clinic where they see the child and young person, undertaking tests before a Registrar or Fellow reviews them. Brisbane has nurses in clinic who have designated space and time as well. This highlights an area that the CNS role within PCCS outpatients could be utilised effectively to provide opportunities for education to support the acquisition of knowledge about their cardiac diagnosis, treatment plans, symptom management and ongoing surveillance. It provides opportunities for the CNS to begin to address self-management behaviours and give occasions for young people to practice these skills, setting them up to succeed in the long term, ultimately optimising health outcomes, improving well-being and reducing hospitalisation usage (Boyle et al., 2015; Estacio et al., 2020; Lambert & Keogh, 2014a; Modi et al., 2012).

Acknowledgement of unexpected challenges during the data collection phase

There were several unexpected and challenging events that impacted on this project that I would never have accounted for in the planning of this project. From June 2021 onwards at Starship Children's Hospital, with winter in full swing there was a substantial surge in Respiratory Syncytial Virus (RSV). This affected a significant amount of our children and young people, resulting in an increase in admissions throughout the hospital, and subsequent increased pressure on the inpatient service at Starship Children's Hospital. During the weeks of the upsurge in admissions during June, July and beginning of August I, alongside others in my

Nurse Specialist team were required to work clinically to cover the shortfall in staffing across all areas. On the days I wasn't working clinically I had to ensure there was appropriate cover in the nurse specialist role. This obviously had a significant impact on my ability to take leave and be available to undertake the observations in clinic.

The second event that occurred, which I could not account for was Covid-19 Delta strain being detected in the Auckland community in mid-August. This led to a nationwide level 4 lockdown on 17th August, followed by a lengthy level 3 lockdown for Auckland, from 22nd September until we moved to red, in the traffic light system on 3rd December. The impact on my ability to be able to continue observing in clinic was significant. Firstly, there was a substantial reduction in the number of patients in clinic and the number of clinics that ran during the level 4 phase. The second issue was that there were restrictions to the number of people who could be in clinic. Families were asked to only have one caregiver present and there was minimal movement of staff through the outpatient department itself to reduce the risk of spread of Covid-19 Delta. It would have been inappropriate for me to have been in a clinic setting observing. These two unpredictable events had a detrimental effect on my ability to undertake observations not only in the PCCS outpatient but also in being able to observe in the other outpatient clinics I had arranged to go to: diabetes and respiratory.

Summary

With improved care across all facets for congenital and acquired heart disease the life span for individuals will continue to improve. Clinicians in the PCCS outpatient clinic are engaging with children, young people and their caregivers to provide the building blocks of knowledge and skill to be able to self-manage their chronic illness. Comparing the literature to the observation that was undertaken, I saw that we do provide health information that is useful for the development of skills for self-management. However, there are areas where gaps were identified, acknowledging these and providing strategies to address them will ensure we meet the needs of this population more fully.

Chapter 6 – Recommendations for Practice Change

Utilising the first three steps of Rosswurm and Larrabee's (2009) framework has given the opportunity to assess the need for practice change, compare to other internal and external providers and critically appraise the literature (Melnik & Fineout-Overholt, 2015). Step four of Rosswurm and Larrabee's model is about designing practice change and although unable to undertake this there are some key recommendations that have come out of the first phases of the project. These recommendations hold potential to lead to significant practice change and address the delivery of health information in the outpatient setting in a way that would support the development of self-management skills and improve health literacy. These are outlined below:

Nurse Specialist presence in clinic:

Nurse Specialists are pivotal to providing information to families, children and young people and supporting them along their cardiac journey. In the current set-up in the PCCS outpatient clinic this role is underutilised. Providing dedicated time and space in the allotted clinic time would open the opportunity for the nurse specialists to deliver patient-family focused education. Using the criteria that has been developed as part of the PCCS Nurse Specialist role (PCCS Nurse Specialists, 2019) we would work collaboratively with the wider team and children, young people and their families to provide clear and concise information to support them to gain good understanding of the cardiac diagnosis, medications, signs and symptoms and other areas to maintain good health. Essentially, the overall aim being to work with them to develop skills in self-management, health literacy and enabling them to be empowered to make informed decisions in a more structured healthcare encounter (Lozano & Houtrow, 2018). It offers opportunities to work alongside the children and young people in a developmentally appropriate way so they learn to effectively interact with the healthcare system and its workers and enhance their understanding of health information (Boyle et al., 2015; Bruce et al., 2014; Lambert & Keogh, 2014a, 2014b).

