To care and be cared for:

Co-designing healthcare with caregivers of children with bleeding disorders.

A thesis
submitted in partial fulfilment
of the requirements for the degree
of
Masters of Applied Psychology (Community)
School of Psychology and Social Sciences
at
The University of Waikato
by
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2025

Abstract

This thesis investigates the experiences of caregivers of children with bleeding disorders in New Zealand, focusing on the co-design of healthcare services to enhance caregiving outcomes. Bleeding disorders such as haemophilia and von Willebrand's disease present significant challenges for caregivers, including emotional, financial, and social burdens. Grounded in a Community Psychology framework, this research employs an Experience-Based Co-Design (EBCD) methodology to centre caregivers' lived experiences, enabling the identification of key areas for healthcare service improvement. Drawing on literature concerning chronic illness, relational healthcare, and social determinants of health, the study situates caregiving experiences within a broader socio-cultural and historical context. Particular attention is given to the implications of New Zealand's Pae Ora (Healthy Futures) Act 2022, which mandates collaborative healthcare design involving consumers and their whānau. Through a participatory process utilising one-on-one experience-based co-design workshops with caregivers, focussing on their experiences of children from 0-2 years of age, and integrating perspectives from healthcare professionals, this study identifies systemic barriers and opportunities for creating more inclusive, supportive healthcare services. The findings highlight the critical role of relational factors in healthcare, the influence of cultural identity on caregiving experiences, and the potential of EBCD approaches to inform policy and practice under the Pae Ora's co-design requirements. This research underscores the need for culturally competent, relationally-centred care models and offers practical recommendations for enhancing caregiver engagement in healthcare co-design.

Acknowledgements

Firstly, to each of the caregivers who shared their story, thank you. Your love, bravery, resourcefulness, and willingness to improve the journey for new caregivers left me humbled. There was no greater privilege for me in this work than to ask “How is your child now?” and to see each caregiver’s eyes light up as they shared stories of thriving children and young adults.

I would like to thank my supervisors, Drs Ottilie Stolte and Cate Curtis. Your support and expertise have been invaluable.

Lastly, to my wife Laura, my daughter Lucy, and son Joseph (you made it just in time!). You are the core of my community, I hope that I can nudge the world you live inhabit in the right direction.

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Chapter 1: Introduction.

1.1 Caregiving in context.

In New Zealand, caregiving plays a pivotal role in the lives of many, with one in ten people providing care to family members or loved ones. This caregiver population spans all demographics, cutting across age, ethnicity, and socio-economic lines (Ministry of Social Development, 2021). Among these caregivers are parents and guardians of children with bleeding disorders, a group whose experiences remain underexplored yet are critical to understanding the intersections of healthcare, family dynamics, and community well-being. Bleeding disorders such as haemophilia and von Willebrand's disease are rare but life-altering, requiring not only routine clinical care but also continuous vigilance and emotional resilience from caregivers. For many, this caregiving journey is further complicated by the hereditary nature of these disorders, which means caregivers may themselves carry the genetic traits or have prior personal experiences with the condition.

The role of a caregiver in this context extends beyond the physical aspects of administering treatment or managing symptoms. It involves coordinating complex healthcare needs, acting as a bridge between healthcare professionals and the child's day-to-day life, and advocating for the best possible outcomes in a system often fraught with inequities. In New Zealand, these challenges are amplified for Māori and other minority groups, who face additional systemic barriers, including institutional racism and a lack of culturally competent care. The physical and emotional toll of caregiving is significant, with caregivers reporting heightened levels of stress, anxiety, and financial strain as they navigate this intricate and often isolating role (Blom et al., 2023; Zimmerman & Valentino, 2013).

The dual nature of healthcare, comprising technical care (what is done) and relational care (how it is experienced), is particularly relevant in the context of chronic illnesses like bleeding disorders, where support from healthcare services is lifelong and established at a very early age. While advancements in treatment technologies, such as the new medication Emicizumab, and genetic therapies, offer promising clinical outcomes, the relational aspects of care remain underdeveloped. Research consistently shows that healthcare outcomes are enhanced when caregivers and patients experience compassionate, culturally aware, and relationship-centred interactions with healthcare professionals (Beach et al., 2006; Fernando & Consedine, 2014). However, these relational elements are often overlooked in favour of transactional efficiency, leaving caregivers feeling undervalued and unsupported.

The Pae Ora (Healthy Futures) Act (2022) marks a watershed moment for healthcare in New Zealand, providing a legislative mandate for healthcare systems to collaborate with consumers and their whānau in the design and delivery of services. This co-design approach aligns with a global movement toward participatory healthcare, recognising caregivers and patients as subject matter experts with unique insights into their experiences. Yet, while the Act sets the stage for transformative change, it stops short of prescribing a standardised framework for implementing co-design, leaving healthcare entities to navigate this complex terrain independently.

1.2 Research aims and approach.

This thesis responds to these gaps by adopting an Experience-Based Co-Design (EBCD) methodology to explore the lived experiences of caregivers for children with bleeding disorders. Rooted in the principles of Community Psychology, EBCD emphasises collaboration, empowerment, and the democratisation of knowledge. By centring caregivers' voices, this research seeks to uncover the systemic barriers and relational dynamics that shape their experiences while identifying actionable strategies for healthcare improvement.

Specifically, this research aims to:

1. Understand Caregiving Experiences: Examine the lived experiences of caregivers of young children (from birth to two years of age) with bleeding disorders in their interactions with the healthcare system.
2. Scope Opportunities for Co-Design: Utilise the insights gained from caregivers to identify areas for potential improvement in healthcare service delivery.
3. Evaluate EBCD for Pae Ora Compliance: Assess the suitability of EBCD as a methodology for meeting the co-design requirements outlined in the Pae Ora (Healthy Futures) Act 2022.

1.3 Significance of the study

The significance of this research lies in its potential to bridge critical gaps in knowledge and practice. By foregrounding the voices of caregivers, it challenges the traditional hierarchies of expertise that often marginalise those with lived experience.

This study also addresses an urgent need for culturally responsive and relationally centred healthcare in New Zealand, particularly for Māori caregivers and their whānau. This research seeks to contribute to the broader discourse on participatory healthcare, offer practical recommendations for integrating EBCD into policy and support practice under the Pae Ora framework.

1.4 Thesis Structure

This thesis is organised into six chapters. Chapter 2 provides a comprehensive literature review, situating the research within existing scholarship on health and well-being, caregiving, co-design, and the unique challenges of bleeding disorders. Chapter 3 outlines the methodological approach, detailing the use of EBCD within a Community Psychology framework. Chapter 4 presents the results of the research, highlighting key themes and insights from caregiver narratives. Chapter 5 discusses these findings in the context of existing literature, exploring their implications for healthcare policy, practice, and future research. Finally, Chapter 6 concludes the thesis with a summary of findings, recommendations, and reflections on the study's limitations and contributions.

Chapter 2: Literature Review

In this chapter, I provide an overview of research that will allow the reader to understand the experiences of caregivers for those with bleeding disorders, and also for the reader to critically situate themselves (and the researcher) in relation to lived experiences of wellbeing, healthcare, privilege, and racism. In choosing this approach, it is my intent to centre the caregivers and bleeding disorder community.

I begin by exploring concepts of health and wellbeing, and how these apply to the lived experience of those with chronic illness. I then describe bleeding disorders, and in particular haemophilia and von Willebrand's Disorder ("vWD"), as these two conditions are the most common in New Zealand. It is necessary to describe each disorder's treatment so that the reader can understand what caregivers must do and the lived experience of bleeding disorders in New Zealand.

The reader is then introduced to Haemophilia New Zealand, a foundation providing support, advocacy, and community for those with bleeding disorders, before a detailed exploration of community and identity which will serve to ground the reader in preparation for subsequent sections, particularly the relationship between clinical treatment, non-clinical facets of care, and lived experiences.

The experiences of Māori and other minorities are discussed throughout this chapter, before dedicating particular focus to the role of Te Tiriti o Waitangi to understand cultural safety, and the obligations of the Crown and Healthcare Professionals ("HCP's") in providing healthcare services.

Equipped with an understanding of wellbeing, bleeding disorders, and identity, I describe for the reader what is currently known about the experiences of caregivers for young children with chronic illnesses.

Finally, the Pae Ora (Healthy Futures) Act 2022 ("Pae Ora (Healthy Futures) Act," 2022) is described, as it is this legislation that has mandated the co-design of services and resources by healthcare entities for those communities with particular needs, without mandating a methodology for doing so. Pae Ora's intent and implementation can be viewed as underpinning the practice of healthcare service co-design in New Zealand from this point forward.

3.1 Health and Wellbeing

It is now widely understood in Western society that health is greater than the absence of disease or infirmity, and can instead be conceptualised as a "state of physical, mental, and social well-being" (Committee on Quality Health Care in America, 2001; World Health Organization, 1995, p. 1). To be appreciated and achieved, health must be understood to represent collective cultural experiences of wellbeing (Durie, 1985), and personal, idiographic, perspectives (Gulliford et al., 2002).

This understanding reflects long held understandings of wellbeing in indigenous cultures (Tsai, 1999). Many attempts have been made to bring Māori conceptions of wellbeing to mainstream medicine in New Zealand to both address the deep harms of colonisation, achieve health equity, and benefit all New Zealanders (Moewaka Barnes & McCreanor, 2019). Different approaches have been developed, with perhaps the Meihana Model (Pitama et al., 2007) , and Te Whare Tapa Whā (Rochford, 2004) being best known. These approaches, and others, share a common understanding that wellbeing is achieved through relational engagement of person and community at all stages of healthcare design and delivery. Wilson et. al., (2021) further observe that health and wellbeing is a product of historical and socio-political factors.

In the Western healthcare model predominant in New Zealand, disease and illness can be described as a form of "biological discontinuity" (Fabrega, 1973, p. 781) and yet all illness and disease occurs in living people, whose personal characteristics coalesce to produce uniquely subjective experiences of "body, self, and world" vastly more complex than their diagnosis (Fisher, 2014, p. 34). It is through accessing healthcare that individuals and their caregivers seek to achieve improved wellbeing (Gulliford et al., 2002).

These holistic, adaptive, definitions are especially true for those living with chronic diseases, such as bleeding disorders, where disease and its effects are not transitory events, but rather part of lifelong experience. Health, while living with chronic disease, can be understood as the "dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment." (Krahn et al., 2021). Adaptive definitions of health understand and celebrate individual strengths, values, and quality of life just as they help guide meaningful treatment where cure is not possible (McClimans & Browne, 2012).

"Health is an elusive as well as a motivating idea. By replacing perfection with adaptation, we get closer to a more compassionate, comforting, and creative programme for medicine—one to which we can all contribute." (Lancet, 2009, p. 781).

When utilising healthcare services, consumers seek care comprised of technical and relational aspects (Iles, 2013) in order to support the adaptation required to balance all facets of wellbeing. Technical, or transactional care, comprises those aspects of treatment delivered by Healthcare Professionals ("HCP's") while the second aspect, relational care, is comprised of the consumer's interactions with HCPs, and broader experiences throughout the process of accessing care. It is well established that these two aspects are co-reliant in producing healthcare outcomes (Mazzarelli et al., 2019) and that relational experiences in healthcare may undermine treatment goals (Graham & Masters-Awatere, 2020), or enhance them (Beach et al., 2006). Indeed, once health is viewed as an adaptive process of seeking to balance facets of wellbeing, distinctions between technical aspects of care – *what* is done – and relational aspects of care – *how* it is done and experienced – begin to become permeable.

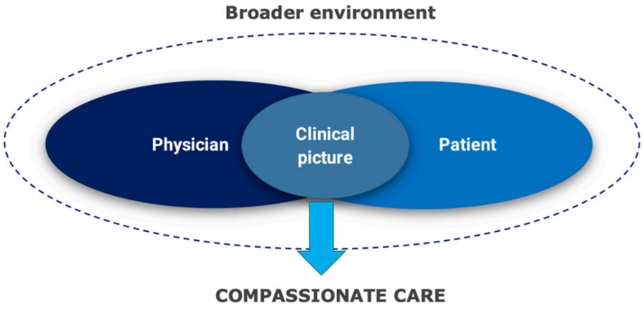
When consumers seek healthcare, it is the excellence of clinical skills that is the primary driver of outcomes (Mazzarelli et al., 2019). However in order to benefit from technical aspects of care, the consumer must present to clinics (Byrne et al., 2021), comply with treatment protocols (Beach et al., 2006), and experience being cared for (Aboumatar et al., 2013). However, technical knowledge is of no value if those who may benefit from it are unable or unwilling to utilise it.

The role of relational care, particularly in the treatment of chronic illness, means that the HCP can be regarded as not only the provider of treatment, but as a means of treatment (McKay et al., 2006). When assessing the quality of this relational medicine, research establishes a trend of HCPs overestimating their own relational competency, indicating that the most accurate measurement of the relational experience is gained from understanding the consumer's perspective (Hollinger-Samson & Pearson, 2000). Successful care for people with lifelong, chronic conditions, such as bleeding disorders, is reliant upon compliance with treatment protocols, consumer perceptions of personal responsibility, and the consumers perceived threats of failure, where blaming consumers can undermine relational care (Jallinoja et al., 2007).

In accepting that relational aspects of care are critical to outcomes, it becomes apparent that for relational care to be delivered, HCPs must know the patient as a person in order to establish a relationship supporting safe, expert, care (Zolnierek, 2014). A high quality of relational care creates a therapeutic relationship between consumer and HCP. This relationship emerges from HCP factors, consumer (patient) factors, clinical picture, and the broader environment, as described by the Transactional Model of Physician Compassion and shown below (Fernando & Consedine, 2014).

Figure 1

The Transactional model of physician compassion suggests physician compassion is the result of dynamic influences of physician, patient, clinical, and environmental factors.



Note. Reprinted from Fernando and Consedine (2014), Copyright 2014 by Antonio Fernando and Nathan Consedine.

Pavlova et al.'s systematic review (2022) shows that factors contributing to, or detracting from, this relationship are predictable, and correlate with a range of heuristic processes, biases, and stressors such as ease of communication, judgement of the consumer's condition, racism, and organisational pressures contributing. Pavlova et al. further show that organisational values and practices influence the practice of relational care independently from the practice of technical care (2023).

Treatment for Haemophilia and vWD are discussed below, however it is advances in the understanding and provision of relational medicine which offer one of the most significant opportunities to improve the care of those with acute or chronic disease. A variety of emerging approaches such as compassion skills training and co-design of services are now placing the consumer at the heart of their own care, improving healthcare outcomes, reducing costs, and even improving the wellbeing of the HCPs providing care (Bertakis & Azari, 2011; Egbert et al., 1963; Lelorain et al., 2012; Wilkinson et al., 2017).

3.2 Social Determinants of Health

Health is also determined by broad social factors beyond the control of individuals or families.

Social determinants of health "are the conditions in which people are born, grow, live, work and age, including the health system" (Hodgetts et al., 2016, p. 426). Social determinants of health explain the avoidable and inequitable experiences of healthcare experienced across society and include:

"employment patterns and conditions, income, physical hardship, social exclusions, colonialism and racism, violence, educational processes, stigma, food and housing [in]securities, and access to health and social services" (Hodgetts et al., 2016, p. 425).

These factors of advantage or disadvantage become cumulative over time, driving widening gaps between groups across a broad range of measures (Melo et al., 2019). In the case of chronic diseases, the experiences of these social determinants of health, may become part of communal experience, "forming a vector of cumulative disadvantage" (Park et al., 2019, p. 44).

Social determinants of health in Aotearoa are responsible for Māori experiencing significant and enduring health inequalities, regardless of illness type (Waitangi Tribunal, 2019a; Tribunal, 2019b), undermining technical and relational aspects of care. Specifically, colonialism, racism, and the resulting social disadvantage which has accumulated since Māori's first contact with European explorers in 1642 (Saunders, 1896) has caused inequitable health access and outcomes for Māori in Aotearoa (Lorgelly & Exeter, 2023).

The Pae Ora (Healthy Futures) Act (2022) ("("Pae Ora (Healthy Futures) Act," 2022)") came in to effect on 1 July 2022, seeking to address the health inequalities experienced throughout the healthcare system through widespread changes to both the structure of the healthcare system, and how care is provided to consumers. Changes to the provision of care are enacted through a Code of Expectations ("The Code") for health entities' engagement with consumers and whānau (Te Tāhū Hauora Health Quality & Safety Commission, 2022). The Code centres the lived experience of consumers, whānau, and their communities as “experts by experience”, and requires health entities to engage with these groups to co-design collective development of “organisational priorities, processes, and evaluation” (Te Tāhū Hauora Health Quality & Safety Commission, 2022) (2.1).

Health care experiences are key predictors of outcomes, costs, experiences, and as interactions with public systems, contribute critically to identity and relationships. These interactions are governed by power, in a system that has excelled at understanding pathology, rather than wellbeing, in what Sturmberg et al. describe as the role of a “repair shop” (2019, p. 2; Woolliscroft et al., 2023) .

A research gap currently exists in the practical application of co-design methods with communities experiencing chronic illness in New Zealand. This gap is important, because communities may develop amongst groups of people experiencing shared chronic conditions (Steinberg, 2020), and research shows that outcomes and experiences are improved where consumers contribute to service co-design and experience being known as people by HCPs (Beach et al., 2006; Eyles et al., 2016; Haines et al., 2019). Healthcare is a complex, adaptive system (Covvey, 2018), and the process of service co-design allows consumers to influence this system in ways that may help it to not only know them, but to reflect and respond to their lived experiences (Noorbergen et al., 2021).

3.3 Bleeding Disorders: Haemophilia and von Willebrands Disorder

This research is centered upon the caregivers of those with bleeding disorders. Bleeding disorders are defined as any disorder compromising haemostasis: “the tightly regulated processes of blood clotting, platelet activation, and vascular repair" (Versteeg et al., 2013, p. 1). Bleeding disorders can occur through genetic factors from birth, and be acquired later in life, often as the result of other medical conditions and their treatment (Triplett, 2000). The severity of all bleeding disorders can vary significantly based on complex, interrelated factors such as the deficiency of a particular blood factor, the existence of inhibitors that reduce treatment efficacy, co-morbid conditions, and progression over the life course of the individual (McLaughlin et al., 2017).

It is estimated that approximately 500 people in New Zealand live with haemophilia (Park et al., 2019), while vWD affects 1 in 100 people (Bowman et al., 2010; Rodeghiero et al., 1987), suggesting up to approximately 50,000 people in New Zealand are affected, although research suggests up to 90% of vWD cases are undiagnosed (James, 2017).

Although haemophilia and vWD are genetically heritable, the underlying cause is a genetic change which can occur randomly, in the absence of family history. Approximately one third of haemophilia cases are the result of random genetic changes, and occur with no family history (Lorenzo et al., 2000). In addition to these novel cases, parents may be unaware of familial bleeding disorders and pass these to their children unknowingly (MacLean et al., 2004).

In babies and toddlers, the challenges of bleeding disorders are amplified due to the range of standard medical procedures they may experience, injuries experienced as a result of normal exploration and development, and the child's inability to communicate pain in a detailed way resulting in a need for caregivers to monitor the child carefully

(Kulkarni, 2001; Ljung, 2002). Caregivers often report discovering their child's haemophilia after the routine heel prick test conducted at birth or after minor injuries bleed uncontrollably. The mis-evaluation of these injuries as instances of child abuse is common and discussed in detail later in this chapter (Carpenter et al., 2013).

Haemophilia and vWD differ in cause, heritability, presentation and symptoms. Each disorder is discussed separately below.

3.4 Haemophilia

Haemophilia is the result of the absence or deficiency of plasma proteins, resulting in blood that is slow to, or unable, to clot effectively. Haemophilia has two common subtypes. Haemophilia A (a deficiency in factor VIII) and haemophilia B (a deficiency in factor IX). Haemophilia is further categorised by severity in to three groups: severe haemophilia, where a person has less than 1% of normal factor levels, moderate haemophilia, where levels of factor are 1-5%, and mild haemophilia where factor levels are 5-40% (Berntorp et al., 2021).

Haemophilia A is more common, occurring in 1:5000 male births, whereas Haemophilia B occurs in 1:30,000 male births. Haemophilia A and B are inherited via a sex-linked recessive pattern, meaning that while haemophilia occurs only in males, it is carried by females who do not experience symptoms, but who may in turn pass it to their male children (Zimmerman & Valentino, 2013).

While blood loss and bruising are superficially observable and associated with haemophilia, it is the musculoskeletal bleeding inside joints, and internal bleeding, that can cause long term damage. This bleeding results in inflammation that may be slow to resolve even if treated. Repeated inflammatory events within the joints can result in permanent arthritis, compromising mobility and quality of life. The predisposition to these musculoskeletal bleeds, and their severity, correlates with the degree to which a clotting factor is deficient, with those experiencing severe haemophilia prone to bleeds that may be spontaneous, or the result of microtraumas unnoticed by the person (Madhok et al., 1991; Stephensen, 2000). In contrast to microtrauma, haemophilia also presents acute risks in the event of intracranial bleeding, which is the leading cause of death in people with haemophilia. The challenges of managing risks of bleeding and blood loss complicates many other areas of routine medical care, including dental treatment, and many forms of surgery.

3.5 Von Willebrand's Disorder

Von Willebrand's Disorder (vWD") is hereditary. Unlike haemophilia, it can be passed from male or female parents, and can affect people of any sex.

vWD is caused by quantitative or qualitative deficiencies in blood plasma von Willebrand's factor ("vWBF"), which mediates platelet function and blood coagulation (James & Goodeve, 2011). Deficiencies in vWBF may also result in reduced blood clotting factor VIII, similar to that experienced by those with Haemophilia A. It affects between 0.1% to 1% of the population (Werner et al., 1993), with common symptoms including nosebleeds, easy bruising, sloughing of scabs and coagulation due to the unstable platelet adhesion. In severe cases, spontaneous bleeding into joints and tissue, similar to haemophilia, may occur.

vWD poses additional risks to females, complicating bleeding involved with menstruation, pregnancy, and childbirth, with 70-80% of females with vWD experiencing menorrhagia, elevated risks of miscarriage, post-partum haemorrhage, and bruising following giving birth (Baker et al., 2024; Tosetto et al., 2006). These risks can be attenuated by specialist obstetric care continuing pregnancy (Kadir et al., 1998). For caregivers who are biological parents of a child with a bleeding disorder, birth is a pivotal part of the caregiving journey, where a caregiver's own bleeding disorder may impact their role as caregiver.

3.6 Diagnosis of Bleeding Disorders

Diagnosis of both haemophilia and vWD takes one of two routes. The first of these routes is confirmation of an anticipated condition, where the genetic risk is known prior to birth, while the second route of diagnosis occurs through testing following symptoms.

3.7 Where a bleeding disorder is anticipated.

In the case of babies with a known family history of bleeding disorders, an expectant mother may be offered prenatal diagnostic testing for haemophilia (Ljung, 1996). This testing requires cells of foetal origin and is not without risk to the growing foetus (Tabor et al., 2009), a factor contributing to some mothers of children with haemophilia reporting during research that they declined testing. It is important to note that as there is no cure or prenatal treatment for haemophilia, the decision to undergo testing, and if a positive test is returned, how to act on this information, in particular whether to seek abortion, is a complex set of decisions influenced by "moral, social, financial, and religious factors" (Knight & Miller, 2023, p. 14).

Where a bleeding disorder is confirmed or anticipated, birthing protocols will adapt in order to reduce the risks of bleeding, in particular intracranial haemorrhage. These changes to birthing are clinical decisions made in relation to each specific birth, with no difference in risks reported between caesarean or vaginal births (Kulkarni et al., 2017).

In cases where no prenatal testing has confirmed a bleeding disorder diagnosis will occur through genetic testing and testing of blood in order to determine type and severity of any disorder (Bick, 2019).

3.8 Where no bleeding disorder is anticipated

Where no bleeding disorder is anticipated, diagnosis occurs as the result of symptoms occurring, for example bruising while crawling, bleeding post heel prick test, circumcision, or trauma, with a correlation between higher severity of the disorder and earlier diagnoses (Chambost et al., 2002; Rosner, 1969). The risk of mild and moderate bleeding disorders not being diagnosed until symptoms become severe, or complications occur is significant (Benson et al., 2018) with an elevated risk of iatrogenic (treatment related) injuries prior to diagnosis, in particular during instrumental births (MacLean et al., 2004).

Observable symptoms, such as bruising and bleeding may also be misattributed to abuse or neglect, particularly where clinicians do not account for biases such as racism or socio-economic biases. Where this occurs, these social determinants of health actively inhibit the accurate diagnosis and treatment of people with bleeding disorders and cause ruptures in the caregiver-clinician relationship (Carpenter et al., 2013; Park et al., 2019).

Once a bleeding disorder is suspected, diagnosis occurs through genetic testing and testing of blood in order to determine type and severity of any disorder. Testing may also involve the evaluation of other family members with a possible bleeding history (Bick, 2019; Castaman et al., 2013). Communication of a confirmed bleeding disorder is made to caregivers by the Haematologist, and following diagnosis, caregivers will be referred to Haemophilia clinic for ongoing care.

3.9 The Haematologist and Clinic

Haematologists are doctors with specialist training pertaining to disorders of blood and blood producing organs such as bone marrow, spleen, and lymphoid tissue. In order to become a haematologist, a person must successfully complete:

- training as a medical doctor,
- at least two years post-graduate clinical years,
- the Basic Pathological Sciences Examination
- competitive application for a place on a 5-year haematology training program accredited by either the Royal College of Pathologists of Australasia (RCPA) or the Royal Australasian College of Physicians (RACP).

In addition to this, all practising doctors must register with Te Kaunihera Rata o Aotearoa / Medical Council of New Zealand and adhere to its standards.

The Haematology clinic uniformly invites those with bleeding disorders to attend “Haemophilia Clinic”, where a specialist multidisciplinary team provides care which may include physiotherapy, monitoring, and administration of medication. These clinics are located at main centres, formerly known as DHB's, meaning that many patients and caregivers must travel to attend.

3.10 Treatment and Management of Haemophilia and von Willebrand's Disorder

Treatment and management of bleeding disorders can be broadly distinguished in to two categories: prophylactic and on-demand.

Prophylactic treatment involves the regular administration of therapeutic products in order to reduce the risk of symptoms. This will vary from person to person in order to reflect their particular disorder characteristics, risks, personal goals and situation.

In contrast to prophylactic treatment, on-demand treatment involves the administering of therapeutic products in order to address symptoms of bleeding disorders as they arise. Treatment for vWD and Haemophilia are discussed below. The intent of this description is not clinical comprehensiveness, but rather to allow the reader a view in to how those living with bleeding disorders, or caring for children with one, go about their lives and manage their condition. Many caregivers of those with bleeding disorders will be simultaneously managing their own bleeding disorder, or providing care for other immediate family members with one.

3.11 Treatment of Haemophilia

Advancements in the treatment of haemophilia, especially severe haemophilia, has seen the average life expectancy of a person with haemophilia improve from only 11-13 years until the 1970's, with life expectancy now in the normal range, provided prophylactic treatment is started in the early years of life (Franchini & Mannucci, 2012; Srivastava et al., 2013).

Prophylaxis in haemophilia is primarily used by those with severe haemophilia, following research that those with moderate and mild forms of the disorder are much less likely to experience spontaneous bleeding (Fischer et al., 2001). Prophylaxis is achieved through the intravenous injection of a synthetic blood factor concentrate to replace that which the person lacks. Prophylaxis prevents bleeding and damage to joints, in order to preserve biomechanical function and avoid the chronic pain caused by joint disease and treatment interventions such as joint replacement (Roosendaal & Lafeber, 2006). This primary prophylaxis is long term, beginning before 2 years of age, and is required approximately 2-3 times per week.

A key challenge with the administration of intravenous injections in babies and toddlers is venous access to small, hard to locate, veins. Caregivers will be trained to administer these injections by specialist haematology nurses, however even with this training, the process of restraining a baby, inflicting the pain of injection (or often several, if a vein cannot be accessed), means that many toddlers with receive a central venous access device, referred to by people with haemophilia as 'porta-caths'. These devices are small, bubble like, receptacles fitted in the chest cavity and connected to a central artery, allowing factor to be injected through the skin. Although these devices significantly ease administration of blood factor, the come with risks of sepsis, infection, and thrombosis, meaning that many children will require surgery to relocate, replace, or remove these. Surgery is performed under general anaesthetic, and also carries risks to the child. Children with haemophilia will learn to self-administer, with the age of competent self-administration beginning from approximately 6 years of age, and complete self-management of prophylaxis being achieved at approximately 23 years of age (Kulkarni et al., 2017; Ljung, 2002; Schrijvers et al., 2016).

On-demand treatment of haemophilia occurs when the person experiences a bleeding event, or traumatic injury likely to cause one, and takes the form of a supplemental administration of the deficient factor (Steen Carlsson et al., 2003). Where haematoma form as the result of pooled blood, a combination of physiotherapy and clinical monitoring is required (Sorenson et al., 2012).

Many people with haemophilia will develop inhibitors to treatment factor. Inhibitors can be thought of as a form of resistance to treatment not dissimilar to antibiotic resistance. Where a person develops treatment inhibitors, management may become significantly more complicated and less effective (Scharrer et al., 1999), also elevating risks where the person requires surgery of any sort.

3.12 Haemophilia Treatment Revolution: Emicizumab and Genetic Therapy

Haemophilia treatment was revolutionised with the advent of Emicizumab in 2017 (Mahlangu et al., 2022). Emicizumab is a sub-cutaneous injection with a half-life of approximately four weeks. Marketed under the brand name “Hemlibre”, it mimics the effects of Factor VIII, the deficient factor in Haemophilia A, and is not compromised by the presence of inhibitors such as factor replacement therapy.

The impact of a simple to administer, lower frequency treatment that does not require intravenous access has been described as “game changing” (Alcedo Andrade et al., 2024, p. 1) Emicizumab administration frequency varies based upon personal characteristics, varying from one to four weeks.

Emicizumab was originally approved for use in New Zealand in 2020, and restricted to those with severe haemophilia and the presence of inhibitors (Pharmac, 2020) at a cost of over NZ$700,000 per year based upon an 80kg person consuming 6240mg per year. Based upon the efficacy of this initial roll out, Pharmac extended Hemlibre availability to all people living with severe haemophilia in 2023 (Pharmac, 2023).

Genetic therapy to cure illness and disease heralds a new era of medicine. Treatment for haemophilia has been developed, however costs are prohibitively high, with an estimated best-case costing of USD$3,500,000 per person, and significant treatment hurdles still not overcome meaning that at this point in time, genetic therapy is not viable for New Zealanders (Bolous et al., 2021; Páramo, 2021). Gene therapy may soon offer haemophilia free future for New Zealanders.

3.13 Von Willebrand's Disorder Treatment

As with haemophilia, the severity of bleeding risk for people with vWB is usually proportional to the vWBF deficiency. Treatment involves the administering of Desmopressin, a synthetic hormone which triggers the release of vWBF stored in the body, by intravenous injection, intramuscular injection, or nasal spray, with the method dictated by symptoms and personal characteristics (James & Goodeve, 2011).

People receiving Desmopressin may experience reduced treatment efficacy where repeated doses are administered, along with side effects such as hyponatremia (dangerously low levels of sodium in blood), which poses particular risk to babies and young children, requiring careful monitoring (Castaman et al., 2013).

Tranexamic acid, a synthetic antifibrinolytic used to reduce bleeding in a wide range of applications, is also administered intravenously to improve clotting and reduce bleeding (Eghbali et al., 2016). Factor replacement therapies using concentrated vWBF and factor VIII blood products may be used to supplement Desmopressin and Tranexamic acid. Recent advances in the treatment of haemophilia, such as Emicizumab, or genetic treatment, have not coincided with similar advances for vWB.

3.14 Living Together with Bleeding Disorders: the Experience of Caregivers

Caregivers for children with chronic illnesses face unique challenges, while also contributing irreplaceable strengths in the care of their child. Conditions such as haemophilia and von Willebrand disease (VWD) not only affect the child but also impose significant emotional, financial, and social burdens on the parents and caregivers. It is also important to note that it is the caregiver who primarily monitors the child for symptoms of bleeding, administers therapies under normal circumstances, and provides comfort for children experiencing pain or distress as a result of treatment the caregiver has just administered. The identity of caregiver can best be viewed as additional to that of parent or guardian.

The following discussion explores this experience to provide a well-rounded perspective on the experiences of caregivers.

Emotional and Psychological Impact

Caregivers for children with chronic illnesses often experience profound emotional and psychological strain. Bleeding disorders require continuous vigilance and care, in particular as babies are unable to communicate symptoms such as stiff joints, which can lead to chronic stress, anxiety, and depression among caregivers (Zimmerman & Valentino, 2013). Research shows that the process of receiving a diagnosis of a bleeding disorder for one's child is in itself traumatic, with parents describing feelings of shock, sadness, guilt, and emotional overwhelm (Sheridan et al., 2023).

The burden on caregivers of children with haemophilia is deeply influenced by the child's medical condition and the family's sociodemographic background (Myrin Westesson et al., 2019). Parents frequently report high levels of anxiety due to the risk of spontaneous bleeding, which is a constant threat in haemophilia.

Research emphasises that caregivers of children with chronic illnesses often experience significant psychological distress (Cousino & Hazen, 2013). Cousins and Hazen report that the constant responsibility of managing the child's health can lead to feelings of helplessness and guilt. The psychological toll is also linked to the anticipation of future health complications, which can create a pervasive sense of uncertainty and fear. Parents of children with haemophilia, for example, may worry about long-term joint damage, complications from repeated bleeding, or the social challenges their child might face.

Financial Burden and Economic Strain

The financial implications of caring for a child with a chronic illness can be overwhelming. Price et al. (2015) explore the unmeasured costs of haemophilia, pointing out that families often face significant financial hardships. Many parents are forced to reduce their working hours or leave their jobs entirely to care for their child, resulting in a loss of income, in addition to bearing additional costs such as special equipment, travel to hospitals, and making homes safer for young babies and toddlers. Price et al. highlights that these financial strains are exacerbated by the financial and time burdens of care. These findings were echoed in the current research.

Furthermore, Castaman et al. (2023) discuss the economic burden associated with vWD, noting that the cost of ongoing care can be particularly challenging for families with lower socioeconomic status. The study highlights that the economic strain is not limited to direct medical costs but also includes the broader impact on the family's quality of life ("QoL"). For example, the need to prioritise healthcare expenses may lead to sacrifices in other areas, such as housing, education, and leisure activities. This can create a cycle of financial stress that is difficult to break, further exacerbating the emotional and psychological burden on caregivers.

Social Isolation and Impact on Family Dynamics

Social isolation is a common experience among parents of children with chronic illnesses. The demands of caregiving often limit opportunities for social interaction, leading to feelings of loneliness and isolation. This isolation can be compounded by a lack of understanding from others about the child's condition and the challenges it presents.

Myrin-Westesson et al. (2019) highlight that the isolation experienced by parents of children with haemophilia is often linked to the need for constant vigilance. The fear of their child experiencing a bleeding episode can lead parents to avoid social situations where they feel their child might be at risk, such as mothers or play groups. This can result in a reduction in social support networks, which are crucial for coping with the stresses of caregiving.

Additionally, the social stigma associated with chronic illnesses can further isolate families. Barlow and Ellard (2006) in their study on the psychosocial impact of caring for children with chronic illnesses suggest that parents often feel judged or misunderstood by others who do not comprehend the complexity and severity of their child's condition. This lack of understanding can lead to a withdrawal from social activities and a reluctance to seek support from extended family and friends.

It is common for children with haemophilia to exhibit distressing bruising, haematomas, and cuts that may continue to bleed (Ljung, 2002). This can be distressing to members of the public who do not understand the nature of bleeding disorders, often being misattributed to abuse, or more concerningly, impacted by the racist biases (MacIntyre et al., 2023; Park et al., 2019).

The impact on family dynamics is also significant. The focus on caring for young children with specialist needs can lead to feelings of neglect among siblings, which can strain relationships within the family, the development of behavioural issues, and conflict between parents as a result of differing styles (Dauz Williams PhD et al., 2010).

Quality of Life and Caregiving Challenges

QoL for parents and caregivers is often significantly affected by the demands of caregiving. Castaman et al. (2023) emphasise that caregivers of children with VWD experience a diminished QoL due to the constant care required by their child. This includes managing medical treatments, attending regular medical appointments, and being continuously vigilant about the child's condition. The study suggests that this constant caregiving can lead to physical exhaustion, sleep deprivation, and neglect of the caregiver's own health.

The physical demands of caregiving are compounded by the emotional strain, leading to a phenomenon known as caregiver burnout. Litzemlan (2019) discusses how the chronic stress of caregiving can lead to burnout, characterised by physical, emotional, and mental exhaustion. This burnout not only affects the caregiver's well-being but also their ability to provide care for their child. Caregivers who are burned out may struggle with maintaining the high level of vigilance required for managing a condition like haemophilia, leading to increased risk for the child. Building on this, research shows that for caregivers, all QoL domains are correlated, providing opportunities for HCPs to impact caregiver QoL in a range of ways – positively or negatively (Blom et al., 2023).

Caregivers often have to navigate complex healthcare systems to obtain the necessary care for their child. This can be particularly challenging in cases where access to specialised care is limited. Treadwell (2020) highlight that navigating healthcare systems can be a significant source of stress for caregivers, particularly in rural or underserved areas. The study suggests that improving access to care and providing better support for navigating healthcare systems could alleviate some of the burden on caregivers. Participants in this current research commonly cited dealing with Pharmac to access new, restricted, or unfunded, medications that would be beneficial for their child as a source of significant stress.

Coping Mechanisms and Support Systems

Despite the challenges, many caregivers develop effective coping mechanisms to manage the stress associated with caring for a child with a chronic illness. These coping strategies often include seeking support from healthcare providers, joining support groups, and engaging in self-care practices.

Price et al. (2015) and Castaman et al. (2023) emphasise the importance of strong support systems in improving the QoL for caregivers. Access to a multidisciplinary care team that provides not only medical support but also psychological and social support can significantly reduce the burden on caregivers. The availability of counselling services, for instance, can help parents manage the emotional toll of caregiving, while social workers and the Haemophilia New Zealand Outreach Team can assist with navigating financial and logistical challenges.

Support groups also play a critical role in providing emotional support and practical advice. Dellve et al. (2006) suggest that parents who participate in support groups often feel less isolated and more empowered in their caregiving role. These groups provide a space for parents to share their experiences, gain insights from others in similar situations, and build a sense of community. This social support is crucial for mitigating the effects of stress and preventing caregiver burnout.

Finally, the role of healthcare providers is critical in offering guidance and resources to help families navigate the challenges of chronic illness management. Gómez-Zúñiga et al. (2019) found that parents who receive regular education and support from healthcare providers feel more confident in managing their child's condition. This sense of empowerment can reduce anxiety and improve the overall well-being of the caregiver.

It is notable that HNZ attends to many of these domains through the Outreach Team who support those with bleeding disorders with education and connection with services. HNZ also co-ordinates camps for children and families to come together, connect, learn, and play together. These camps provide a forum for experiences and resources to be shared, and for members to lead discussions that are meaningful to them, all the while surrounded by other caregivers who share similar struggles.

Caregivers enhance care.

Despite these challenges, caregivers demonstrate enhanced proactivity in caring, improving communication and the co-ordination of care, seeking to be supported as a member of the care team for their child (Anderson et al., 2013; Gómez-Zúñiga et al., 2019). Many caregivers will become subject matter experts on the care and lived experience of their child (Brewer et al., 2008). Research shows that caregivers gain crucial support from other carers, allowing experiences to be shared, stresses alleviated and normalised, and for a shared identity to be fostered (Clifford & Minnes, 2013; Shilling et al., 2013).

Caregiver Experiences Summary

The experiences of parents and caregivers of children with chronic illnesses such as haemophilia and von Willebrand disease are shaped by a complex interplay of emotional, economic, and social factors. The psychological burden is profound, with many caregivers experiencing chronic stress, anxiety, and depression. The financial strain adds another layer of difficulty, often leading to significant sacrifices in the family's QoL. Social isolation and strained family dynamics further exacerbate the challenges faced by these caregivers. Despite this, caregivers provide uniquely proactive care, quickly becoming valuable subject matter experts for both clinicians providing care to their child, and for others sharing similar journeys.

However, the research reviewed highlights the importance of strong support systems and effective coping strategies in mitigating these challenges. By providing comprehensive support that addresses the medical, emotional, and social needs of families, we can help to alleviate some of the burdens faced by these caregivers and improve their overall QoL. The advent of new therapies for bleeding disorders may result in changes to these experiences, providing an important avenue for future research.

3.15 Pae Ora (Healthy Futures) Act 2022 and co-design.

The "Pae Ora (Healthy Futures) Act" (2022) aims to transform New Zealand's healthcare by prioritising equity, accessibility, and responsiveness to the country's diverse population groups, with a particular focus on the experiences and outcomes of Māori. A key mechanism for achieving this is co-design**,** where consumers actively participate in shaping health services, ensuring they are culturally appropriate and tailored to specific community needs. The Pae Ora Code of Expectations guides how health entities should engage with consumers, focusing on inclusivity and removing barriers for marginalised groups (Te Tāhū Hauora Health Quality & Safety Commission, 2022).