CNS presence in outpatients should not be limited to Auckland-based patients. We currently do not attend the national visiting clinics. If this is not possible in the current climate, then development of a clinical template or guidance should be developed. Our teams of clinical nurses that support our SMOs in their away clinics could utilise them, ensuring all children and young people, no matter their domicile, will have equal opportunity to develop skills of self-management.

Interactive app/passport for cardiac children and families:

Lane et al. (2019) explored opportunities to improve home care education with clinicians and families who cared for children with heart disease. The aim was to develop a tool that would enhance delivery of the right education at the right time, in a way that would suit different learning needs, to foster safe transition from hospital to home. They developed a unique web-based app that could also be printed, utilising diverse parent education opportunities and incorporating multi-modal learning tools; such as the teach back method, pictures, icons and colour coding for easy navigation. The intervention could be used from the beginning of the family's heart journey with their child, continuing throughout their inpatient and outpatient care. Health passports have also been mooted by other authors as a technological mode for facilitating communication between healthcare providers and the young person, particularly, in preparing and transitioning to adult services (Lozano & Houtrow, 2018; P Moons et al., 2021; Tong & Kools, 2004). Meyers et al. (2019) found in their study about the use of technologies of health management that there was a desire for parents to communicate using the internet and cell phone, regardless of health literacy, with increased access to digital technologies even amongst the most disadvantaged populations. However, care would need to be taken to ensure that there is still a multi-modal approach to address access for all. As the group found that with lower health literacy there were still disparities with parent use of technologies, particularly when there was also a language barrier.

Developing and adopting a web-based application that is complemented by printable materials would be a valuable tool to reinforce information given in both the inpatient and outpatient setting. Integrating surgical pathway and follow up guidelines from the Cardiology Team at Starship (Stirling, 2019, September 30) provides the family with clear outlines of what to expect with follow-up and when, reinforcing the importance of lifelong commitment. Incorporating key aspects of self-management along the cardiac journey as the child and young person develops, they too can participate in learning and managing their own cardiac condition. Ensuring that by the time they are at transition age they have improved self-management and cardiac knowledge.

Consistent utilisation of alternative modalities for information sharing:

Providing health information in a variety of formats helps to address different learning styles of both parents and the young person. From the observations of clinicians in the PCCS outpatient

clinic it was clear that a verbal method of sharing information was preferred. The challenge with this is families being able to firstly understand what is being said, then remembering the aspects of the discussions that are important for ongoing care of their child. As I alluded to previously, there was no clear and consistent way clinicians checked-in with families to assess understanding. Providing general written information which covers the common areas that should be addressed during outpatient appointments, such as health promotion and prevention could be useful. This would complement their clinic letter, which has more descriptive information about their current state and what the surveillance plan is going forward. Utilising pictures to describe heart conditions and possible interventions and tests that may be ordered, provides another mode of delivery that can be easier to understand than the written word. Directing families to reputable internet resources that provide valuable information could perhaps be a permanent part of a letter.

Consideration of individuals health literacy skills is key to improving health promoting behaviours. We can provide all the educational materials in many different formats but underlying all of this is the ability of parents, children, and young people to be able to understand it. Health literacy is complex and entails not just a person's ability to read and write but also the capacity to understand how health and health systems work, to also follow a directed course of treatment that will improve health and well-being and prevent disease progression (Estacio et al., 2020; Lambert & Keogh, 2014a). We should be utilising tools to assess the health literacy skills of children, young people and families; this can be done in a non-judgemental way that is not time consuming (Jacobs et al., 2016; Lambert & Keogh, 2014b). Driessnack et al. (2014) mooted utilising an evidenced-based health literacy screening tool, which is easy-to-use and not time-consuming, to assess health literacy in an inpatient or outpatient setting – it is described as the “newest vital sign”. However, care needs to be taken where English is a second language and the assumption that it covers all aspects of health literacy but in the absence of other tools it is a starting point. We can then begin to tailor resources and interventions that ensures that health-related information and direction is understood (Driessnack et al., 2014; Hilton-Kamm & Haskell, 2015; Keim-Malpass et al., 2015).