The Act seeks to address longstanding issues, including health disparities and inefficient services, with a particular focus on improving outcomes for Māori, Pacific peoples, and rural communities. It emphasises partnerships between healthcare entities, including the New Zealand Blood Service, and consumers, fostering a collaborative approach for better health outcomes. This approach explicitly recognises that health and wellbeing is realised through transactional and relational medicine (Iles, 2013) and that where the consumer is known and responded to, better outcomes can be achieved.

Co-design, as outlined in the Act, involves collaboration between consumers, providers, and stakeholders, recognising the valuable insights of service users. The Code requires health entities to engage with diverse consumer groups, form advisory panels, and promote cultural competence among providers to ensure services meet the needs of various communities. The Act mandates co-design, however it leaves flexibility for healthcare services to develop their own tools in collaboration with consumers. Transparency and accountability are critical, with health entities required to communicate how consumer feedback influences service design and to provide regular reports on co-design outcomes.

Capacity building and consumer empowerment are also prioritised, with the Code offering resources, training, and support to ensure meaningful participation. Health entities must create detailed plans for implementing co-design processes and continuously review their effectiveness through metrics such as consumer satisfaction and health outcomes.

The Act initially included the establishment of Te Aka Whai Ora (Māori Health Authority) to ensure Māori perspectives were central to health services for Māori. This was disestablished following the 2023 General Election, raising concerns about whether the Act's goals can be achieved without it. Nonetheless, the Code continues to emphasise deep engagement with Māori communities, honouring the principles of Te Tiriti o Waitangi**.**

In summary, the Pae Ora Act and its Code of Expectations represent a comprehensive plan to improve healthcare by involving consumers in service design, with a strong focus on inclusivity, cultural competence, and transparency to achieve better health outcomes for all New Zealanders.

3.16 Haemophilia New Zealand

Haemophilia New Zealand ("HNZ") is a registered charity supporting the lives and long-term outcomes of those impacted by bleeding disorders in New Zealand. HNZ provides support, education, and advocacy for people with haemophilia and related bleeding disorders. HNZ has raised awareness about bleeding disorders, and collaborated with healthcare providers and government agencies.

The contaminated blood crises of the 1980s presented an acute focus for HNZ, with the organisation supporting affected individuals and lobbying for safer blood products and better screening procedures. As medical treatment of bleeding disorders has allowed people to live comparatively long, normal, lives, HNZ's work has evolved to support longer term outcomes and quality of life (Franchini & Mannucci, 2012).

Today, HNZ focusses on advocating for better healthcare policies, comprehensive support services, and research in the field of bleeding disorders (Park et al., 2019).HNZ's initiatives and programs provide a valuable set of resources for the co-design of service improvement.

HNZ has developed various educational resources and programs to inform and support individuals with bleeding disorders, their families, and healthcare professionals. Haemophilia outreach workers try to visit each person with haemophilia at least once a year, with supplementary visits and calls for special needs such as hospital inpatients, extended periods away from work or school, or when confined to home. They also help plan and implement educational and social events, camps, and workshops. The outreach workers are intended to form a community link, helping to ensure that those who seek support are able to find and access the right services. HNZ also engages in the provision of Support Services for its members, advocacy to influence healthcare policy, bleeding disorder research, and community building. HNZ has played a crucial role in improving the lives of individuals with haemophilia and other bleeding disorders (Park et al., 2019).

3.17 Historical Context of Bleeding Disorder Treatment: Bad Blood

An inseparable part of the experience of bleeding disorders pertains to those who received treatment prior to 1992, using blood products derived from donated blood. Blood products administered prior to 1992 were of donated origin and susceptible to contamination with blood-borne disease (Anderson, 1992). In a tragic period for the New Zealand bleeding disorder community nearly 70% of people administered these tainted products contracted Hepatitis C, and a significant number also contracted HIV (Park et al., 2019), although this was lower than the near 100% infection rate in other countries (Mehta & Reddivari, 2019). Many of these people would go on to die not of a bleeding disorder, but of HIV/AIDs, with several participants in this current research reporting having lost family members to AIDS. Many survivors are now caregivers or parents of caregivers.

> "Haemophiliacs got this thing [HIV] and family by family they shriveled into little balls and dealt with it the best way they could and there was nobody that…fought for them. It was too much of a great tragedy." – A member of the haemophilia community, cited in Park et al. (2019, p. 139).

The trauma of these deaths cannot be understated, and was compounded once the community became aware that New Zealand health officials had known of the risks of HIV contaminated blood products at least 12 months prior to warning the community. This betrayal of trust, and the ensuing failure of HCPs to adequately or compassionately communicate, educate, or support the haemophilia community caused immense social suffering, damage to the trust between consumer and HCP, and the cessation of treatment for many who did not want to risk infection (Park et al., 2019; Zielbauer, 2006). This experience forms a critical part of the identity and experience of those with bleeding disorders and their carers.

3.18 Te Tiriti o Waitangi and Healthcare

Te Tiriti o Waitangi (1840) is the founding document of New Zealand, signed between the British Crown, via its consul William Hobson, and most rangatira (Māori chiefs), in order to govern the relationship between the British Crown, its settlers, and Māori (Orange, 2017).

Māori experiences in seeking healthcare for bleeding disorders mirror the systemic failings laid bare in the Waitangi Tribunal's Hauora Report ("Hauora"), in particular Chapter 10, which addresses issues of privilege and inequity in primary healthcare (Waitangi Tribunal, 2021).

Hauora identifies persistent health inequalities experienced by Māori compared to other groups, reflecting systemic healthcare structures privileging non-Māori, and the privileging of non-Māori models of care that do not honour Te Ao Māori values such as the role of whānau and the centrality of wairua to wellbeing.

These systemic issues marginalise Māori, resulting in a lack of culturally competent care for Māori patients, and demonstrating the Crown's failure to meet its obligations under Te Tiriti o Waitangi, in particular Article Two – Rangatiratanga (self-determination). In the context of healthcare, it has been observed that other structures of power and privilege, such as forms of hierarchy that exist in the medical profession, may uphold colonialist structures and impede changes to enhance cultural safety (Curtis et al., 2019). Racism is inescapable for Māori caregivers of those with bleeding disorders, with haematoma and other symptoms misattributed to child abuse and neglect, rather than prompting inquiry that would diagnose a bleeding disorder, in a stark of example of how social determinants of health can alienate Māori from seeking healthcare and compromise the provision of routine technical care that would occur in the absence of racism (Carpenter et al., 2013; Graham & Masters-Awatere, 2020; Park et al., 2019).

As Hauora articulates, the experiences of Māori in accessing and receiving healthcare in New Zealand are pervasively inequitable. In the context of bleeding disorders, the importance of toto (blood), must be understood and honoured. For Māori, toto is considered sacred, carrying a person’s mauri (life force), and inextricably connected to whakapapa (genealogy). In healthcare practice, the taking, handling, and treatment of toto requires particular tikanga (customary observations) as wairua (the spiritual wellbeing of a person) is impacted.

Where toto is involved, and tikanga not observed, a person’s wairua (spiritual wellbeing) is compromised. Wellbeing cannot be achieved where te taha wairua (the spiritual dimension of wellbeing) is neglected (Durie, 1985). Common forms of enacting tikanga in the taking or handling of toto include the invocation of karakia, the presence and engagement of whānau, and the importance of clinicians speaking to the person from whom blood or blood products are taken or introduced – even where that person is a baby.

The inescapable implication of Hauora is that where cultural safety is not present, wellbeing is compromised, even in the provision of technically adequate clinical care.

Research establishes that the absence of cultural safety contributes to poorer accessing of care.

3.19 Bleeding Disorders and Identity: Self, Social, and Community

The identity of caregivers and those with bleeding disorders as individuals and a community is foundational to understanding that when receiving treatment, it is not the disease or its symptoms treated, but rather, the person (Kearsley & Lobb, 2013). In treating the person, HCP's have an opportunity to know them as a person, and understand their identity to proactively counter bias, leverage resources, and support efficacy (Beach et al., 2006; Hartzler & Pratt, 2011; Stone & Moskowitz, 2011).

Kihlstrom and Klein (Kihlstrom & Klein, 1997) posit that identity is the result of a person's self-knowledge about the past, present and future, and how the person relates to these forms of knowledge cognitively, emotionally, culturally, and spiritually. These forms of knowledge are the product of stories, and in this way, identity is created, enacted and maintained, through story telling. This narrative conceptualisation of identity is elegantly congruent with Te Ao Māori, where whakapapa, social connection, and story form the knowledge structures through which identity is experienced and created maintaining an un-severed connection to whakapapa (Durie, 1985; Houkamau & Sibley, 2010). Identity may develop or change through experience, discourse, and social connection (Haslam et al., 2022; Te Rito, 2007).

Identity is intersectional, experienced individually and communally, and reflects diversity between individuals and within communities. The relationship between different aspects of identity, for both the individual and the group shape privilege, power, and conflict (Cole, 2009). Identity is dynamic and individuals may actively choose how to engage with their identity and use their power from setting to setting (Adam, 1985; Bradatan et al., 2010; Peacock et al., 2001; Rivera, 2016).

Caregivers of those with bleeding disorders are a part of this community, even where they do not have a bleeding disorder, or the same bleeding disorder as the child they care for. Research shows that the identity of these caregivers is influenced by the condition of the child they care for, the changing needs of that child, and by caregiver-HCP interactions (Neumann et al., 2021). When considering the experiences and identity of caregivers in the bleeding disorder community, a distinguishing facet can be found in the genetic peculiarities of haemophilia, which results in females carrying the causative gene, and only males experiencing the consequences of it. Despite this identity as a caregiver being central to the care of the child, Neumann et al. demonstrate it is something HCP's rarely enquire about, a finding echoed in this present research.

The identity of the caregiver may also develop over time, with particular parts of the identity becoming dominant, in what Eifert et al. (2015) refer to as the existence of a master identity. This master identity itself can become maladaptive, for example through the experiences of grief and loss which may come with a radically altered life due to caregiving, and may be reinforced by how others refer to the person as primarily a caregiver, failing to acknowledge other parts of identity (Skaff & Pearlin, 1992).

Social identity underpins "we" and "us", with meta-analytical research showing that interventions fostering healthy social group identity and belonging improve quality of life, self-esteem, agency, physical health, anxiety, depression, and stress (Haslam et al., 2022). Social identities provide resources for psychological support, and experiential platforms through which knowledge of self, and personal story can be healthily processed, healthy identity fostered, and positive outcomes achieved (Haslam et al., 2021; Haslam et al., 2022). In the case of changing life events, such as diagnosis with illness, research suggests that health and wellbeing can be fostered through maintaining existing group memberships, and the acquisition of new group memberships. An important caveat is that how identity is experienced individually or socially can be adaptive or maladaptive, and may be mediated by the extent to which a caregiver accepts the role of caregiver, distinct from performing its tasks (Eifert et al., 2015; Oris et al., 2018).

Community identities, like other forms of identity, are intersectional: communities exist and develop within complex systems. The dynamic, emergent nature of community identity, is well suited to participatory action research methods, celebrating and working with communities where they are in the present, as opposed to the abstract, analytical, or directive approaches (Gilpin & Miller, 2013; Vito, 2020).

A core aspect of community identity is the emotional attachment individuals feel towards their community: social belonging. This sense of belonging is an emergent state reflecting feelings of acceptance, value, and understanding from other community members. It contributes significantly to individuals' psychological well-being and their motivation to participate in communal activities (Darlaston-Jones, 2007). For those with a chronic illness, advocacy and support groups, such as Haemophilia New Zealand, form the cloth social belonging is woven from, bringing together people with common conditions and experiences. Community groups empower members' stories to create adaptive experiences of identity (Oris et al., 2018).

The collective history and shared experiences of any community, including significant events, cultural traditions, and historical milestones, shape its identity, mediated by group norms and language. These elements contribute to a shared memory that reinforces community bonds and a common identity:

> "To have an identity is to have a history: the story of the enduringness of something over time" (James, 2018, p. 8).

The traumas experienced by the bleeding disorder community, such as loss of members caused by a bleeding disorder, or HIV-AIDS contracted through treatment, are experienced in the context of these relationships and networks, becoming an aspect of identity (Berkman et al., 2000).

Symbols, rituals, and cultural practices are significant in reinforcing community identity, providing a sense of continuity and shared meaning (Wenger, 1999). For those with chronic illness or bleeding disorders, the treatment protocols, and adaptive practices become defining rituals which each member may have practiced alone or in family groups, prior to becoming a member of a community such as HNZ (Crespo et al., 2013). This convergence of existing ritual and practice with a group of people engaging in the same presents a dynamic experience where identity through rituals are simultaneously recognised and created through contact with others. It is in these circumstances that the interplay between forms of identity is illustrated, with one research participant describing how the experience of a common practice, the use of crutches to protect an ankle after a spontaneous bleed, was changed by intra-community experiences. Where previously the person had experienced self-doubt through others at school mocking the use of crutches as unnecessary, attention seeking behaviour, this experience was changed through discussion with others in the HNZ community through both normalising the experience and providing material responses for dealing with it through humour and educating fellow students.

The physical environment and geographical location of a community also contribute to its identity. Environmental influences, activities, and interactions of community members, shape their collective identity (Relph, 1976). This physical positionality, layered with whakapapa forms a fundamental part of identity for Māori, and is shared through pepeha and mihi (Pihama et al., 2015).

"A person cannot stand if there is nothing supporting them. We need to know where we are from, where our roots are and to maintain those ties to whānau, hapū, and iwi to enable us to ensure strong connections for current and future generations". (Pihama et al., 2015, p. 4).

Within the context of the diversity and fluidity of identity, communities may choose to foster particular identity groups. Haemophilia New Zealand's Piritoto group, which consists of those who identify as Māori or are connected to tangata whenua, and HNZ's National Youth Committee, which represents members aged 18-35, demonstrate proactive approaches to recognising and supporting two such identity communities.

Given the current advances in treatment for haemophilia, it is possible that identity for individuals and groups will similarly adapt, tracking the changing stories about present and future that a radically different prognosis enables. This is a valuable area for future research.

Projecting the understanding of an intersectional identity as knowledge about the past, present, and future, we are able to begin to focus on the critical impact HCP's have in making sense of information – the diagnosis – and shaping it into the stories which caregivers and those with conditions themselves will use as their first experience of a changed identity – one who cares for a child with haemophilia. This experience is the kernel from which story and identity grows. This presents an important question for HCPs: what stories does this diagnosis create or change?

In summary, this chapter has outlined the critical context for understanding the experiences of caregivers of children with bleeding disorders in New Zealand, emphasising the dual challenges of navigating chronic conditions and systemic inequities in healthcare. This chapter has introduced the historical experiences of the bleeding disorder community, the community led initiatives that exist today, and the important role that individual and community identities play in how living is experienced. Guided by the principles of relational care and the legislative framework provided by the Pae Ora (Healthy Futures) Act 2022, this research centres caregivers' lived experiences to explore transformative opportunities in healthcare.

Specifically, the research seeks to:

1. **Understand caregiving experiences**: Examine the lived experiences of caregivers of young children (from birth to two years of age) with bleeding disorders in their interactions with the healthcare system.
2. **Scope opportunities for Co-designed improvement**: Utilise caregiver insights to identify areas for potential improvement in healthcare service delivery.
3. **Evaluate EBCD for Pae Ora compliance**: Assess the suitability of Experience-Based Co-Design (EBCD) as a methodology for meeting the co-design requirements outlined in the Pae Ora (Healthy Futures) Act 2022.

By linking these aims to the broader healthcare landscape, this research positions caregivers as essential contributors to system-wide innovation and equity in healthcare delivery. The foundation set in this chapter paves the way for a more detailed exploration in the following chapters.

Chapter 4: Methods; An Approach Grounded in Community Psychology, Compassion, and Relational Ethics

This chapter comprises five parts. The first part discusses the epistemological grounding of the research in Community Psychology, which centres the participants' lived experiences and position as subject matter experts using an experienced based co-design methodology. Part two describes how participants were recruited, how methods evolved to meet participant constraints, and introduces each participant caregiver. Part three describes the scheduling and recording of workshops. Part four discusses ethical issues in conducting the research and the steps taken to address them. In part five, I discuss how I transcribed and analysed the participant workshop output.

This research thesis employs a form of participatory action research (PAR). PAR prioritises the value of lived experience to understand and address challenges, and places power in the hands of those with lived experience to define problems, create solutions, and own outcomes (Cornish et al., 2023). This methodology has implications for how extant research is dealt with, in this case in the form of literature review. While research can be reviewed to provide an overview of what is known, the challenges this thesis seeks to address, and inferences that might be made, PAR is wholly grounded in an understanding that what researchers know is of limited value if it is not of relevance or use to those participating in the research at hand. This understanding could perhaps be rendered in to traditional research terms by acknowledging that it is lived experience that confers ecological validity upon research.

The following literature review aims to be comprehensive, and perhaps this may lead the reader to question if new research can be generated by research activities. Within the context of this thesis, generating new research is not the researcher’s primary intent. While on its face this statement may seem oxymoronic, it is my hope that through PAR, the reader appreciates that new lived experience is prioritised over new research.

4.1 Part One: A Community Psychology Grounded Approach

While classical, positivist approaches to psychology purport to be objective, and free from community perspective, bias, or values (Gough & Madill, 2012; Hetherington, 1983; Levitt et al., 2022; Reiss & Sprenger, 2014), Community Psychology adopts a paradigm of promoting social justice, liberation and wellbeing through collaboration with the subjective experiences of communities. Community Psychologists act to “enhance wellbeing and promote social justice for all people by fostering collaboration where there is division and empowerment where there is oppression” (Riemer et al., 2020, p. 4). The implications of community psychology’s expressly values-driven approach requires the researcher to depower themselves, in order to create space for communities to claim their own power to create a more just, equitable, and healthy community (Gaventa, 2021).

Community psychology prioritises collaboration with, rather than research on, participant groups. This is not to say other disciplines of psychology and the social sciences do not share similar values or methods. The interconnectedness of academic research and transdisciplinary practice has supported the continual reflection and progress of academics in all fields in order to strive for outcomes and methods that are responsive, safe, rigorous, and reliable (Perkins & Schensul, 2017).

4.2 Experienced Based Co-design

This research employed experience-based co-design to understand the lived experiences of caregivers and scope the challenges and opportunities that they see as valuable to improving this experience. In order to work within the limitations of a single researcher project, this research was limited to an initial scoping process to understand experiences, identify themes, and validate the application of EBCD with the bleeding disorder community. Findings are intended to inform future co-development of healthcare experiences with the bleeding disorder community, HCPs, and healthcare entities.

Experience-Based Co-Design (EBCD) is a transformative approach in healthcare that integrates the principles of Participatory Action Research (PAR) to improve service delivery and patient outcomes. EBCD emphasises the active involvement of patients, caregivers, and healthcare staff in identifying issues and collaboratively designing solutions. EBCD exemplifies the core tenets of PAR as articulated by Cornish, Breton, Moreno-Tabarez, Delgado, Rua, de-Graft Aikins, and Hodgetts (2023) recognising the authority of direct experience, knowledge in, and through, action, the understanding that research is, of itself, transformative, and collaboration through dialogue. EBCD is congruent with the model of healthcare presented by Iles (2013), by acknowledging and grappling with the fact that how we approach research, and those with whom the researcher collaborates, is distinct, yet inseparable from the technical aspects of research produced. These collaborative models of research depend on a rebalancing of power amongst all parties to create empowered participant groups, prevent the facilitator operating as hegemon, and the fostering of processes grounded in relational ethics (Gaventa, 2006; Hopner & Liu, 2021; Kashwan et al., 2019; Schensul et al., 2008).

Cornish et al. (2023) argue that PAR is grounded in the belief that those who experience a problem are best positioned to understand and address it, echoing healthcare understanding that the consumer is a subject matter expert in regard to their experience of wellbeing and management of their health (Carlini et al., 2023). This principle is central to EBCD, which actively involves patients, caregivers, and healthcare professionals as equal partners in the co-design process.

In EBCD, the principle of participation is evident in the way stakeholders are engaged throughout the research and implementation phases. Patients, caregivers, and healthcare staff are not merely consulted; they are integral to defining problems, generating solutions, and implementing changes. This collaborative involvement ensures that the insights and experiences of those directly affected by healthcare services shape the design and delivery of these services. The participatory nature of EBCD aligns closely with PAR's commitment to involving participants as co-researchers, as highlighted by Bate and Robert in their foundational work on experience-based design (2007). EBCD seeks to translate experiential knowledge into concrete service improvements. The iterative cycle of planning, action, and reflection emphasised by PAR is mirrored in the EBCD process, where stakeholders continuously assess the effectiveness of implemented changes and make necessary adjustments. This approach ensures that interventions remain relevant and effective, fostering a culture of continuous improvement and trust between stakeholders.

Democratisation of knowledge is another critical aspect of EBCD, by challenging traditional hierarchies in knowledge production by valuing the expertise and experiences of all participants. Cornish et al. (2023) argue that democratisation is essential for addressing power imbalances and ensuring that research benefits marginalised groups. EBCD respects and integrates the experiential knowledge of patients and caregivers, treating them as experts in their own right. By doing so, EBCD promotes a more equitable distribution of power and decision-making in healthcare. This approach ensures that service improvements are informed by the lived experiences of those who use and provide healthcare services, thus enhancing the relevance and effectiveness of interventions.

The EBCD process begins with engagement and contextual understanding, where researchers gather narratives from research participants. Workshops with participants encourage creative thinking and draw on the diverse perspectives of participants to generate innovative ideas for service improvement.

EBCD, like PAR, emphasises the importance of inclusivity and equity. Cornish et al. (2023) note that involving marginalised and underrepresented groups in the research process can begin to address systemic inequalities and fostering social justice. EBCD strives to ensure that all voices are heard and valued, particularly those of vulnerable populations who may have unique healthcare needs. By actively involving diverse stakeholders, EBCD promotes a more inclusive and patient-centred approach to healthcare.

Despite its strengths, EBCD, like any participatory approach, faces challenges. The process can be time-consuming and resource-intensive, requiring careful planning and coordination. Ensuring genuine and equitable participation can be difficult, particularly when power imbalances exist among stakeholders. Additionally, sustaining engagement and maintaining momentum throughout the process can be challenging, especially in complex and busy healthcare environments or politically volatile times where strategy and purpose are in flux.

In conclusion, Experience-Based Co-Design is a powerful application of Participatory Action Research in healthcare. By centering lived experience of patients and their caregivers EBCD embodies the principles of participation, action, and democratisation of knowledge. This approach not only enhances the relevance and effectiveness of healthcare interventions but also fosters a culture of collaboration, respect, and continuous improvement. As healthcare systems strive to become more patient-centered and responsive, the principles and practices of EBCD and PAR offer valuable insights and strategies for achieving these goals.

4.3 Part Two: Recruitment and Workshop Evolution

Participants were recruited through an email campaign conducted by HNZ to its members, inviting caregivers meeting the research criteria to contact the Lead Researcher directly.

Prior to contacting caregivers, two meetings were conducted with HNZ's Board to ensure that the proposed research was appropriate, safe, and would produce research of value those with bleeding disorders. This consultation indicated that due to HNZ's diverse and geographically dispersed membership remotely hosted workshops would enable broader participation than in-person workshops. It was made clear to participants in recruitment and workshops that the lead researcher did not work for HNZ.

In order to enact Te Tiriti o Waitangi principles of rangatiratanga and co-operation, discussions were also held with HNZ's Piritoto group co-ordinator to explore cultural safety, and facilitation options. A key point of this discussion was to allow Piritoto's members to elect to participate in a workshop reserved solely for Māori caregivers, to participate in general workshops for any HNZ members, or to choose not to participate. After this discussion, Piritoto members were consulted by HNZ and indicated a preference for a workshop reserved for Piritoto members.

Recruiting participants solely through HNZ introduced a risk that a participant's experience with HNZ might bias a choice to participate or not. Although there is no way to ascertain this, what can be said is that all participants shared nuanced views regarding HNZ, including positive and negative assessments.

This research was originally intended to focus on caregivers of those with Haemophilia. After receiving communication from HNZ members with other bleeding disorders, indicating a preference to also participate in research, the workshop criteria were extended to allow those caring for people with any bleeding disorder to participate. Upon reflection and with the benefit of hearing the participant stories, I realise this decision to focus on haemophilia to the exclusion of other bleeding disorders was not necessary.

The result of this engagement was to create two remote co-design workshops for HNZ members who were caregivers, with up to eight participants per workshop. One of the two workshops was intended to be reserved for Piritoto members.

Research design also focused on the experiences of caregivers during the time or conception if a bleeding disorder was expected, or birth if not expected, until two years of age. This decision was made in order to limit the research scope to a manageable period, and focus on the earliest experiences of caregivers with the healthcare system. These early interactions with healthcare offer significant value in the establishment of long-term relationships and behaviours for the management of chronic conditions.

4.4 From Group to One on One Workshops.

"Plans are worthless, but planning is everything" Dwight D. Eisenhower, as cited by Blair (1957, p. 4)

This research project encountered some of those challenges described by Cornish et al. (2023). Initial planning for EBCD research with participants intended to employ two workshops, one of which was to be reserved for HNZ's Piritoto group members with the remaining workshop open for other HNZ members. The intent of a workshop format was to allow for participants to collaborate, to de-power the lead researcher, empower participants, and allow for coincidental learning and opportunity to occur (Schensul et al., 2008).

All prospective participants were eager to share their experiences, however the complexity of acting as caregiver while also negotiating life's commitments resulted in intractable challenges scheduling participants for each workshop to be able to attend as a group. After reflecting upon this challenge and seeking supervision regarding its impact upon research aims, I elected to offer participants the option of participating in the same EBCD process one-on-one. Participants quickly and unanimously indicated this was preferable with several participants stating that they were relieved, and preferred a one on one setting to discuss their journey.

In order to preserve the opportunity for participants to learn from one another, the researcher asked permission from each participant to share themes, or non-identifying information, where it was congruent with the stories told or questions asked by subsequent participants.

The sharing of themes and information from participant to participant introduced risks. In particular, risks of researcher bias shaping what was shared, of fidelity in recalling and sharing information, and of the researcher's power presenting themes as fact, rather than experiences of others.

These risks were managed through sharing with each participant the researcher's desire to be able to benefit other participants by sharing stories that felt important to both participant, and researcher. Where this was agreed to, the researcher reflected emergent themes to each participant, such as racism, in order to allow the participant to reflect, validate, or falsify the researcher's observation. Where subsequent participants shared similar stories, the researcher was able to share the experiences of others in a non-judgmental way, cautious to share only the information from previous workshops, without attributing causation or assuming experiences were the same. Where themes or stories consistently emerged, but were not reported by a subsequent participant, the researcher asked open questions such as “Have you encountered racism in your journey?”, “How have you experienced accessing medication for your child?”, to allow for a participant the reflect and respond regarding emerging themes, without being led to a particular response, or experiencing any expectation on the part of the researcher.

The effect of this decision was to create a form of living, iterative, EBCD process, with the researcher acting as a facilitator of the session at hand, and conduit between prior sessions. This is discussed in more detail below with regard to Harm, Reflexivity, and Ensuring fidelity to participants.

4.5 The Caregivers

During the recruitment process, a high profile political debate was occurring in New Zealand, prompted by the incoming National-led Government’s disestablishment of Te Aka Whai Ora, in what has been referred to as an act of “blatant institutional racism” (Perrott, 2024) and a series of political decisions intended to specifically disregard Te Tiriti o Waitangi in healthcare decision-making (Gabel & Plummer, 2024). The impact of this political climate upon Māori participants and their willingness to participate was difficult to predict, with concerns that political and institutional racism may result in Māori with bleeding disorders becoming disengaged from healthcare and research related to it, a phenomenon made explicit in the Waitangi Tribunal’s WAI2575 Inquiry (2019c).

The racist messaging present in political discourse and media at the time of recruitment presented particular considerations for my reflexive practice in order to prevent “…the production and reproduction of dominance rather than subordination, normativity rather than marginality, and privilege rather than disadvantage”

(Frankenberg, 1993, p. 236). As a white, middle class, male, asking a diverse group of participants including Māori to share their experiences, reflexivity and cultural humility were crucial to the successful completion of this research.

The impact of this discourse is discussed as part of Chapter 4. Its impact was observed from the earliest stages of recruitment, with Piritoto members replying affirmatively to the recruitment email within hours of HNZ's first recruitment email which invited interested participants to contact the researcher directly.

Twelve prospective participants made contact following the recruitment email, with three people falling outside the participation criteria due to the time that had passed since they acted as caregivers. In these cases, the time elapsed since acting as a caregiver was 20 years or more, introducing some concern that their experiences, though unique and valuable, may not pertain to the current experiences of caregivers. One prospective participant was about to leave New Zealand for a long-term holiday, meaning that they were unavailable to commit to participate in the workshop. This resulted in eight participants meeting the participation criteria and willing to participate.

The privacy of participants has been protected by changing some non-essential details, including names. Due to the small population of caregivers with bleeding disorders and their connections through HNZ, some details of participants' experiences which are referred to in the Results Chapter are not linked to the participants introduced in this chapter. This is to limit the extent to which a participant's privacy could be compromised through narrative completeness. Demographic information, such as location, that could compromise specific participant's privacy, but which is still of value in the analysis is included in Table 1, following participant introductions. Information in Table 1 is dis-associated from the individuals to protect privacy.

Each participant is introduced in the sequence with which the workshops were conducted. Liberty is taken to introduce caregivers using some of their own language.

Table 1

Participant Demographics (n=8)

Characteristics		n
Gender	Female	7
	Male	1
Ethnicity	Māori	4
	Pākehā	4
Caregiver prior experiences with bleeding disorder	Yes, previously experienced a bleeding disorder in self or family.	
	No previous experience of bleeding disorder in self or family.	
Bleeding Disorder of child	Von Willebrand's Disorder	2
	Haemophilia	5
	Other Bleeding Disorder	1
Diagnosis	Expected, or aware of risk	4
	Novel or unexpected	9
Country of birth	New Zealand	8
Locality while caring for child 0-2	Northland	1

	Auckland	2
	Waikato	1
	Hawke's Bay	1
	Wellington	1
	Nelson Marlborough	1
	Canterbury	1
	Resided outside New Zealand	1

Hinē is tangata whenua and a mother of three boys. Hinē was aware of a family history of haemophilia when she became pregnant. Hinē's oldest boy is in his twenties and does not have haemophilia, and following his birth she was advised by a haematologist not to have further children – no further genetic or reproductive counselling occurred. Hinē gave birth to twin boys, now in their early teens, who were diagnosed with Haemophilia A in-utero via amniocentesis. One of the twin's experiences haemophilia symptoms more severely than the other. Due to complications during the birth of her twins Hinē was in a coma for several weeks following the birth, meaning that she did not meet the twins until several weeks after they were born and simultaneously managed her own recovery from a life-threatening event with caring for her twins.

Maia is tangata whenua, has three children: two girls and one boy. Maia's son is 13 and was born with severe haemophilia A. Maia was unaware that she was having a child who could have haemophilia, with diagnosis occurring only after her baby continued to bleed profusely following the routine heel prick test at birth. Maia is a single mother. Maia works in a management role related to community services.

Jo is Pākeha, and a mother to a 12-year-old boy with severe haemophilia A. Jo is now a mother in a blended family with three children. Jo's son was diagnosed with haemophilia at 8 months of age after an injury he suffered playing continued to bleed profusely.

Mark is Pākeha and has two children, one of whom has a rare bleeding disorder and is an obligate carrier of haemophilia. Mark has haemophilia A himself, with a family history of haemophilia established back several generations, however he is the first person with haemophilia in his family for two generations. Mark's family did not discuss the haemophilia experienced by his great-grandfather, meaning that he was not diagnosed until symptoms occurred for him as a child. Mark's mother was proactive in advocating and caring for him as child and young person. Mark also has another rare bleeding disorder, and this is the bleeding disorder experienced by his daughter. Due to Mark's awareness of the risks, he was able to prepare a birthing plan to manage the risks of haemophilia. Mark's daughter is in her early teenage years. Mark works in a professional capacity related to project management.

Kiri is Pākeha, her husband is Māori, and she uses his surname which is Māori. Kiri has three children, two boys, one girl. Her eldest son has severe haemophilia A with inhibitors. Kiri works in an administration role in a school for children with special needs.

Rylie is Pākeha. She and her husband have an 18-year-old son with haemophilia A who was born in the United Kingdom. Rylie has an established family history of haemophilia, with her father, uncles, and others all living with it. This meant that Rylie expected to have a child with haemophilia, with in-utero testing confirming her son would have the disorder. Rylie works in a professional role, and in contrast to the other caregivers now lives overseas. As a result of her employment, she has experienced care for her child in the UK, USA, and New Zealand. While Rylie had not experienced being a caregiver of a young child in New Zealand, her experience as caregiver in different systems provided a unique perspective when contrasted with New Zealand based caregivers.

Jane is Pākeha and was born with vWD. Jane is one of the older participants, her children are now parents themselves. vWD runs in her family, affecting her parents, siblings, a daughter, and now a grandchild, and so her journey has many facets. She is a healthcare professional herself, now working in quality and patient safety, and is based in rural New Zealand.

Hana is tangata whenua and a caregiver of seven children. Hana works as an emergency responder, as does her husband, who also has a rare bleeding disorder. Hana has vWD, as does her mother. Hana’s husband is a New Zealand citizen of Pacific Island origin. Two of Hana’s children have medical conditions in addition to bleeding disorders, and lives with autism. Hana and her husband have also acted as foster carers for children with bleeding disorders. Hana is a staunch advocate of cultural safety, respect, and creating opportunities for all people, and is actively involved with HNZ.

4.6 Part Three: Workshop Structure and Recording

The workshop structure (see Appendix 5) was informed by established EBCD practices, prioritising a focus on participant experiences rather than making the EBCD methodology and tools a distraction from their purpose by seeking to do too much in this initial scoping stage (Robert, 2013). This structure was created through discussions with the research supervisor, and through test runs with trusted colleagues.

Three additional questions were asked in the workshop. Each of these is now introduced and its rationale explained.

The first question, “Have you been asked to share or talk about your experiences before?” was asked after introductions and before beginning the formal structure of the workshop. This first question served two purposes: firstly, to understand if the participant had been involved in service improvement, and secondly, to safely provide the participant a soft opportunity to share their experiences free of a task to achieve.

The second question, “Throughout your journey, did you encounter any racism or behaviour of that sort?” was intended to meet the challenge of Hauora (Waitangi Tribunal, 2021) by embracing an anti-racist approach and make it clear to participants that racism was a key area of enquiry. The question was carefully structured and asked to avoid leading the participant to any answer, placing power with the participant to discuss their experiences openly, free of the researcher seeking to infer what might constitute racism, or use research methodology based reasons to avoid clearly identifying racism as a consideration of this research (Acosta & Ackerman-Barger, 2017; Dovidio et al., 2002; Sue, 2005).

The third and final question “Throughout your journey, would you say you felt known as a person? Perhaps at some points, if not always?” sought to leverage research demonstrating that those who experience being known as a person in treatment for chronic illness experience improved outcomes (Beach et al., 2015). The elegance of an open question enquiring about being known as a person is that it does not prescribe parameters, values, or criteria for personhood, leaving space for the participant to reflect.

The combined effect of these three questions was intended to further model a relational ethic between researcher and participant, and establish an interpersonal dynamic reinforcing that all people are intrinsically valuable, capable of meaningful contribution, and accountable to one another for their behaviour (Hopner & Liu, 2021; Regier, 2017, 2023).

All participants were invited to make contact at any point following the workshop if they wanted to share, clarify, or retract information.

4.7 The Role of Healthcare Professionals in this Research

This research was designed to centre and empower caregivers, and therefore depower the role of HCPs. This deliberate choice is intended to honour the intent of Pae Ora and avoid creating an environment where caregivers felt defensive or less expert. At the same time, HCPs have uniquely valuable expertise in the treatment of bleeding disorders.

Following discussions with my supervisor I decided to have informal discussions with two HCPs who focus on bleeding disorders. The purpose of these discussions was to check assumptions I may have made about care, understand reasons for aspects of care, and to share the themes emergent from the workshops. In sharing workshop themes, my intent was to gather another perspective and ensure I did not carry any incorrect assumptions into analysis.

I held discussions with two experienced Consultant Haematologists. One is New Zealand-based acting in a role across several hospitals, the other based overseas, leading a large, specialist haematology centre. Special care was taken to share only themes, and not any information relating to particular caregivers.

The contribution of these two haematologists is discussed further in Results and Discussion Chapters.

4.8 Recording

In order to focus on interpersonal process and participants, all workshops were video recorded, with express agreement that the recordings would be used for analysis and not shared or otherwise used. Recordings were generated by the Zoom video conferencing software used for the meetings and stored on a password-protected computer hard drive. A back-up copy of recordings was stored on an encrypted external hard drive accessible only by the researcher.

4.9 Part Four: Ethical Considerations

This research was approved by the Human Research Ethics Committee at the University of Waikato. Ethical guidelines for this research were consistent with the Code of ethics for psychologists working in Aotearoa New Zealand (The New Zealand Psychological Society, 2002)) and the Principles of Community Psychology (Thomas et al., 1997). The research was assigned the identifier code HREC(Health)2023#51 (Appendix A).

4.10 Harm

In considering the risks of harm and my steps to mitigate or manage them, I took preliminary steps to understand what risks might be likely and how they might present. This included informal discussions with members of the HNZ Board and a research psychologist from the Murdoch Children's Research Institute in Melbourne, Australia. The primary risks were those related to historical family trauma, including the risks of family members having received contaminated blood products, risks of caregivers having unresolved trauma from their journey as caregivers, the risks of caregivers being under acute stresses at the time of the research, and finally, the risk caregivers may not wish to participate fully should representatives of the HNZ outreach team be present in the workshops. Following correspondence with the chair of the ethics committee it was decided HNZ Outreach team members would not be invited to participate, and to exclude parents of newborns, or where other factors such as acute illness, indicated an increased risk of caregivers experiencing distress. The decision to exclude caregivers currently caring for a child zero to two years managed the risk that the research process could have unintended consequences for the relationship between caregivers and HCPs, or turn the research into an active intervention. The identity of participants was not shared with HNZ or any other person or organisation.

In order to manage the remaining risks of harm, I took the following steps:

- I explained to all participants that all power to participate resided in them, and that they could share as much or as little as they felt comfortable to, take as much time as they wished, and choose how they did so.

- I informed participants they could withdraw from the research at any time without the need to provide a reason. I explained I was not associated with HNZ and that there would be no consequences for withdrawing consent. This information was included in the written consent form, and reiterated in workshops.

- Each session began with a commitment to confidentiality, a brief introduction of the researcher, along with my connection to the topic and my research aims. I also shared that I was a parent of a young child, with another baby due soon, in order to allow the participants to assess one pertinent aspect of my positionality to the research.

- The sharing of themes from workshop to workshop was explicitly discussed at the outset, introducing that I may share some themes others had experienced should it be relevant, and also ask permission to share themes that emerged with the present participant where it felt valuable to us both. When themes that might be shared emerged, each was explicitly discussed as something that could or could not be shared with others. When sharing themes from workshops, it was done in such a manner as to avoid identifying the person who had generated it, and also in such a way as to avoid blaming or identifying any HCPs or hospitals it might relate to.

- Each participant was asked if they had participated in any research previously, if the timing for our meeting was good, and if there were any boundaries or information they would like to share with me at the outset.

Conducting workshops for Māori participants, enquiring as to cultural experiences presented a further issue to consider. As a Pākehā researcher seeking to create a visible space for participants to claim as their own, it was critical for me to de-power myself in a way visible to each participant (Gaventa, 2006). This de-powering related to myself as a Pākehā researcher, in relationship to each participant, who may themselves have different experiences of their role as caregiver, their culture, and interactions with HCPs and researchers.

My approach to this interpersonal dynamic was informed by the work of Waitoki, Dudgeon, and Nikora, (2018) emphasising the obligation of researchers to maintain the cultural dignity of participants. My approach to implementing this was to introduce myself using a mihi, and to ask each participant at the outset of the workshop how they would like to introduce themselves. Some participants responded using the language and format of their choice. I would also like to acknowledge the invaluable guidance received from Dr Mohi Rua in the PSYC575 – Kaupapa Māori Psychology course at The University of Waikato for changing the paradigm through which I understood Te Ao Māori, and my own cultural identity.

4.11 Power, reflexivity, and connection.

I worked to manage the power and privilege I had in the research process by selecting methods of research and analysis that explicitly empowered participants and encouraged reflexivity. My experiences with family members who have haemophilia, and professional career training HCPs presented clear risks for co-opting participant experiences with my own. One strategy I employed to manage this was to explicitly share with participants that they were the experts in their experiences, and that the space was for them to use as they wished. This explicit relinquishing of control was as much for participant and it was for myself.

I practiced reflexivity for myself throughout the research through the taking of notes, conversations with my wife, a trained psychologist, and an active consideration of relational ethics in the moment. Regier's (2017) compassionate accountability framework provided the framework for my interpersonal process, by working to manage any distress I experienced, and reinforce the inherent personal value of each participant, their expertise, and my accountability in our interactions.