Future direction

This project has provided an opportunity to examine and reflect on the way our service provides information to children and young people to support self-management of their cardiac illness. There is potential for research projects in the future that would provide more rounded and robust qualitative data about the experiences of children, young people and

families with congenital and acquired heart disease and also the clinicians that care for them. Two potential projects could look at:

1. Interviewing children, young people and their families to ascertain what their current experience is of the outpatient clinic, what we do well and what are areas that we need to work on to meet the needs of their children.
2. Interviewing clinicians who provide the care in the outpatient clinic to elicit what works for them currently, what areas they feel they do well and what direction we could take to continue to improve health outcomes for our population.

Conclusion

Undertaking a research based approach to this project utilising the framework of Rosswurm and Larrabee, 2009 (Melnik & Fineout-Overholt, 2015), has provided insight into what our service currently provides in health information to support the development of self-management for cardiac children and young people. Immersing myself in the practice environment by taking in the outpatient physical space and observing clinicians in the practice environment provided useful information on which we can build our future state. Clinicians that work in the paediatric cardiology outpatients provide care that addresses aspects of self-management, however after reviewing the literature and analysing what was observed we have the propensity to improve health outcomes, not only for cardiac children but also for other chronic conditions in the paediatric population. The paucity of literature about what the purpose of a cardiology outpatient clinic is, who should be involved and what the structure of the appointment should be, could be addressed by the recommendations identified in this project. However, this was not possible within the timeframe of this particular practice project. Developing practice change that is evidence-based and incorporates the findings outlined will only strengthen our current practice.

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Appendix 1 – Letter for clinicians

To:

Thank you for taking the time to consider being part of this exciting project that I am undertaking in the Paediatric Cardiac Outpatient department.

The aim of the project is to look at “Supporting chronic cardiac illness self-management in young people: how can we optimise health information delivery in the Paediatric Cardiology Outpatient department?”

I would like to invite you to participate in being observed during consultation with our young people and their families. I will be looking at how we deliver information and the different modalities we use to provide this. As well as what information is shared during the consultation by different clinicians.

I will be comparing what I see to what is currently in the literature and observing other paediatric outpatient areas who see chronic illnesses (e.g. diabetes, cystic fibrosis). If a gap is acknowledged, then a practice change would be developed to enhance what we already provide and ultimately improve outcomes for our young people and their families.

It is anticipated that this will not impact on your daily work, it will be incorporated into the daily running of a normal outpatient clinic. If further information is required it would be at the convenience of you, as the clinician. The material that I gather will remain anonymous, there will be no personal identifiable information included in the final presentation of the project.

Thank you for taking the time to read this sheet, if you would like further information or would like to discuss this further with me, please contact me by:

Phone – 021723584 or email NAnderson@adhb.govt.nz

If you are willing to participate, please write your name and date below:

Name:

Date:

Thank you
Nikki Anderson
Post Graduate Student – Masters of Health Practice
Auckland University of Technology

Appendix 2 – Letter for Caregivers

Hi,

My name is Nikki and I am a clinical nurse specialist who works here in the paediatric cardiology department. I am doing a project looking at how and what information is shared with you and your child in the outpatient clinic, as part of my master's at Auckland University of Technology.

I will be observing how the doctor or nurse interacts with you and your child during your clinic appointment and making notes on how and what they talk to you about. What I won't be doing is making notes on how you interact with the doctor or nurse. None of your child's information will be shared in the final presentation.

As a parent though, if you do not wish for me to be present it is your right to say no and this will be respected. I will not observe you and your child's clinic appointment for the purpose of the project.

Thank you for taking the time to read this sheet, if you would like further information or would like to discuss this further with me, please contact me by:

Phone – 021723584 or email NAnderson@adhb.govt.nz

Thank you
Nikki Anderson
Post Graduate Student – Masters of Health Practice
Auckland University of Technology

Appendix 3 A – notation version 1

How – is the information delivered.	What is the purpose of the visit today
Healthy lifestyle coaching	Psychosocial – how are you and the family doing

Appendix 3 B – Notation version 2

How – is the information delivered.	What is the purpose of the visit today
Healthy lifestyle coaching	Psychosocial – how are you and the family doing

Date	NHI	Ethnicity
Personnel	Time in each session	Diagnosis
SMO		
REG		
Fellow		
Nurse		
Other		
NOTES		

Appendix 4 – Internal data

Clinician who saw them	Number		Ethnicity	Number
SMO only	2		NZ European	5
SMO and Fellow	3		Maori	7
SMO and Registrar	8		Pacific	2
SMO and Adolescent Nurse Specialist	1		Other	
Total	14			