I continue to reflect on the lived experiences shared with me, realising that hearing these stories, being in a position to use them to improve experiences is in itself a form of privilege that carries significant gravity.

4.12 Consent

At the commencement of recruitment, I supplied a recruitment email, information sheet and consent form to HNZ, which was then forwarded by HNZ to its membership database, alongside a short email explaining the purpose of the research (Appendices 2,3,4) and providing details to contact me directly. I offered to meet with any members who wished to discuss the research before giving consent, however all participants were happy to proceed without this.

Prior to the workshop each participant received a copy of the consent form and information sheet, and returned it prior to the session. All were informed they could ask questions and clarify any concerns.

At the beginning of each workshop I reiterated the research purpose, what I hoped to achieve, and shared the consent form details again, with a focus on the participant's rights. All participants were asked if they understood and agreed to these conditions, if they consented to recording of the workshop, and informed that they could change their mind about this at any point. I also explained I did not work for HNZ and would not share identifiable information with any other person. Each participant was informed that as the research utilised an EBCD method, I invited them to consider themselves empowered to suggest changes or contribute in any way that they felt meaningful to them.

4.13 Privacy and Confidentiality (rolling workshops)

I protected participant privacy and confidentiality, and communicated this to participants by assuring them only I would have access to the recordings of workshops and that pseudonyms would be used in publications. I also advised I would not identify other workshop participants directly, or through oversharing information related to their stories. Participants were advised that recordings and notes would be kept securely and destroyed once they were no longer required. Where participant information was discussed with my supervisors this was done without identifying the participant.

4.14 Fidelity and Accuracy

Accurately capturing what participants said was made simple with recording, however accurately capturing the meanings they sought to convey, and their intent, was something I worked to curiously and openly practice throughout workshops. I found reflexive practice made this easier by helping me to actively shed any pretence of expertise and instead focus on listening and ensuring a safe environment existed. Managing my power as researcher was achieved by avoiding summarising or assuming meaning, and instead asking the person to tell me, so that I could record it.

One participant emailed following the workshop to advise they had more they would like to discuss. We made time to meet again and used the workshop structure to scaffold what was an important part of the participant's experience as a caregiver.

4.15 Part Five: Transcription and Synoptic Unit Analysis

All workshops and the one subsequent discussion were transcribed in full using an open coding process (Hopwood, 2018; Strauss & Corbin, 1990). This process was carried out by reading transcripts and making notes capturing data emergent insights, or what Hopwood (2018) would refer to as synoptic units. Once this first pass was complete, analysis entailed considering what the data was telling me, my relationship to it, and thematic links between participant experiences and literature. Recordings and transcripts were then reviewed to make connections between synoptic units.

This process informs the final question posed in synoptic unit analysis: 'What more do I want to know?". The answer to this question is the key consideration in taking this scoping project to further co-development stages.

4.16 Conclusion

This chapter has provided a comprehensive outline of a methodological framework rooted in the principles of Community Psychology, Participatory Action Research (PAR), and Experience-Based Co-Design (EBCD). Recruitment decisions to include carers for children with vWB and reserve a workshop for Māori carers were made to emphasise inclusivity, ethical engagement, and a participant-centered approach. By adapting to include caregivers of those with vWF, proactively create a workshop reserved for Māori caregivers, and make deliberate efforts to maintain cultural sensitivity this research design empowered participants. At each step, the researcher practiced reflexively in order to create and maintain a space alongside participants.

The adoption of an iterative, relational methodology ensured that the voices of caregivers were authentically represented and respected. The decision to transition from group workshops to one-on-one engagements exemplifies adaptability in research design, addressing logistical challenges while preserving the integrity of the EBCD process. Additionally, the engagement with healthcare professionals and the incorporation of their perspectives added depth to the analysis while maintaining the primary focus on caregiver experiences.

Ultimately, this chapter highlights how a well-grounded, participatory methodology can facilitate meaningful insights and foster a collaborative environment for co-designing solutions in healthcare. The next chapter will build upon these methodological foundations by presenting the analysis and discussion of key themes emerging from participant narratives, offering critical reflections on their experiences and insights into future research directions.

Chapter 5: Results

This chapter presents the research results. Results are shared across broad themes relating to the provision of technical care, experiences of relational care and caregiver experiences, and results pertaining to the broader system within which caregivers exist.

This chapter comprises parts and presents an analysis of the main results that emerged from participant workshops. These parts are: technical aspects of care, relational aspects of care, broader systemic aspects of care, perspectives on these findings from two haematologists, results that relate to the interactions between technical, relational, and broader systems results, and finally, findings related to the EBCD process itself.

5.1 Participant Experiences of the Technical Aspects of Care

This section focusses on the experiences of caregiver participants in accessing and receiving technical components of care for their child. While distinguishing between technical and relational aspects of care is at times difficult, technical care can be considered what is done, such as specific treatments, whereas relational care is how it is done and experienced.

Access to Services is Compromised by Geographic Location, Socio-Economic Status, and Costs

Six of eight participants reported that socio economic status and geographic location impacted access to, and experiences of, care. This included caregivers having to travel to access the necessary services, and being unable to access some services due to their child attending a low-decile school.

Maia reported that her child’s school, classified as a low decile school, was unable to offer support for her child to attend when in a wheelchair due to a bleed.

He couldn't go to school because, you know, he couldn't walk a lot and he couldn't walk a lot of the time and the school didn't have… it wasn't accessible. So, he couldn't even go to school with the wheelchair and then they wouldn't even offer school online…

He only spent 25% of the time at intermediate and primary school due to [bleeds].

Maia also reported being told by a haematologist to access the school physiotherapist, despite her child’s school having no physiotherapy services available.

Five other participants explained challenges and costs associated with travelling to Haemophilia Clinics from rural areas, accessing medication, or giving birth.

You have to be in Wellington [for the birth] because that's where the haematology department is. Kiri

General Practitioners Were Not Familiar with Rare Bleeding Disorders (n=2)

Hana reported educating General Practitioners (GPs) with regard to bleeding disorders.

I've had other doctors that have been, thank you for this information because they only do a six-hour period on bleeding disorders. And 90% of that is haemophilia. They don't cover off the Von Willies and the platelets. Hana

Jo also reported her son’s GP missing signs of haemophilia, which is discussed further in non-technical factors results, below.

The Impact of Emicizumab is Changing the Relative Severity of Bleeding Disorders and the Experience of Caregivers for Those with Haemophilia

All participants of children with haemophilia reported that the introduction of Emicizumab/Hemlibre was life-changing for child and caregiver. The ease of subcutaneous rather than intravenous administration coupled with the efficacy of Hemlibre was reported to change outcomes of treatment, and also ease the technical challenges of administration faced by caregivers and children.

Hemlibre - the miracle drug. It's revolutionised our lives for the last 3.5 years… it's the difference between trying to find veins three times a week and shoving it into your tummy. He does it himself. He's been doing it himself since we started on it. Kiri

Hana and Mark both described how observable the changes brought about by Emicizumab for those with haemophilia has been, and how this may occasion changes for prioritising those with other bleeding disorders, which have not yet benefited from such a transformative treatment.

I've always felt we're second class [with vWD] and now because things are shifting because it's such good control now of haemophilia and we've got a really good regime going. They're now looking at the vWD. Hana

Mark also shared a fear that with the emergence of Emicizumab, longer term care of those with bleeding disorders may be compromised, particularly if haemophilia appears to less severe in its acute symptoms.

Long-term treatment may be compromised, especially from a community perspective as well. You see, it comes in waves, so people all of a sudden become more independent and they don't [interact with healthcare as much] … You know HepC, HIV, we were banded together and there was this huge community to have that commonality with that cause. [After] people just went off and did their own thing to try and get people back into the fold and busy lives and whatnot. It's difficult. But I think there still needs to be a community there to make sure that ongoing care is provided for that population.

Comprehensive Care Teams Ease the Challenges of Accessing Care

Participants reported that the multidisciplinary nature of comprehensive care teams made discussing challenges and accessing other services efficient and effective. The HNZ Outreach workers were identified as key parts of this multidisciplinary effort.

For me leaning on the comprehensive care team is what I've taken the most value from being able to get. especially from a referral from haematology, being able to get key referrals through to other departments. Mark

The HNZ Outreach team performs a valuable function in linking caregivers with care teams and resources across the healthcare system.

[The HNZ outreach worker] really cleared a path for us [accessing services]. Kiri

For Biological Parent Caregivers, Birth is a Pivotal Event

For caregivers who were biological parents of children with bleeding disorders, the process of giving birth was difficult due to the special requirements for delivering a baby with a potential bleeding disorder, and also the care of mothers who also have a bleeding disorder. Jane reported angst where birth plans intended to minimise risks for mother and child were not adhered to.

Jane reported despite having a bleeding disorder herself, no changes to the birth plan were made during her second and third births:

> My experience was before she was born there was no issues. You know what I mean? Well, there were issues because health professionals wouldn't talk to me about vWD disease and bleeding disorders and I was quite terrified, I guess of, dying giving birth to both girls. I mean haemorrhaging and because I knew my sister had actually had a blood transfusion, you know what I mean? So, I knew there was risk.…They did the clotting test and said no, you'll be fine. And so, they just did a bleeding clotting test which as you may know by now that when you're pregnant, your clotting factors can become higher. So, they said, “oh, there's no risk, there's no risk”. And so, I felt very vulnerable and needing to advocate and look after myself during, during labour, believe it or not, you know, and afterwards, and so I self-medicated.

When asked about her first birth, Jane shared that no additional planning was made to cater for her vWD, resulting in a highly traumatic experience.

> So, I had an episiotomy and so that's with no cover at all for the vWD.

> My husband will tell you that it was just like being at the meat market, there was blood everywhere and I, and we can both still hear the snip when they, you know, did the episiotomy. So, by that stage I just closed my eyes and thought they can just get on with it.

Hinē reported that complications in her birth caused severe challenges for her role as a caregiver.

> The surgeon nicked my main artery. So, I bled out during the C section. I don't really remember much of their birth. I was out for a while, probably two weeks until I was transferred to HDU. And then they had the twins there. I thought I'd been in a car accident and when I woke up and the twins were there and I was like, oh my gosh, whose babies of those? And they said “they’ll be yours”. And I was like, “oh my gosh”. And I did. Yeah, I forgot, I've had the twins so that I think that sort of took over my mental health. Then having twins with hemophilia. It was then getting myself up walking again, learning to write again. There was a lot that I had to do quickly to get myself out of the hospital because I'd had enough being in there and I just wanted to get home and here for the babies.

These events resulted in trauma and distress, with both Hinē and Maia reporting seeing a clinical psychologist for support to address traumatic experiences.

Kiri reported that the inability of her midwife to attend the birth of one child resulted in the cord blood testing used to diagnose bleeding disorders being incorrectly performed and unable to be used, losing “a huge piece of information”. Kiri’s planned midwife had training to conduct the testing, but the midwife who eventually attended the birth did not have specific training for the test.

5.2 Relational Factors Results

These results relate to the experiences of caregivers of the relational components of care, primarily relating to communication, and experiencing being cared for.

Diagnosis is a Critical Event for Caregivers

Three participants, all of whom had children with novel cases of haemophilia, reported that the delivery of diagnoses by the haematologist was extremely distressing. Each of these participants interacted with a different haematologist.

Jo and Maia both explained that the communication of the child's haemophilia was extremely upsetting.

> When he [son] got diagnosed, they literally said this is, it's stuck with me… They literally said to me your child has a life-threatening illness, a chronic disease. Jo

> We went into the doctor's office and he sat us down and said, your son has got severe haemophilia. You might as well move by the hospital, all these horrible things, you know, preparing us for the worst, I suppose. - Maia

> The nurses would have better at having those conversations and the doctors would, um, the doctor who first told us would be the only Haematologist

> I've met where I feel like she would have taken this off the approach because she is a mother herself. Kiri

Kiri shared that dealing with another Haematologist was similar to Maia and Jo’s experiences.

> [Haematologist] was all doom and gloom to start off with. Kiri

The impact of poorly delivered diagnoses can be viewed as a self-fulfilling prophecy, where caregivers who were left feeling scared, unsupported, or powerless, altered their behaviour and management of their child in response to fear, and in so doing suffered the consequences of increased stress, alienation from family, or compromised mental health. It is notable that these diagnoses are delivered in situations where the child has already been admitted to hospital for unexplained bleeding, and that caregivers of children with novel diagnoses are not well versed in bleeding disorders and the implication of caring for children with them.

This contrasted with the experiences of participants who saw other haematologists, demonstrating the variability of relational care.

> They did a check in and I had the midwife still on hand so she was able to check in with me and I checked in with [the haematologist] up at the hospital. So, the service at the time, they were amazing. I can't really fault them. Hinē

They were really good at going “we're showing you how you have to look after your child”. Rylie

It is important to note that the nature of these diagnoses does not accurately reflect the prognosis for children with severe haemophilia at the time. Maia and Jo shared the impact of coping with bleak prognoses:

> Yeah, there was a shock of us like being in grief because he's our boy that we had dreams of, you know, but we were told, you know, that you might as well just live by the hospital because he's going to be in and out all the time. And so that, that grief probably made things worse for me…
>
> I felt that when he told us it was a death sentence that he was going to have, he, he didn't. [The haematologist] said that he probably won't be walking when he's older. It just, I don't know if he underestimated us or what he was just, I didn't think there was hope there. That's what it was, but there was no hope. It was just like, fuck it. Excuse my language. Maia
>
> I didn't enjoy having a child…Haemophilia took all the joy out of having a child because I felt so guilty because I'm obviously the carrier… I literally just thought that my baby was going to die. Jo

These diagnosis deliveries impacted support networks around the caregivers. In Maia’s case, extended family were scared to assist due to the bleak prognosis, further increasing the burden on her as caregiver.

> So, we lost a lot of support with our family… and when he was learning to walk and they were so scared of him falling down there. I just know that they couldn't, they couldn't handle coming over and seeing us. Maia

Maia and Jo reported seeking psychological support from therapists to make sense of the diagnosis and what they were experiencing.

Jo perceived bias as playing a role in her experience of the diagnosis.

> It's a bit like if you're white and you look privileged and tidy and you look like a professional, you get the better version of the Haematologist. But if you look like you're like, if you're Māori or you're a bit of a bogan or young, you get treated like you're second class basically is how I see it, they give you the worst case of the disease. Jo

Jo’s statement above reflects the totality of her experiences as a caregiver, and demonstrates how lived experiences of caregivers can be markedly changed by their expectations for their child’s future, and how the stories learnt at this early point in their journey contribute to the formation of a caregiver identity.

Primary Care Physician Behaviour

Jo reported that following the diagnosis of her child with haemophilia, she sought explanation from her primary GP as to how symptoms of serious bruising had been missed, and was told “we could have got you done for child abuse”. Whether this statement was true, or intended to defer criticism of a failure to diagnose, it demonstrates that the GP’s failure to engage with the challenging topic of the child’s care compromised the delivery of technical care.

This is consistent with stories articulated by Park et al. (2019), where HCP biases confound accurate diagnosis, while also raising serious questions regarding compliance with mandatory reporting of child abuse by HCPs.

Caregiver Experiences with Bleeding Disorders Shaped Experiences

Participants who grew up with family members who lived with bleeding disorders reported a greater degree of familiarity and comfort with treatment, with three of four participants who had a known family history of bleeding disorders reporting matter-of-factly on the technical aspects of care.

Mark reported his early experiences as a person with a bleeding disorder, prior to becoming a caregiver, were influenced by his own caregiver who chose to take responsibility for his care and learn to administer treatments in order to avoid overreliance upon clinicians: “We just sort of just get on with things and whatnot.” Mark

Hine reported that testing to confirm she carried the haemophilia gene mutation meant she had existing connections with the hospital once she became pregnant.

> It was pretty good because when I was 11, my mum had us tested to see if we were carriers. So, I had already made the connection with [name] at the hospital. She knew us and I think from there, she was there for a long time and she still relieves. - Hine

For participants who had no known history, understanding and mastering the technical aspects of care was confronting, particularly for Māori participants for whom the taking of blood and injection of medication raised concerns regarding tikanga. Maia explained:

> I'm injecting my son with something. Not only am I nervous about hurting him because of my lived experience with that is that this is an object going into my son as well into his body, which is sacred as well…
>
> …it was just really rushed and like, why can't you do it?"

While the challenges for each child were different, all participants reported that the provision of treatment for their child, adapting to challenges, and learning to live with a bleeding disorder was effective.

Family Histories of Bleeding Disorders were Sometimes not Known

Two participants reported family histories of bleeding disorders that were not spoken about until after they, or their child were diagnosed. Mark shared that:

> It got to a point where it had sort of been suppressed in the family. My great grandfather and his seven brothers all passed away from haemophilia-related bleeds before they were 21.
>
> They sort of moved on, didn't really speak about it and didn't really think about it or realise the genetic link.

Maia explained that while her child's disorder appeared novel, she later discovered a family history:

> There’s a lot of pain. There was shame in it too when I found out through my side, a great uncle had it. And so, there was within my Maori family there was shame there. It wasn't talked about.

Caregiver Trauma Contributes to Experiences

Maia shared that her traumatic experiences as a child contributed to make injecting her young baby much harder.

> So, we had to learn how to do the intravenous infusion of factor. And for me, because I've been through a traumatic childhood, I just could not bring myself to. It was hurting him. And so, the haemophilia specialist nurse was teaching me and my husband how to do the infusion and he picked it up just like that. He was, he was really good at doing Factor, but I couldn't get it because I'd shake and then I told her I hate to tell her, you know, look, I've been through some heavy stuff and, to me in my brain it, it feels like I'm hurting my son. That's why I can't do it. Maia

Jane described similar experiences as a result of her own journey with vWD.

> I've actually had a journey of having a bleeding disorder as well as being a parent of a child with a bleeding disorder… my journey wasn’t a sweet journey. Jane

Outcomes were more Effective than Caregivers Expected Based On Severe Diagnoses

When asked how their child or children with a bleeding disorder is today, all participants shared joy at how well the child was, how they lived full lives with their disorder, and that treatment had exceeded expectations. Caregivers did not diminish the challenges their children faced, and described young people living full lives despite their bleeding disorder.

> He's amazing. H is the man. He is 13 years old. He’s just such a good bloody person. He's a good guy here and he's active and athletic. Maia

> And he's a very articulate boy and a very like runs his own business and everything. Hana

> He's an awesome kid and the haematologists, they don't realise that’s what's going to happen. These kids are going to be cool. They're going to be good kids. Jo

Caregivers Described the Impacts of Purpose and Identity

All caregivers reported that following the diagnosis of their child, they developed a strong sense of purpose to administer treatment, facilitate care with the clinical care teams of HCPs, and contribute to others experiencing similar challenges.

Mark, Hana, and Rosie have contributed to HNZ governance, while Hinē described assisting parents at hospitals with practical advice such as Citizen’s Advice Bureau support details.

> I said, call the Citizens Advice, see if there's an advocate for you and make sure you take someone with you to the, to your appointments if you're up at the hospital and you don't understand. Hinē

Maia shared she has taken a proactive role on her Marae, talking openly about bleeding disorders, offering support to anyone who would like to discuss it.

> Within my Maori family there was shame there. It wasn't talked about but I go down to our whenua, and I'm talking about it all the time. Hey, guys, we've got this in our family. If you have a boy or even a girl that's carrying with haemophilia, give me a call. It's all good. Every time I can talk about haemophilia, I will. Maia

Caregivers Become a Crucial Member of Care Team Linking Care with the Child’s Everyday Life

Caregivers described becoming vital parts of their child’s care team, administering care, providing connections between services, and actively advocating for their child.

> But if you're like, ok, when, when are we going to hear back? Yeah, before the end of my shift this happening. Ok, great. And then I'd be able to say the nurse, oh, they said they were going to hear back before that and the nurse will go. Oh, yeah, I'll remind them of that and so often it was just the navigate the system, I guess you learn to know who to talk to, to talk to who to try and get that information passed along to get to the next step in the process. Kiri

Caregivers Support One Another

Caregivers described proactively sharing resources with other caregivers, helping to ensure that the community as a whole benefited from individual caregiver successes.

> I was able to go, hey, send all this information to some of our parents that were also looking for the same sort of thing. So, we were successful. Hinē

The HNZ Youth Camp emerged as a venue where this sharing and connecting occurred:

> You know, some great things and the camps have been amazing, their information stuff. We went to inhibitor camps and workshops, which were really helpful when you kind of felt almost slightly isolated even from everyone else who had hemophilia because you're just on a completely different journey with different medications. Kiri

Racism and Bias

When asked “Have you ever experienced racism when accessing care”, all participants reported they had not. However, a critical analysis of experiences provides a more nuanced view where institutional racism, and violations of cultural safety were reported. This included refusals to engage in karakia before the taking of blood or administering of intravenous treatment, refusals to meet with whanau to explain haemophilia and treatment, and HCPs articulating views of Māori or Pacific Island caregivers or children that appear racist in effect, regardless of intent.

Hana reported that she, and her husband, who is a Cook Islander and therefore a New Zealand Citizen, experienced racism.

> Um, over the years I've had it said to me, “oh, well, obviously you got it from him [Hana's husband, and father of her children] because he's an islander because they carry the gene.”. Well, no, that came from me… so just listen, actually listen, don't judge, the judge, don't judge so fast and quickly that you've made an assumption when we've walked in, especially being a of our combined race. I have like, had the looks that, has he done something to the kids?
>
> The other thing is that we've had said to us is “he's Cook Island”. He's already allowed to have medical care because, you know, the Cook Islands have an understanding and everything. We've been told [by a doctor at the hospital] that we're taking away the medication from the New Zealanders.

Hana reported that these interactions resulted in times where she chose not to take a child to the Hospital and instead treated them herself at home.

> There were times we didn't, we just, we just, I couldn't be dealing with the fight.

Maia also reported repeated instances where culturally unsafe practices were employed by HCP’s, despite requests from Maia and her family for small changes to how care was delivered.

> So wairua is really important to Māori - spirituality. So, with medical procedures, it felt like our son was a pin cushion. It was just like he was an

> object. Not even really talking to him, even though he was a little baby and didn't understand but like, none of that so that he could feel the other person's wairua or that he'd be safe…there was no, there was no aroha or yeah, nothing like it was just, “he's an object” and he's not because he's, he's got ancestors around him, you know…I don't know how many times us saying talk to our son. He's right here. [They refused] Maia

When asked what she would change, Maia answered:

> It would be supports that made every person in the family important, and when we discuss things, not just we're going to have a meeting at such and such a time. Let’s find a time that all the family can get together and let's have a hui together, you know, not fitting in a little hospital appointment room. Let’s sit around the table if we can, and discuss things that would have really changed things.
>
> Having family there and people caring about our son’s wairua and our family’s wairua. It's not just an appointment, it is a journey. Yeah, that would have really helped to be the core of our journey moving forward together.

Hana echoed Maia’s comments on the importance of meeting the family where they are, in part due to the historically poor experiences many non-Pākehā families have had in hospitals.

> That simple barrier being removed by going to the comfortable environment. A hospital brings a thing in itself. A lot of Islanders are afraid of hospitals.

> And my husband’s family have had quite a bit of trauma with their father passing and the way that went down in the hospital, so that they don't forget. They are very good at having these memories. I think a simple barrier of you going to them, their house or environment, even to the local doctors and meeting them, there would have a lot more comfortable and I think it's, that would take a bit of the sting out of it.

Hinē reported that although she did not face racism, it was perhaps because she does not “look Māori”. Hinē reported:

> I did see it with other people. The way people were spoken to there was a lot of bias, and probably assumptions based on because someone's not turning up on the right clothes or, you know, pregnant women who were tired and, they didn't do their hair or whatever, you kind of see that. And I heard a receptionist say something like, oh, she didn't even brush her hair, or receptionist or admin would talk to the, talk to different cultures like they were deaf. So, I was very aware of things like that.

Kiri reported that while she did not experience racism directly, she observed its effects around her.

> [Racism] comes to the crux of why a lot of Maori don't go to doctors. Power. People are seen in those kinds of positions by a lot of Maori, they intrinsically don't trust them. My husband still won't trust the police. Um grew up in a housing development where there's lots and lots of flats, like for half a street, you know, like it was a massive, um, housing great. When your kids you've

> got lots of people to play with. You know, he said it was great growing up but, you know, it's lots of things but he got stop that but the place, place end up and did things to people he knew, um, they were probably not warranted. His mum got stopped by the police. Lots of times he got stopped in his twenties by the police lots of times for no good reason…
>
> And so intrinsically, Doctors have this kind of authority, you know, people who come in with this kind of authority, and I see some of the doctors be like that, Māori find that hard to take and then just don't go to the doctor.

Caregivers Make Sacrifices

All caregivers described making sacrifices in their careers to support their child. Hana, Kiri, Maia, and Jo, reported changes in career or temporarily leaving the workforce in order to support their child. This was largely due to the intensive requirements of caregiving for a child with severe haemophilia.

A more inclusive bleeding disorder clinic

Hana observed that people with bleeding disorders are all seen at hospitals at what is referred to as the Haemophilia Clinic, resulting in a sense of other disorders being less serious than haemophilia.

> I was still treated second class because we didn't have that one specific thing, which is haemophilia and that's why it was so important that it should be renamed Bleeding Disorders Clinic, not haemophilia clinic. Hana

5.3 Broader System Factors

These results regard participant experiences of factors in the broader healthcare system, and their day to lives.

Systemic flaws can inadvertently create conflict and a perception of bias.

An example of systemic flaws biasing caregiver communication emerged from Mark, who explained challenges being copied on communication from healthcare entities for his daughter for whom he shares joint custody.

> Every medical thing would go to mum and mum would not communicate that and I could not for the life of me just be copied into letters or emails or anything like that. Mark

Mark's contribution demonstrates a systemic issue where co-parents are not treated equally, and the design of communication systems requires the HCP entering data to choose which parent to preference, where equality would dictate the requirement in itself should not exist. This systemic flaw is likely to affect all parents sharing custody, not just those of children with bleeding disorders.

Pharmac Access and Fears of Removing Funding

Caregivers of children with Haemophilia reported the significant relief provided with access to Emicizumab. Several reported significant hurdles encountered when initially seeking access, and fears that funded access could be removed in future. This was attributed in part to the current government messaging on healthcare sector costs.

> Yeah, my, my concern always sits with, you know, someone in Pharmac could always decide to just pull something as an option. You know, they, they only fund so many medications what happens if they decided to not fund Hemlibre. Kiri

Carer Support Subsidy

The carer support subsidy provided meaningful assistance, in the form of funding for respite, however for many, it was difficult to access to restrictions to how it cannot be used if the respite caregiver is living under the same roof as the primary carer. In effect, this decision results in excluding those most able to provide technical aspects of care, and who enjoy existing relationships with children, from receiving the respite carer payment.

> It can be a relative that's not living with you. But it can't be like, couldn't be my son, which I found ridiculous who lives with me. So that's a big brick wall that I've come up across. There are a lot of people that just don't bother applying for it because it's just too hard basket. I can see why there's so many people that are getting let down from our system because it's set up to fail people. I've seen the paperwork just for the disability forms. It's insane amount of paperwork just for a form that could be five minutes at a counter between appointments. Hinē

Maia also reported the carer support subsidy was helpful, and introduced to her by the HNZ Outreach worker.

> It’s a really needed break. Yeah. So that was, that's amazing. Career support having that.

Political Messaging is Felt by Caregivers

Political messaging at the time of this research indicated services, support, or medication funding could be reviewed or cut.

> Yeah... there's a lot of anxiety around, I think a lot for a lot of us just accessing all the support systems. I think that the politics and the government at the moment is it just toughened everything up and just put a whole lot of anxiety on people and there's going to be, a lot of people that aren't going to reach out and just going to disappear or just become homeless because they, you know, that's the only other option. Hinē

5.4 The experience-based Co-Design process

The use of an experience based co-design (EBCD) methodology to engage with and empower caregivers to contribute to scoping service improvement proved highly effective. Chapter Three details the decisions to conduct the EBCD workshop one-on-one with caregivers, and while this resulted in a more time consuming process for the researcher, a space was created for individual caregivers to consider for the first time how their experiences informed their perspectives on change. When caregivers were asked if they had been invited to contribute to service improvement prior to this research, all responded that they had not.

The findings laid out in this chapter present new insights to the experiences and outcomes expereinced by caregivers, while also presenting phenomena already known, such as the impact of poor communication, through a paradigm – that of the caregiver. When considering these findings, it can be seen that many of the insights shared by caregivers do not require significant or costly changes to what is done, but rather a reconsideration of how care is done. The stated purpose of Pae Ora (2022) at section 3 of the Act is to:

> “ (a)protect, promote, and improve the health of all New Zealanders; and
>
> …
>
> (c)build towards pae ora (healthy futures) for all New Zealanders.”

This research demonstrates that by adopting an EBCD methodology, a crucially valuable component in building towards health for New Zealanders is to be found in doing so with New Zealanders. Viewing a healthy future through improved healthcare in New Zealand is a fundamentally participatory action congruent with Cornish et al.’s (2023) understanding that experientally led change can be effective in complex systems.

Chapter 5: Discussion

This discussion chapter synthesises the findings of this research with literature introduced in Chapter Two to evaluate the lived experiences of caregivers of children with bleeding disorders and the efficacy of employing Experience-Based Co-Design (EBCD) methodology. By integrating participant narratives, the research highlights systemic challenges, relational dynamics, and culturally specific considerations that shape caregiving and healthcare outcomes. This chapter explores the implications of these findings for relational care practices, healthcare policy, and co-design processes, offering recommendations for advancing inclusive and equitable care models in New Zealand's healthcare system.

Caregivers form a purposeful connection between their child and the healthcare system. In providing care, connecting with services, and advocating for their child, the expertise of caregivers is invaluable to ongoing efforts to improve healthcare experiences and outcomes in New Zealand. Caregivers possess personal attributes, skills, motives, and identities that allow for inclusive and nuanced exploration of challenges they have experienced and solutions which are actionable and impactful.

By placing the caregiver and their experiences at the centre of this research, the themes discussed in this chapter draw upon the results discussed in Chapter Four, and existing research discussed in Chapter Two to demonstrate how this research has generated new knowledge, validated existing knowledge, and identified avenues for future research. The position of caregiver co-ordinating care, collaborating with care teams, and fostering a relationship of care with their child uniquely positions caregivers to contribute to the co-design of service improvement.

Diagnosis can be viewed as a critical event in establishing the trajectory of caregiver experience.

Research participant Jo articulated a novel, powerful, understanding of caregivers experiencing the diagnosis of their child. In articulating that haematologists, through their communication and behaviour can contribute negatively to the trajectory of a caregiver's lived experience by "giving you the worst case of the disease", Jo echoed the findings of Beach (2006), World Health Organisation (1995), and Aboumatar et al. (2013), whilst advancing them in the context of caregivers. Similarly, Maya's articulation of how the diagnosis of her child collided with her own cultural identity demonstrate the coalescence of Durie's (1985) understanding that wellbeing must be assessed within a cultural context, and Neumann's observation that HCP's infrequently engage meaningfully with caregivers (2021). Both Maya and Jo went on to describe scenarios characterised by anxiety, fear, and alienation that resulted in not just mental health challenges, but damage to their relationships with their child and broader family.

The implications of these experiences suggest that research and interventions targeted at improving the experience of receiving a diagnosis of one's child would be highly valuable. Interventions improving this experience may provide an opportunity for HCP's to diagnose the best case of the disease, rather than the worst, and support caregivers at a time when small changes in trajectory are more impactful. Diagnosis can be viewed as an event at which the stories caregivers use to make sense of their past, present, and future crystallise, and in that moment, the identity of caregiver changes (Mankowski & Rappaport, 1995). Discussions with one Haematologist dealing primarily with adults, detailed that where care experiences have been poor during childhood, extensive efforts are required to rectify both the person's relationship with their bleeding disorder, and their relationship with care teams, in order to adjust the trajectory of their disorder. This observation may suggest new opportunities exist for diagnosis and support to be improved during paediatric care of those with bleeding disorders. Future scoping of this process is well suited to EBCD, and consistent with Pae Ora's (2022) aims.

For caregivers of a child with an unexpected bleeding disorder diagnosis, this event can be seen to have additional implications as it is the first time that the caregiver meets the haematologist who will oversee the care of their child in the future. This is in stark contrast to caregivers with a known family history of bleeding disorders or prenatal diagnosis, given the understanding that unexpected diagnoses of bleeding disorders usually accompany trauma resulting in unexplained bleeding for the baby which as reported by Maia and Jo was an acutely stressful experience. The coinciding of the stressors accompanying unexplained bleeding may increase the stress of the diagnosis meeting and conversations with haematologist, at a time when the long-term relationships between caregivers, haematologist, and care team are first established. Reframing of this discussion as one that will establish a long term relationship of care, support, safety, and knowing the caregiver as a person (Beach et al., 2006) may present an opportunity to also reassess how the diagnosis is communicated. Co-designing in order to move closer to the best-case care team-caregiver relationship presents an opportunity to create conditions under which the best case of the diagnosed bleeding disorder can be communicated and supported. It is also notable that novel bleeding disorder diagnoses make up approximately one third of diagnoses (Park et al., 2019), and that HCPs who predominantly communicate with patients and caregivers with a known family history and lived experience of bleeding disorders are not sufficiently modifying their communication and relational care approach to support caregivers for whom this news will be unexpected.

When using the term ‘best case’, it is critical to clearly convey that the diagnosis and relationship does not change the clinical status of the bleeding disorder at the time of time of diagnosis, but that the qualities of the diagnosis conversation and relationship with caregiver does influence the trajectory of caregiver experience, and clinical treatment efficacy from the point of diagnosis forwards. Just as haematologists and care teams monitor symptoms of bleeding disorders in order to adapt their care to meet present needs, so too may they monitor the qualities of the caregiver relationship, adapt to address shortcomings, and seize opportunities to enhance the relationship, in order to realise the best case of relationship and disorder.

An expectation that the haematologist-caregiver relationship is consistently established in best case fashion is unrealistic, regardless of interventions to support this outcome with existing research shows expectations of perfection undermine skill acquisition in medical cohorts (Kleinrensink et al., 2021). A more realistic approach is presented by the process of EBCD itself, where parties share power to understand perspectives, share resources, and create valuable improvements. The process for collaboration in order to establish relationships closer to best case, and to adapt where we fall short is one of communication and humility. As discussed below with regard to formal haematology training, the absence of patient centred communication training may be seen to make the establishing of best-case relationships less likely, and the correcting of relationships that do not support optimal care much harder.

The opportunity to create best case relationships presents an opportunity to enhance the likelihood that those with bleeding disorders and their caregivers experience the best cases of their condition, is clear. Seizing this opportunity can reduce costs of care, improve healthcare outcomes for patient and caregiver, and improve the wellbeing of clinicians (Aboumatar et al., 2013; Mazzarelli et al., 2019; Wilkinson et al., 2017).

The Role of Haemophilia New Zealand

All participants in this research spoke positively of HNZ. While it must be noted all participants were recruited through HNZ's network, the experiences described regarding HNZ's support are demonstrative of the importance of community to provide connection, resources, and the power to advocate for change. HNZ's annual youth camps for young members and caregivers create connection, something of particular value to those caring for a child with a novel bleeding disorder, where experiences and resources for managing bleeding disorders do not yet exist within the family unit.

Throughout this research, HNZ's outreach workers emerged as a critical component of care teams. The role of outreach worker supporting caregivers, interpreting information and attending diagnosis meetings was reported to have a positive impact. This helping role may also see outreach workers working to address experiences caregivers have with HCPs in a way that addresses a symptom, at the cost of rectifying the cause. This is discussed further below, with regard to the role of the Haematologist.

The decision to exclude outreach workers from this research reflected a desire to ensure caregivers could contribute openly, even with regard to outreach workers. For future research, the inclusion of outreach workers to provide perspectives bridging the gap between care team and child may offer a particularly valuable contribution to the co-design process.

HNZ's role in the creation of community through its activities has also demonstrated an existing mission congruent with both Pae Ora (2022) and Hauora (Tribunal, 2019a), with particular attention given to Māori with bleeding disorders, through the creation Piritoto.

The Role of the Haematologist in New Zealand

The role of Haematologists came into focus throughout this research. Workshops shed light on the significant impact of caregiver experiences with Haematologists, both positive and negative, in shaping identity and outcomes. These are discussed in more detail in Chapter Four. In considering the role of Haematologists in New Zealand's healthcare systems, two Haematologists contributed valuable pieces of information in addition to those discussed above.

Firstly, New Zealand's healthcare system, due to its size, requires Haematologists to practice generally across blood disorders, including oncology. This is in contrast to haematology training and practice in larger, wealthier nations, where Haematologists are enabled to micro-specialise to understand particular disorders and the experiences of those living with them. The more general scope of haematological practice in New Zealand means that the same haematologist may see patients with a broad range of disorders in any given week, with the constant variable remaining that it is the same haematologist communicating with all of these patients and where applicable, their caregivers. Another interpretation of the New Zealand Haematologist's broad scope of practice is that the requirement to continually move between patients with different disorders and lived experiences creates a more complex set of interactions for the haematologist to manage adaptively.

Secondly, an experienced Haematologist offered the insight that the specialist haematology training programs are conducted entirely in a laboratory setting. A review of the Royal College of Pathologists of Australia Haematology Trainee Handbook and Royal Australasian College of Physicians Haematology Advanced Training Curriculum, shows that neither refer to assessment of communication with consumers or caregivers, reducing the role of assessed communication to scientific or academic communications (Royal College of Pathologists of Australia, 2024; Royal Australasian College of Physicians, 2024). This training model results in doctors who have previously seen patients now spending a period of years undergoing extensive training in the diagnosis and treatment of blood disorders, in the absence of communication with people living with the disorders, or their caregivers. Trainee Haematologists who do not have contact with patients are unable to benefit from the contributions of patients and caregivers that come from lived experience. When considering findings relating to non-technical components of care, the training of haematologists in the absence of patients presents a striking opportunity for further research and potential improvement. In practice, specialised patient-focussed communication skills training appears to be an optional pursuit for HCP's with a particular motivation to seek it out, rather than a foundational skillset facilitating the better practice of haematology. In an environment where scientific advances are rapidly changing the treatment of chronic illnesses, it may be tempting to rely upon advances in technical components of care to improves outcomes. A counterpoint to this understanding is that the constant component underpinning care, regardless of technical advances, is communication. Integrating relational skills training to the haematology training program offers an opportunity to support these rapidly changing treatments, rather than expect them to offset shortcomings in relational care.

Finally, one of the haematologists consulted was asked what has shaped how they engage with patients and caregivers. After reflecting, they identified that spending time at conferences and events with people living with blood disorders had significant impact on their understanding of lived experience, in contrast to simply clinical treatment. This proactive engagement with people living with disorders could be seen as the missing piece of a specialty training program focussing upon disorders in the absence of people. In seeking to understand the experiences of the people they serve, this haematologist can be seen to equip themselves to know patients and caregivers as people, harnessing the promise of Beach et al.'s (2006) research.

The implications of understanding the pivotal nature of the haematologists' communication, combined with specialty training occurring entirely in a pathology laboratory setting is that modification to Haematology training curricula in order to enhance communication, behaviour, and understanding of patient lived experience may offer an effective route to improve outcomes. Due to the wide scope of practice for Haematologists in New Zealand, communication, whether poor or exemplary, and behaviours such as bias or racism, are likely to be experienced by patients and caregivers with a range of disorders. This presents the possibility that acting to address clinician relational skills may produce benefits experienced by a much broader community than just those with bleeding disorders.

Racism and Cultural Safety

Findings in this research present a troubling picture of the experiences of Māori and Pasifika children and their caregivers. Experiences of racism were common, ranging from a refusal to adopt culturally safe practices for Maia, to overtly racist statements made to Hana. These experiences negatively affected the caregiver, compromised the provision of technical care, and damaged relationships with whānau. These experiences and outcomes cannot be tolerated. These experiences are emblematic of those recounted in Hauora (Waitangi Tribunal, 2019c) and while applications of cultural safety can be applied specifically to bleeding disorders, it is difficult to see how these would be effective in the absence of institutional prioritisation of cultural safety and anti-racism (Reid, 2021). It is in the context of institutional reform that the disestablishment of Te Aka Whai Ora is so keenly felt, with its sole focus upon ensuring the health care system meets the needs of Māori now leaving a void in addressing the pervasive inequity identified by Hauora (Waitangi Tribunal, 2019b).

The implications of these experiences by Māori and Pasifika caregivers and their children, combined with the de-facto de-prioritisation of equity within the healthcare system will see a reinvigorated need for advocacy groups such as HNZ to protect the interests of their members. HNZ's struggles to protect those with bleeding disorders and seek redress following the tainted blood scandals of the 1990's suggests that it possesses the institutional knowledge, policy craft, and determination to do so. As discussed above, the general nature of haematological practice in New Zealand offers the opportunity that initiatives led by HNZ to improve cultural equity for those with bleeding disorders may have an impact across the broader scope of haematology. By improving cultural understanding and practice of the haematologist in one setting, the experiences of those interacting with the haematologist in other settings may be similarly improved. The power of these effects throughout the healthcare system demonstrate the power of solidarity between advocacy groups and allies.