	Registrar	Fellow	Nurse Specialist	SMO
Symptoms	IIII III	II		I
Medications	IIII	I	-	I
Dental	II	II	-	-
Endocarditis prevention	-	-	-	-
Healthy Eating	II	I	-	II
Exercise	IIII	III	-	IIII
Immunisation/Flu Vaccine	I	-	-	-
School/Development	IIII	III	-	II
Surveillance/Follow up plan	-	-	-	IIII IIII
Engaging or attempting to engage	IIII I	II	I	IIII II
Purpose of visit/why are you here	III	-	-	I
Questions at the end or from family	IIII	I	I	IIII I

Appendix 5 – International Feedback

Questions asked	Melbourne	Brisbane
<p>1) How is information given</p> <p>a) Verbal</p> <p>b) written</p> <p>c) directed to websites, if so any recommendations</p>	<ul style="list-style-type: none"> • Provided in all formats based on assessment of the child and family • Discussion with the cardiologist occurs in relation to their condition or diagnosis, then they may print out material for families to take away or direct to appropriate resources • Nurse may also print or refer to appropriate resources and reinforce elements of chronic health management • For example; the nurse may discuss signs and symptoms of a TOF spell and when to seek help 	<ul style="list-style-type: none"> • Depending on diagnosis we give education about what to look for if there is failure symptoms • We give our own information sheets out when feel it is helpful • We will refer people to have a look at our heartkids website
<p>2) Do you follow a set plan or pathway that you follow for the clinic appointments? Are there areas you always cover?</p> <p>a) Recap diagnosis</p> <p>b) review medications</p> <p>c) where to from here – short term</p> <p>d) what the future journey may look like</p> <p>e) preventative care (i.e. dental, skin care, immunisations, healthy eating, exercise?)</p>	<ul style="list-style-type: none"> • Nursing staff assess general health concerns, diet/feeding, growth (weight loss or gain), exercise tolerance, psychological concerns (school, family, social) • Nurses will refer to dietetics, social work, child life therapy as required • Consultants will cover medications, current state, plan going forward (review timeframe, further diagnostic test required, surgery) timeline for plan • Dental care and immunisations are recommended and discussed at every visit 	<ul style="list-style-type: none"> • We do their height and weight and chart – we go through all the questions about preventative health – ask how feeding is going and how they go with activity and sport etc – do they tire? Do they increase their work of breathing if babies. We do an ECG and a set of obs. • The Doctors will discuss the diagnosis when they are seen either pre or post echo • Nurses list the current medications and the doctors review • Follow up appointment is arranged and we direct the to go to their GP for monitoring. Also, encouraging them to see their general paediatrician • Nurses check all the preventative questions

		every time and reinforce the importance of them
3) Who sees the patients	<ul style="list-style-type: none"> • Cardiology Review <ul style="list-style-type: none"> ○ See nurse, fellow (if consultant oncall/or sub speciality - EP/VAD/Heart Failure), consultant ○ testing occurs by cardiac physiologists ○ Registrar is in clinic one session per week for teaching purposes • Ward Review <ul style="list-style-type: none"> ○ Nurse led clinic ○ See nurse, tests and reviewed by resident/reg +/- fellow • Heart failure – VAD/Tx <ul style="list-style-type: none"> ○ Runs once a week multidisciplinary (Clinical nurse consultant, fellow and consultant all review), allied health invited to attend as needed • Pre Admission clinic <ul style="list-style-type: none"> ○ Runs every day for pre cath and cardiac surgery ○ Nurse led, involves coordinating and assessing admission preparedness, lengthy visit of 5+hours ○ medical review of resident /registrar ○ fellow review ○ surgical consent ○ allied health as required – maybe referred for when patient is admitted • Pulmonary Hypertension <ul style="list-style-type: none"> ○ Once a month, multidisciplinary ○ Cardiac Nurse Consultant, fellow and 	<ul style="list-style-type: none"> • Nurses see all the patient first • It is always a consultant appointment • They are working on setting up a nurse led clinic, they have the support of their consultant

	<p>consultants</p> <ul style="list-style-type: none"> • All clinicians utilise the clinic space on designated days and times. Nursing Staff have their own consulting room for the duration that they are required in clinic 	
4) Do families have an electronic record that they keep with the or access that has their child's cardiac health record	<ul style="list-style-type: none"> • Parents can sign up for the RCH portal and they can access their child's record, appointments for all visits related to the Royal Children's Hospital. They also get sent a hard copy after their visit posted to their home address 	<ul style="list-style-type: none"> • No but how good would that be!