Recruitment in this project disproves, that Māori have been alienated from active participation in improving their experiences, despite the unacceptable experiences of racism and bias experienced. With Piritoto members energetically engaging in recruitment and co-design workshops, I contend that where research and co-design spaces are created in ways that are visible, able to be claimed by participant groups (Gaventa, 2006), and facilitated in ways to affirm the dignity, capability, and accountability of all people (Regier, 2023), transformative outcomes are possible.

Caregivers create connections throughout a complex adaptive system.

Caregivers in this research shared a range of experiences demonstrating that they operate simultaneously at multiple points within the healthcare system, while carrying with them skills gained beyond their role as caregiver.

From connecting their child with HCPs for care, administering care themselves, liaising with support agencies, advocating for change, supporting other caregivers, and contributing to policy discussion through HNZ, the caregiver can be seen as a rare example of a person with lived experience throughout multiple domains of the healthcare system, positioning them as uniquely positioned to contribute to the co-design of services, validating Cornish et al.'s (2023) assertion that the prioritisation of lived experience creates improved outcomes. When the rich and expansive skillset of the caregiver is viewed alongside Anderson et al.'s (2013) observations that caregivers seek to be actively involved as part of the care team, this research project presents the caregiver as a highly valuable and influential actor within the healthcare system their child experiences. The inherent complexity of healthcare as an adaptive system (Covvey, 2018) means that outcomes are not always predictable. The role of the caregiver as present at diverse points within the system positions them uniquely to observe, respond, and report emergent outcomes of healthcare initiatives. Research exploring the impact on the experience of the caregiver in systems holistically engaging their skills in care may offer valuable insight regarding the relationship between care and caregiver outcomes.

The role of caregiver throughout the healthcare system may need accounting for, should caregivers prioritise the immediate needs of their child to the detriment of systemic improvement and this should be considered in future stages of co-design, however it is a truism that each person in any process brings with them their own identity, concerns and motivations. Rather that exclude caregivers on these grounds, it would be preferable to celebrate the investment of the caregiver and provide opportunity for individually focussed motivations to be harnessed and explored, rather than lost under a guise of objectivity. After all, the lived experience that offers such value to system improvement is inextricable from the lives of caregivers. By employing EBCD processes throughout the healthcare system, caregivers may be given the agency to ensure the healthcare system comes to not and represent them, rather than the caregiver suffering the shortcomings of a system that they are removed from. This observation of connection and agency within the healthcare system is yet another echo of Graham and Masters Awatere's (2020) observation that alienation results where respect and agency is lost.

Considering the experience and contribution of caregivers, future research may show that the very process of presenting meaningful ways for lived experience to improve the healthcare system is a process that itself fosters agency, skills, and expertise amongst caregivers that mutually reinforce their existing impact across the healthcare system. Should this come to pass, it would demonstrate that the process of system improvement itself can come to impact the trajectory of caregivers by actively involving the caregiver in a form of meta-relational care.

Identity

Caregiver identity, the result of the stories a person uses to make sense of their past, present, and future, (Mankowski & Rappaport, 1995) can be seen as ever present in this research, by simple virtue of the fact that EBCD is grounded in the stories of lived experience each caregiver brings with them. These stories and their implications are discussed throughout Chapters Three and Four.

A final consideration of caregiver identity is presented when considering caregiver experiences and the opportunity for participation in co-design improvement of the healthcare system. Participation in these processes by caregivers presents new stories to be created, as a caregiver involved in system improvement, one who's experience is valuable and valued, and one who's complex, intersectional identity, is an asset in improving outcomes. Simultaneously, participation in co-design processes, and collaboration with other caregivers, multidisciplinary HCPs, and other stakeholders, presents the opportunity for stories already used to generate identity to evolve or be discarded.

The role of co-design processes in actively contributing to identity has particular implications with regard to what stories, and therefore identities, are valued or devalued, both in the co-design process and broader community. Due to the complex, intersectional nature of identity, a focus on supporting the process of maintaining adaptive, healthy identity is likely to provide the flexibility and support without constraining or privileging forms of identity for caregivers. In understanding that identity and co-design do not occur within a vacuum, it is inescapable that messaging devaluing communities or individuals by way of facets of their identity, such as race, gender, disability, or any other facet, harms not just those communities and individuals, but also efforts throughout New Zealand to improve outcomes through co-design. At the risk stating this too plainly, racism, sexism, discrimination based on socio-economic status, and other forms of discrimination, jeopardise an entirely achievable healthier future for all New Zealanders and should be rejected.

Consideration must also be given to how identity is experienced by HCPs. Each HCP’s identity, in encompassing stories they use to make sense of their roles and relationships. may enhance or inhibit their ability to provide care or adapt as co-designed initiatives are implemented. The role of haematology specialty training programs can be seen to play a critical role in this process, given that this training is the evaluative framework against which performance is assessed, and is likely to play a critical role in forming stories of haematology practice that in turn contribute to professional identity.

Through the lens of identity, the absence of relational skills development in haematology specialty presents an opportunity to explore how professional identities may be supported achieve improved outcomes through improved relational care. Future stages of co-design, bringing together caregivers, members of the care team, and other stakeholders, present a process whereby relationships and identities may can be developed, providing a foundation for the better implementation of service improvement initiatives.

Co-Design led service improvement

Co-design is the practice of designing systems that produce better outcomes with those communities and individuals who will administer, and utilise them This research demonstrates co-design effectively elicits valuable insight and engagement from caregivers in a way that can build a more equitable system and state of health, provided engagement is meaningful and intended to build relationships, build capability, and maintain dignity. As relationships and outcomes are built, these processes become an inextricable part of the stories used to make sense of communal and individual past, present and future, and in so doing can be expected to contribute to changed identities for all involved. The importance of this understanding for all engaged in participatory processes and co-design cannot be understated.

As Pae Ora (2022) does not mandate specific co-design methodology, the flexibility exists for healthcare entities and co-design practitioners to adapt co-design processes to foster equity, inclusion, and better outcomes with the participants of any particular project. Pae Ora’s silence as to methods can be interpreted as one of its strengths.

Limitations

This research, while offering valuable insights into the experiences of caregivers of children with Haemophilia in Aotearoa New Zealand has limitations which must be recognised in order for it to inform further stages of service improvement through co-design.

The study included a relatively small number of participants. While EBCD often prioritises the depth of lived experience over quantity, the small sample size may limit the generalisability of the findings of individual workshops to the wider population of caregivers of children with bleeding disorders. Future research with a larger, more diverse sample may both strengthen the generalisability of findings, and identify other facets of experiences to provide a deeper understanding.

The reliance upon individual workshops as the primary research method may have limited the perspectives gathered. Additional methods, such as observations and focus groups could provide further insights and give more nuance to the findings.

This study engaged with caregivers during a time of significant change within New Zealand's healthcare system, with multiple workstreams seeking to improve outcomes and experiences through engaging with consumers, while other policy initiatives, such as the disestablishment of Te Aka Whai Ora, may harm it. This means that some changes may already be underway, and that the lack of cohesive collaboration between researchers and healthcare entities may result in inefficiencies, and the risk that caregivers are contacted multiple times to repeat their contributions.

Geographical factors may have also limited this research, with all but one participant being located near a major city centre. Future research exploring the experiences of those in rural areas would offer valuable insights to lived experience.

This research was limited by its reliance upon one researcher. Even with careful consideration, action, and reflection, a reliance upon one person reduces the diversity of thought, experience, and engagement with participants. Future research, conducted by a diverse range of researchers may offer new insights not identified by, or offered to me in my research.

Finally, as a scoping study, this research sought to understand experiences and bring in to focus opportunities for improvement. Future development of these findings must take a more granular, multi-disciplinary approach to developing actionable ways to integrate these findings to health care entity practices.

Recommendations

Co-Design process is subject to co-design

This research has demonstrated the effectiveness of EBCD in scoping improvements for caregivers of children with bleeding disorders. The inherent flexibility created by centring participants is critical for the ongoing success of co-design efforts in New Zealand. For this reason, it is recommended that ongoing attention is given to developing co-design process and facilitator competency. This validation and iterative improvement of co-design efforts may be informed by community psychology and PAR principles that it is lived experience that confers validity upon the efforts of the psychological scientist.

Caregiver experiences with HCPs

Caregiver experiences of the diagnosis and treatment of a child has emerged as a pivotal event with potential for improvement. Notably, participant caregivers identified aspects of HCP communication and behaviour that are amenable to change and may in turn benefit groups broader than the bleeding disorder community.

Existing research demonstrates the relationship between HCP communication and outcomes, and the successful role interventions can play in improving HCP communication (Aboumatar et al., 2013; Beach et al., 2006; Fernando & Consedine, 2014; Jallinoja et al., 2007). For these reasons, it is recommended that co-design processes are utilised to engage HCPs and other stakeholders to develop improved resources and training for HCPs. Particular engagement with the Royal College of Pathologists of Australia and Royal Australasian College of Physicians to review the role of patient and caregiver communication in their respective training curriculums is encouraged.

Participant experiences of culturally unsafe practice are concerning. Further engagement with healthcare entities and specialist Colleges to understand how HCPs can more consistently practice in ways that are culturally safe is also recommended, particularly given the void now left with the disestablishment of Te Aka Whai Ora.

Collaboration / Allyship

Participants in this research shared stories demonstrating how they access the healthcare system at multiple points, encountering HCPs, other healthcare consumers with bleeding disorders, and those with other illnesses. Building upon this, the breadth of haematology practice in New Zealand, the permeability of the healthcare system, shows relationships and common interests may exist amongst different consumers and advocacy groups.

This interrelationship of interests between different populations and advocacy groups suggests there may be value in HNZ establishing working relationships with other advocacy groups in order to collaborate, co-design, and implement change from multiple points within the healthcare system.

Future Research

Maintaining contact with the lived experiences of those with bleeding disorders and their caregiver.

The provision of technical care for those living with chronic illnesses is rapidly evolving. Novel medications, such as Emicizumab and curative gene therapies promise to upend our understanding of what it is to live with Haemophilia. Hopefully, similar advances will occur for the treatment of vWD and other bleeding disorders.

These changes present important avenues for future research in order to remain in contact with lived experience, understand how the trajectory changes for those with bleeding disorders and their caregivers, and ensure that treatment and support is remains optimised, rather than reflecting a prior state. Future research may also focus on the lived experiences of those who are for any reason unable to access next generation treatments.

Role of EBCD engagement in caregiver wellbeing and identity.

Participation in the improvement of the same health care which caregivers interact with so intimately may have effects upon those caregivers that can be differentiated from the results of co-design processes. Future research focussing on how participation in co-design affects participants and what factors contribute to this, is a valuable, widely generalisable avenue for research. Specific consideration of the role culture plays in these outcomes will ensure research meets the challenges of Hauora (Waitangi Tribunal, 2019c).

Carrying the torch of relational ethics.

Finally, future research faces the challenge to carry the torch left by Prof. Jim Liu, to ensure “Collaborative relationships grounded in sincerity, reciprocity, and shared purpose become the basis for how psychological knowledge is produced, disseminated, and acted upon.” (Hopner & Liu, 2021, p. 1). These guiding principles provide indispensable guidance for what future knowledge is sought, how it is produced and used. These principles allow the guidance to ensure that the lived experiences and identities of all people are honoured and reflected in scientific progress.

Future research may also seek to explore how these principles are reflected in contemporary research activities.

Chapter 6: Conclusion

Co-design proved to be an adaptable and effective methodology for a diverse group to contribute valuable knowledge.

Research participants in this project proved to be a diverse group, with cultural, socio-economic, gender, bleeding disorder, and age all varying significantly. Perhaps because of this diversity of experience, the insights identified covered a broad range of the experiences caregivers will encounter. Each participant contributed perspective of challenges and possible solutions that were not always visible from outside the caregiver relationship, facilitated by the creation of invited, and eventually claimed spaces where each participant had visible power (Gaventa, 2006), and validating the work of Cornish et al. (2023).

By validating the application of EBCD with a diverse group, this research demonstrates that the flexibility granted by Pae Ora’s (2022) silence on specific co-design methods, a liminal space is created between researcher and participants, where methodology can be adapted to centre research participants, and allow them to contribute to service improvement in ways that are unpredictably rich. The richness created by this flexibility lies not only the discovery of new information, but in the ability for researcher to see what is known through research through the lived experience of caregivers. Standing in the shoes of lived experience, the researcher does not simply see a new perspective known phenomena, but rather, may see something new. A powerful example of this can be found in Jo’s articulation that poor diagnoses experiences create a worst case of the disorder for the caregiver, by creating unwarranted fears, anxiety, and expectations for their child. This finding was echoed by Maia.

Participant contributions enabled by EBCD's responsive approach spanned Governmental policy, HCP behaviour, accessing practical support, the role of HNZ, and the role of political media messaging, amongst other themes, demonstrating that EBCD is an effective tool to understand experiences in a complex system. In addition to this flexible understanding of experience, EBCD provides flexibility to ensure that participants are empowered to identify what changes would be most meaningful for them, ensuring researchers practice in a relationally ethical way (Hopner & Liu, 2021).

Co-design is an active process, and as such, has impacts independent of the process changes which it produces. Similar to mere-measurement effects (Sandberg & Conner, 2009), the process of co-design can produce changes in participant experiences. These effects are discussed with regard to identity, below, and demonstrate that ongoing testing and co-design of the co-design process itself is necessary to ensure it remains relevant and fit for purpose.

Summary of Research Findings

This research focused on co-designing healthcare services with, and for, caregivers of children with bleeding disorders. Utilising an Experience-Based Co-Design (EBCD) methodology, the study gathered insights from caregivers regarding both technical and relational aspects of healthcare delivery. This co-design scoping exercise with caregivers seeks to inform future co-design processes with HCPs and other stakeholders to create service improvements.

Key findings highlighted the caregivers' pivotal role in care coordination, emotional support, and navigating the complexities of treatment protocols. Key themes of caregiver experience emerged that are suited to further co-design processes:

Technical Aspects:

Many caregivers reported challenges in accessing specialised healthcare services due to geographic and socioeconomic factors. They emphasised the importance of healthcare professionals being well-versed in rare bleeding disorders.

Relational Aspects:

Diagnosis was a critical event that shaped the caregiver experience, with relational care playing a significant role in healthcare outcomes. The role of primary care physicians in supporting and guiding families was found to be crucial from the outset of their journey, a relationship that was enhanced by Haemophilia New Zealand's support. Poor experiences at diagnoses emerged as resulting in long term distress for caregivers, position diagnosis as a valuable event to research further and improve.

Broader Systemic Factors:

Systemic challenges, including funding concerns and access to carer support services, were significant barriers faced by caregivers.

Experience-based co-design:

The EBCD methodology utilised in this research proved adaptable to meet the needs of a diverse group, generated new knowledge led by caregivers, and validated the flexibility created by Pae Ora's (2022) silence as to any particular co-design methodology.

Discussion of Implications

The findings underscore the need for healthcare systems to adopt a holistic approach that incorporates both technical competence and relational approaches grounded in compassion. Relational care, in particular, emerged as a critical determinant of healthcare experiences and outcomes for caregivers. This is perhaps in part due to the intractability of chronic condition such as bleeding disorders resulting in long term relationships between caregivers and HCPs.

Implications for policy include the necessity of culturally safe healthcare practices, especially for Māori caregivers. The Pae Ora (Healthy Futures) Act 2022 mandates co-design, offering an opportunity to implement systemic changes that are inclusive and responsive to caregiver needs, while addressing the effects of inequality and colonisation identified by The Waitangi Tribunal (2019). Additional considerations for policy makers and individuals throughout the healthcare system are the weight carried by political messaging, and the impact of unnecessarily complex or restrictive process on service utilisation.

This study also emphasises the importance of caregiver well-being as a component of effective healthcare. Providing targeted support to caregivers, such as counselling services and peer networks, can enhance their capacity to provide care.

Recommendations for Future Research

Building on the insights from this study, several avenues for future research are recommended:

1. Progressing the co-design process with stakeholders from across the healthcare system. Future development of this work provides an opportunity to research the experience of caregivers engaged in co-design processes, the effects experienced by those whom they care for, and the impact of improved systems on healthcare costs, outcomes, and HCPs.
2. . Longitudinal Studies: Conducting longitudinal research can provide a deeper understanding of the longer-term impacts of co-designed healthcare interventions.
3. Exploring lived experiences of caregivers and those with bleeding disorders at other ages: understanding experiences of those after two years of age offers opportunity to understand and support those with bleeding disorders, and their caregivers, throughout their lives.
4. Healthcare Professional Perspectives: Including the perspectives of healthcare professionals can offer a more comprehensive view of the co-design process.
5. Evaluating Co-Designed Interventions: Future research should focus on evaluating the effectiveness of co-designed healthcare services in improving caregiver and patient outcomes.
6. Healthcare Professional Perspectives: Including the perspectives of healthcare professionals can offer a more comprehensive view of the co-design process.

Final Closing Remarks

This study contributes to the growing body of research advocating for experience-based co-design in healthcare. By centring the voices of caregivers, it highlights the importance of relational care and systemic support in managing chronic conditions. The findings serve as a call to action for healthcare policymakers, practitioners, and researchers to collaborate with caregivers in creating inclusive and effective healthcare systems. Caregivers engaged in this research have demonstrated a depth of expert knowledge, critical analysis, and investment in improving systems that uniquely positions them as an indispensable component of a brighter future for caregivers and those living with bleeding disorders.

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Appendix 1

Human Research Ethics Committee Approval

The University of Waikato
Private Bag 3105
Gate 1, Knighton Road
Hamilton, New Zealand

Human Research Ethics Committee
Roger Moltzen
Telephone: +64021658119
Email:humanethics@waikato.ac.nz

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

21 November 2023

Paul Larkin
School of Psychology
DALPSS
By email: paulanthonylarkin@gmail.com

Dear Paul

HREC(Health)2023#51 : parent Experiences and Recommendations for Healthcare Provider support and Interactions: Applying Lived Experience to Support the Haemophilia Parenting Journey

Thank you for your responses to the Committee feedback.

We are now pleased to provide formal approval for your project.

Please contact the Committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

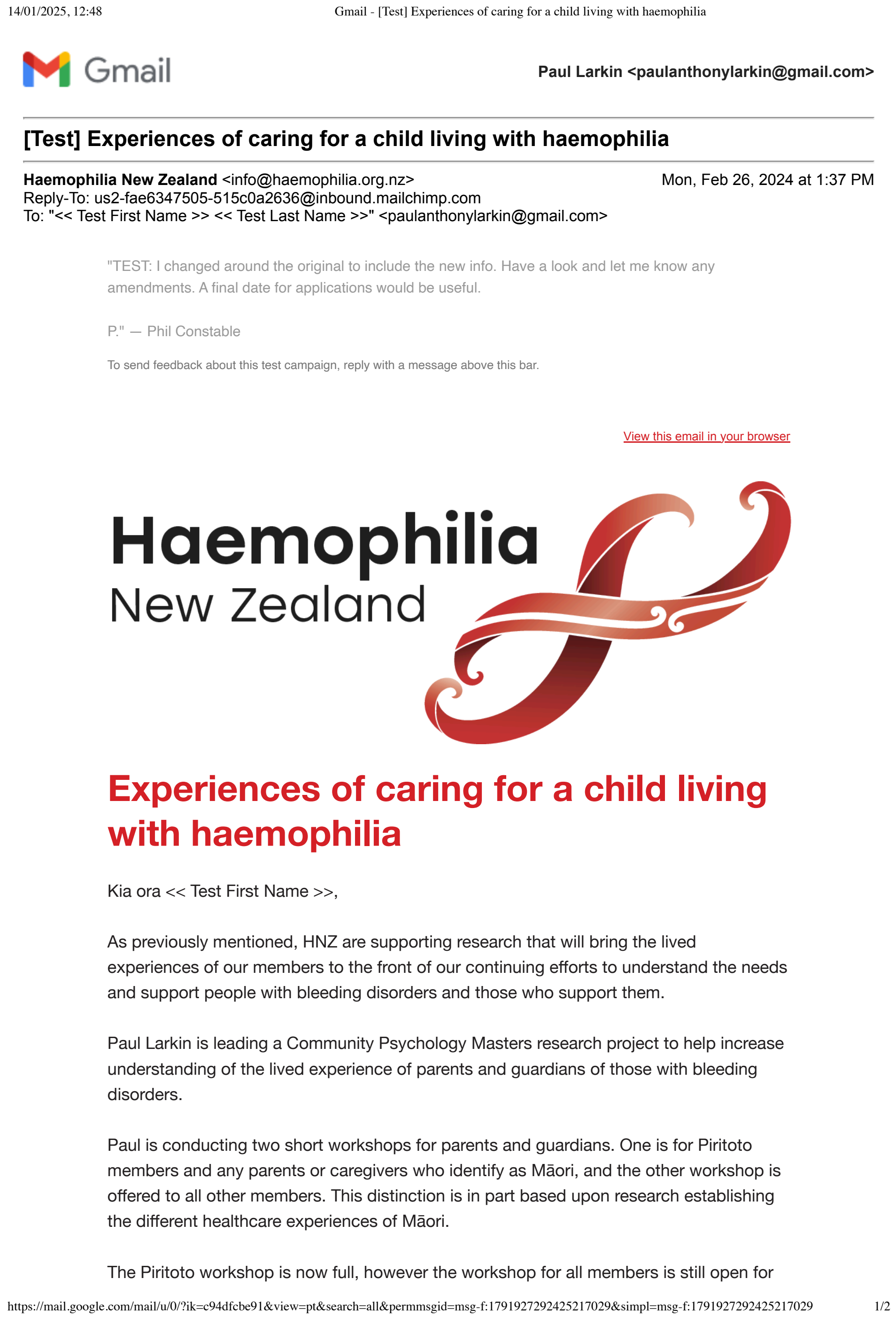
Regards,

____

Emeritus Professor Roger Moltzen MNZM
Chairperson
University of Waikato Human Research Ethics Committee

Appendix 2

Recruitment Email (page 1 of 2)



14/01/2025, 12:48 Gmail - [Test] Experiences of caring for a child living with haemophilia

Gmail **Paul Larkin <paulanthonylarkin@gmail.com>**

[Test] Experiences of caring for a child living with haemophilia

Haemophilia New Zealand <info@haemophilia.org.nz> Mon, Feb 26, 2024 at 1:37 PM
Reply-To: us2-fae6347505-515c0a2636@inbound.mailchimp.com
To: "<< Test First Name >> << Test Last Name >>" <paulanthonylarkin@gmail.com>

"TEST: I changed around the original to include the new info. Have a look and let me know any amendments. A final date for applications would be useful.

P." — Phil Constable

To send feedback about this test campaign, reply with a message above this bar.

View this email in your browser

Haemophilia
New Zealand

Experiences of caring for a child living with haemophilia

Kia ora << Test First Name >>,

As previously mentioned, HNZ are supporting research that will bring the lived experiences of our members to the front of our continuing efforts to understand the needs and support people with bleeding disorders and those who support them.

Paul Larkin is leading a Community Psychology Masters research project to help increase understanding of the lived experience of parents and guardians of those with bleeding disorders.

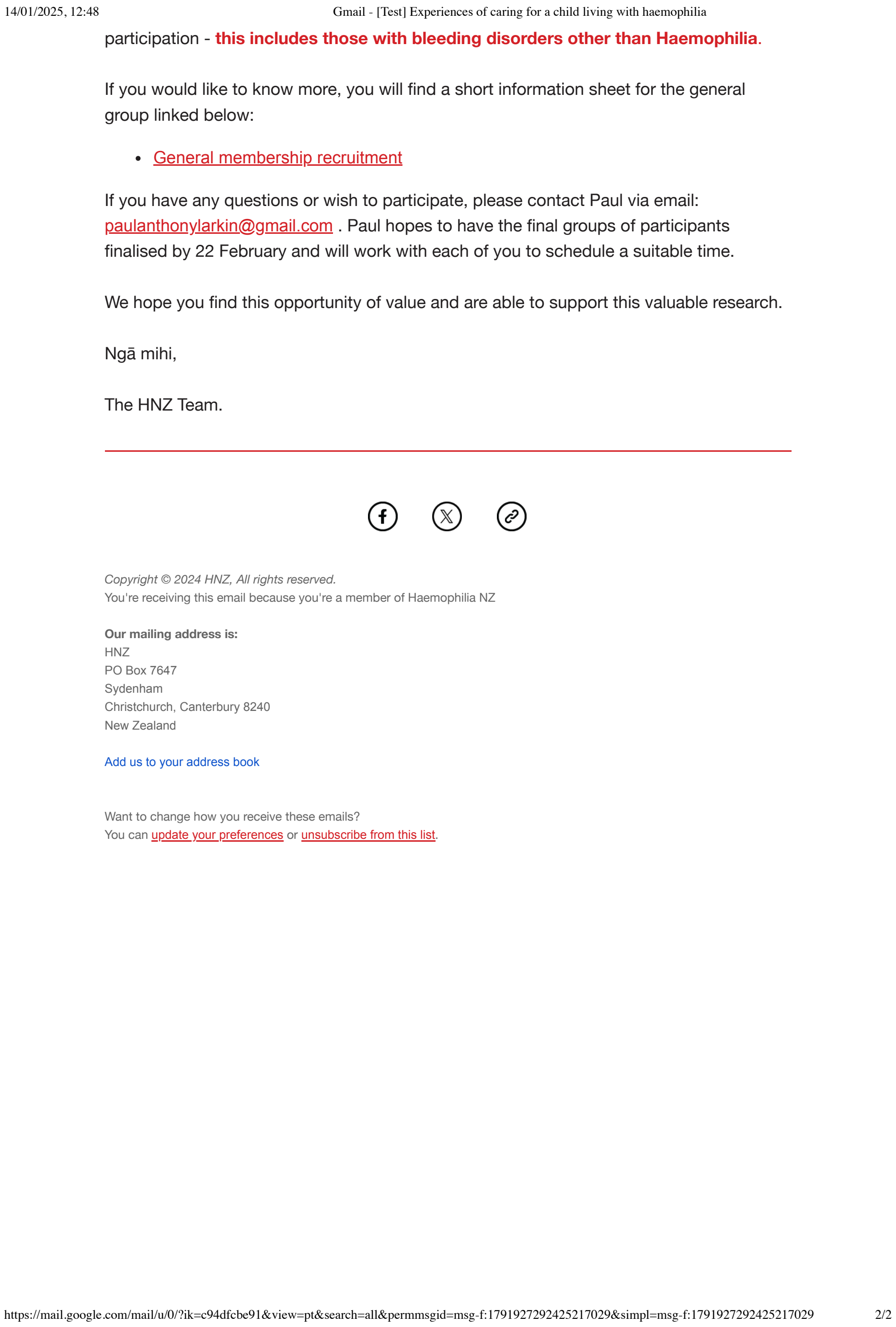
Paul is conducting two short workshops for parents and guardians. One is for Piritoto members and any parents or caregivers who identify as Māori, and the other workshop is offered to all other members. This distinction is in part based upon research establishing the different healthcare experiences of Māori.

The Piritoto workshop is now full, however the workshop for all members is still open for

https://mail.google.com/mail/u/0/?ik=c94dfcbe91&view=pt&search=all&permmsgid=msg-f:1791927292425217029&simpl=msg-f:1791927292425217029 1/2

Appendix 2

Recruitment Email (page 2 of 2)



14/01/2025, 12:48 Gmail - [Test] Experiences of caring for a child living with haemophilia

participation - **this includes those with bleeding disorders other than Haemophilia**.

If you would like to know more, you will find a short information sheet for the general group linked below:

- General membership recruitment

If you have any questions or wish to participate, please contact Paul via email: paulanthonylarkin@gmail.com . Paul hopes to have the final groups of participants finalised by 22 February and will work with each of you to schedule a suitable time.

We hope you find this opportunity of value and are able to support this valuable research.

Ngā mihi,

The HNZ Team.

Copyright © 2024 HNZ, All rights reserved.
You're receiving this email because you're a member of Haemophilia NZ

Our mailing address is:
HNZ
PO Box 7647
Sydenham
Christchurch, Canterbury 8240
New Zealand

Add us to your address book

Want to change how you receive these emails?
You can update your preferences or unsubscribe from this list.

https://mail.google.com/mail/u/0/?ik=c94dfcbe91&view=pt&search=all&permmsgid=msg-f:1791927292425217029&simpl=msg-f:1791927292425217029 2/2

Appendix 3

Recruitment Information Sheet

Kia ora Parents and Guardians,

My name is Paul Larkin and I am the lead researcher of a study that is seeking the views of parents of children living with haemophilia. This research is being conducted as part of my Master of Psychology degree at Waikato University. The New Zealand Haemophilia Foundation have sent this email to you on my behalf.

You have been sent this email due to your experience of being a parent or guardian of a child living with haemophilia. We would like to understand your experiences throughout your child's health journey. We would also like your views about what supports you found helpful and what additional support you would have liked.

The Research

The research is based in a workshop that uses your unique experiences to design improved future services. The workshop will take approximately 2 hours, with a short break part way and is run remotely via zoom in order to be accessible to as many parents as possible. It is our intent to conduct the workshops in late February 2024. A final date and time will be coordinated once the parent group is confirmed.

Parents who attend can share their experiences, and work together as a group to design recommended changes to improve experiences and supports for parents. You will receive $25 koha for participation, as contribution toward your refreshments for the session.

Your views will inform recommendations for improved interactions and support within the health system for parents and guardians of children living with haemophilia. This report will be shared with New Zealand Haemophilia Foundation and relevant health services.

If you would like to know more, or participate, you can click the link below to read more about the study, and should you wish to participate, confidentially provide your consent and contact information.

This research study has been reviewed and approved by the Human Research Ethics Committee of Te Whare Wananga o Waikato /The University of Waikato and is registered as HREC(Health)2023#5.

If you have any questions about the research, please contact me via email paulanthonylarkin@gmail.com or phone 027 277 2585.

Nga mihi nui,

Paul Larkin

Appendix 4

Research Participation Consent Form

UNIVERSITY OF WAIKATO

DIVISION OF ARTS, PSYCHOLOGY, AND SOCIAL SCIENCES

PARTICIPANT CONSENT FORM FOR CO-DESIGN WORKSHOP

[A completed copy of this form should be retained by both the researcher and the participant]

Name of person interviewed: ______________________________

I have received a copy of the Information Sheet describing the research project. Any questions that I have, relating to the research, have been answered to my satisfaction. I understand that I can ask further questions about the research at any time during my participation. Additionally, I understand that I can withdraw my consent and withdraw from the workshop at any time. In the event that I do so, I understand that my contributions to the co-design process may not be able to be removed, however any identifying data will be removed. The process for doing so has been explained to me.

I understand that every effort will be made to ensure confidentiality. If applicable, the limits to anonymity have been explained to me.

I understand that the co-design process will process artefacts such as photos and text.

During the co-design workshop, I understand that I do not have to participate beyond the level which I choose.

I am aware that I have the right to complain about the conduct of the researchers and the process for doing so has been explained to me.

When I sign this consent form, the co-design workshop output will be owned by the Haemophilia Foundation of New Zealand (HFNZ), and the researcher may use this for purposes of the research outlined in the Information Sheet. I also acknowledge that if I choose, my role in this process will be publicly acknowledged by HFNZ.

Please complete the following checklist. Tick [✓] the appropriate box for each point.	**YES**	**NO**
I consent for my role to be shared in the co-design workshop report.		
I wish to receive a full copy of the co-design output document.		
I wish to receive a summarised copy of the findings.		
I wish to have my contributions deidentified in research publications.		

Participant : Researcher :

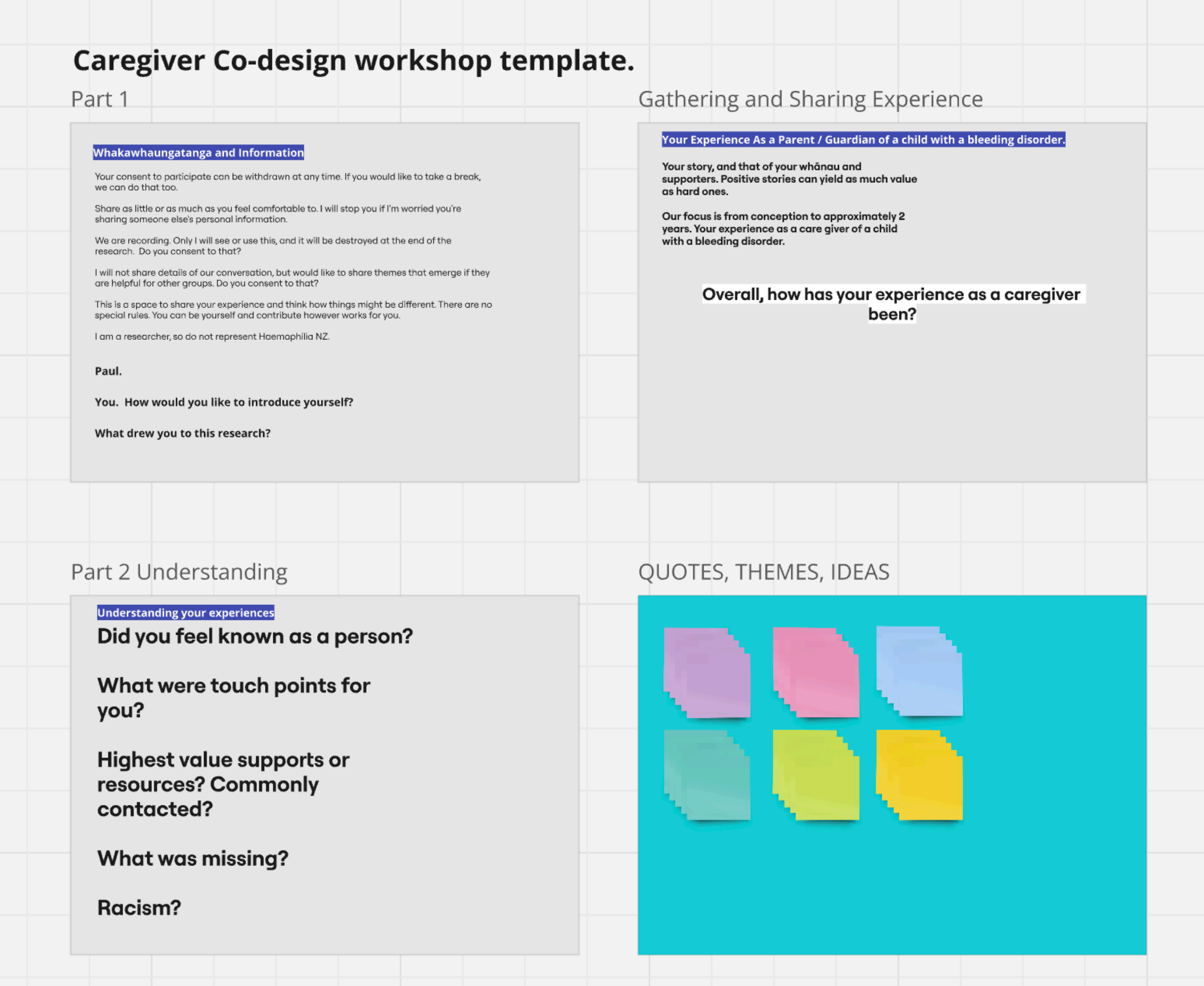
Signature : ______________ Signature : Paul Larkin

Date : ______________ Date : 14 March 2024

Contact Details : ______________ Contact Details : paulanthonylarkin@gmail.com

Appendix 5

Co-design Workshop Template Page 1 of 2



Caregiver Co-design workshop template.

Part 1

Whakawhaungatanga and Information

Your consent to participate can be withdrawn at any time. If you would like to take a break, we can do that too.

Share as little or as much as you feel comfortable to. I will stop you if I'm worried you're sharing someone else's personal information.

We are recording. Only I will see or use this, and it will be destroyed at the end of the research. Do you consent to that?

I will not share details of our conversation, but would like to share themes that emerge if they are helpful for other groups. Do you consent to that?

This is a space to share your experience and think how things might be different. There are no special rules. You can be yourself and contribute however works for you.

I am a researcher, so do not represent Haemophilia NZ.

Paul.

You. How would you like to introduce yourself?

What drew you to this research?

Gathering and Sharing Experience

Your Experience As a Parent / Guardian of a child with a bleeding disorder.

Your story, and that of your whānau and supporters. Positive stories can yield as much value as hard ones.

Our focus is from conception to approximately 2 years. Your experience as a care giver of a child with a bleeding disorder.

Overall, how has your experience as a caregiver been?

Part 2 Understanding

Understanding your experiences

Did you feel known as a person?

What were touch points for you?

Highest value supports or resources? Commonly contacted?

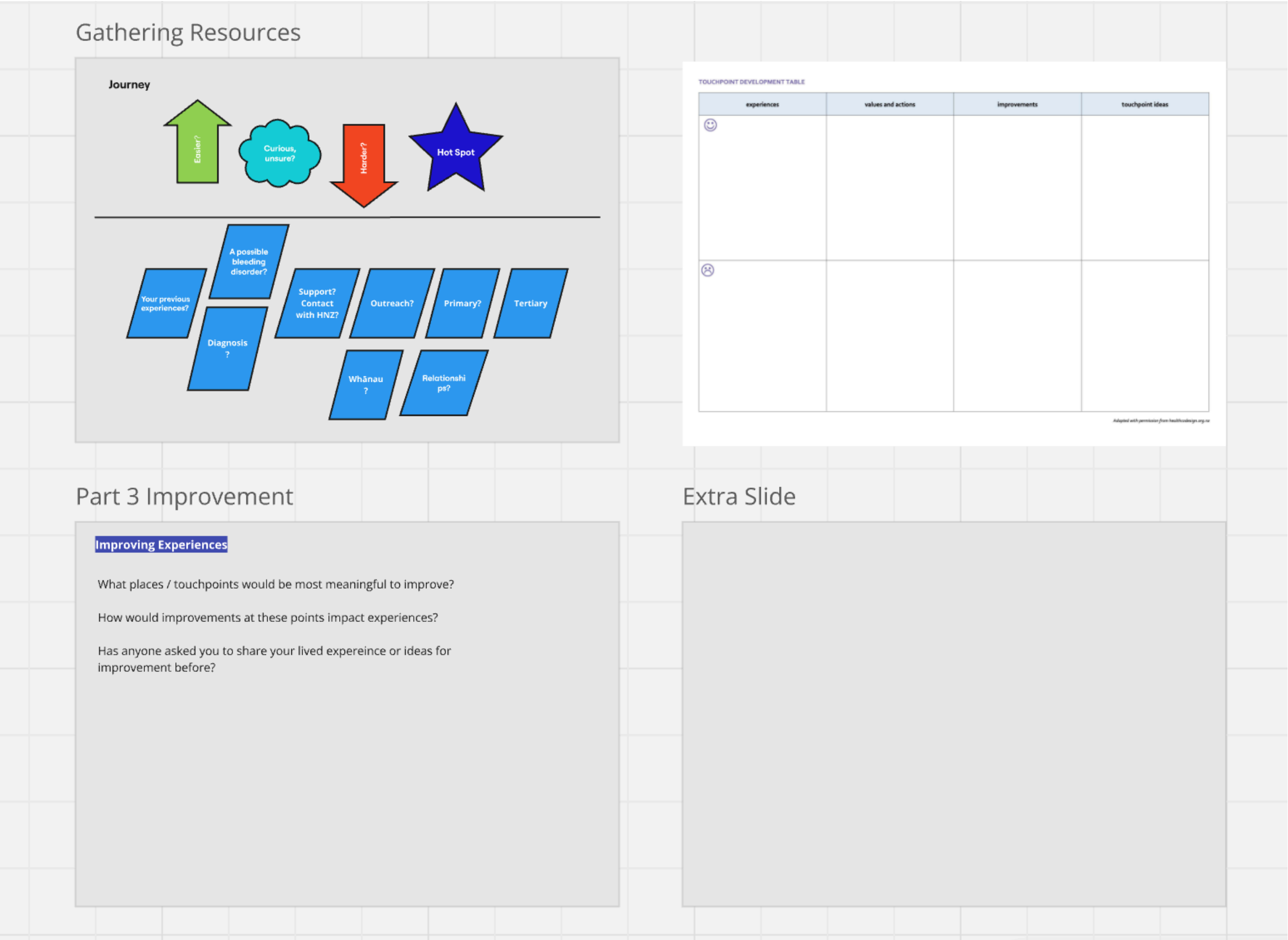
What was missing?

Racism?

QUOTES, THEMES, IDEAS

Appendix 5

Co-design Workshop Template Page 2 of 2



Gathering Resources

Journey

TOUCHPOINT DEVELOPMENT TABLE

experiences	values and actions	improvements	touchpoint ideas
☺			
☹			

Adapted with permission from healthcodesign.org.nz

Part 3 Improvement

Improving Experiences

What places / touchpoints would be most meaningful to improve?

How would improvements at these points impact experiences?

Has anyone asked you to share your lived expereince or ideas for improvement before?

Extra Slide