Trans and Non-Binary People’s Experiences of Cancer Care in Aotearoa/New Zealand

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Keziah Brown

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Abstract

Cancer is a severe and life-threatening disease affecting many people and their loved ones. Much is still unknown about cancer as a disease; however, it is known that the care that patients receive can play a vital role in producing better illness outcomes and improving quality of life during treatment. Understanding people's experiences of cancer care is important for creating better care protocols, understanding barriers to care access, and ensuring patients receive care that meets their needs. This thesis explores the gap in knowledge surrounding trans and non-binary (TNB) people's experiences of cancer care in Aotearoa/New Zealand. There is limited cancer research internationally regarding TNB communities and cancer, and little-to-no known research has been published specific to Aotearoa/New Zealand. The research question of this study was, what are the cancer care experiences of TNB people in Aotearoa/New Zealand? To understand this question, I undertook an interpretive qualitative study theoretically informed by community psychology. Semi-structured interviews were conducted with three participants who identified as trans or non-binary and had received treatment in Aotearoa/New Zealand within the last ten years. A narrative case study approach was utilised, in order for the complexity and diversity of each participant's experiences to be recognised.

It was found that TNB people experience barriers in accessing cancer care and receiving quality cancer care. These barriers are related to wider structural issues resulting from cisgenderism that are reflected within cancer care. Cisgenderism acts to constrain how TNB patients define their own narrative of illness and interrupts the ability to move forward through cancer in ways that are personally meaningful. The study also found that TNB people are not passive in the face of constraint, as the participants each found ways to maintain a sense of agency within their experience of cancer care. There was significant diversity within the participants' experiences, which was an important finding in-itself. This diversity particularly demonstrated the benefit of a methodological approach that could account for complexity and intersectionality, when seeking to understand TNB people's experiences of cancer care. Overall, this thesis provides new insight into an underexplored topic and has important implications for TNB cancer patients in Aotearoa/New Zealand.

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Glossary

Cancer Stage – The stage of cancer is a way to describe the extent of cancer in the body. Higher stages (stage 3-4) mean the cancer is more extensive and harder to treat. Cancer staging helps doctors develop a treatment plan based on cancer extent and location.

Cancer Surgery – A surgical procedure to remove cancer/tumour, investigate a diagnosis, repair a body part affected by cancer, or prevent cancer occurrence.

Chemotherapy – A chemical drug therapy that travels through the bloodstream to stop or slow rapidly growing cancer cells in the body.

Cisgender – A person whose gender identity aligns with their sex assigned at birth.

Cisgenderism - The privileging of cisgender people and the discriminatory practices towards trans and non-binary people that arise from this.

Colonoscopy – A diagnostic test used to check for abnormalities in the large intestine (colon) and rectum. Involves the insertion of a long, thin tube attached to a camera.

Follow-Up Treatment – Care after immediate cancer treatment. Involves checking treatment effectiveness, monitoring for recurrence, managing side effects, and monitoring long-term treatments.

GP – General Practitioner. A doctor who works in a general medical centre or clinic.

LGBTQI+ - (or LGBTQ, LGBT) An acronym for Lesbian, Gay, Bi-sexual, Trans, Queer, Intersex, and more.

Lumpectomy – Surgery to remove a tumour or abnormal tissue from the breast. Also referred to as breast-conserving surgery. Only a portion of the breast tissue is removed, unlike a full mastectomy removal. More often used in earlier-stage breast cancer.

Mastectomy – Surgery to remove all breast tissue from a breast. A bilateral mastectomy is the removal of both breasts to treat or prevent cancer.

Non-binary – An umbrella term for someone whose gender does not perfectly fall into dominant binary understandings of gender.

Oncologist – A medical doctor who specialises in diagnosing and treating cancer related illness.

Oncology – The study and treatment of cancer related illnesses.

Pākehā – Non-Māori, usually of European decent, who lives in Aotearoa.

Reconstruction – When cancer causes damage to the body or affects physical appearance, surgery can be done to restore/repair the body. Often, healthy tissue from one area of the body is used for the repair.

Sigmoidoscopy – A diagnostic test to investigate the cause of bleeding or pain from the colon. Involves inserting a tube with an attached camera to check the sigmoid colon (the lower part of the colon).

Tauiwi – Someone who arrived from overseas to Aotearoa.

Trans – An umbrella term for a person whose gender does not align with the gender ascribed to them at birth.

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Chapter One: Introduction and Literature

Cancer is incredibly challenging and is described as one of the most frightening and stressful illnesses someone can experience. A cancer diagnosis is the beginning of a long and arduous journey that affects people's physical health, mental wellbeing, and ability to participate in normal life. Furthermore, the seriousness of this illness often means an unwelcome confrontation with the uncertainty of survival (Cancer Society, 2022a). The care patients receive can play a vital role in producing better outcomes and reducing a patient's distress (Husson et al., 2011; Mullaney et al., 2012). Quality care produces better patient adherence to cancer treatment, improves a patient's health competence, increases a patient's feelings of control and symptom management, and reduces overall mortality rates (Husson et al., 2011). Cancer symptoms also extend beyond the physical, causing feelings of elevated anxiety and psychological distress which exacerbate already significant symptoms. Quality care can reduce feelings of anxiety, depression, and improve overall quality of life during treatment (Mullaney et al., 2012). Thus, it is important that quality care be upheld for all patients throughout their cancer journey.

In this thesis, I explore the experiences and needs of trans and non-binary people when accessing cancer care in Aotearoa/New Zealand (Henceforth Aotearoa). Trans and non-binary (TNB) communities have had limited acknowledgement in international cancer literature and research. At the time of this thesis, little to no known research has been published regarding these communities' experiences of cancer specific to Aotearoa. To address this gap, this thesis utilises qualitative methodology and is theoretically positioned within community psychology. This method approach is intended to provide rich and in-depth personal accounts of these communities' experiences. Information from participants is gathered through semi-structured interviews with members of TNB communities who are over 18, live in Aotearoa, and have had a diagnosis of cancer and experience with the cancer care system within the last 10 years.

Terminology

In this thesis, I use the terminology 'trans and non-binary people.' Trans is an umbrella term describing a person whose gender does not align with the gender ascribed to them at birth. Those under this umbrella may identify as (but is not limited to), transgender, a trans man, a trans woman, trans masculine, trans feminine, or just trans. Some under this umbrella may simply use man or woman to describe themselves (Gender Minorities Aotearoa, 2020; Veale et al., 2019).

Non-binary is another umbrella term for people whose gender does not perfectly fall into dominant binary understandings of gender (male/female). Those under the non-binary umbrella may identify as simply 'non-binary,' or they may be genderqueer, genderfluid, agender, bigender, demigender, and more (Gender Minorities Aotearoa, 2022). Additionally, there can be some crossover, with some trans people also identifying as non-binary and vice versa. My terminology choice acknowledges that not all trans people are non-binary and not all non-binary people identify as trans (Frohard-Dourlent et al., 2017).

It should be recognised that there is no perfect, agreed upon terminology. Preferred term use is not consistent across every person, nor is it consistent across similar research publications. Additionally, non-European genders do exist, and are not just direct language translations of 'trans/non-binary' but include their own culturally specific experiences. Some of these genders relevant to Aotearoa are takatāpui, tāhine, iriwhiti, fa'afafine, fa'atama, and more (Gender Minorities Aotearoa, 2022). My use of the term 'trans and non-binary' (Henceforth, shortened to TNB), is only intended for clarification purposes in this thesis. This specific terminology was chosen because recent research has indicated that these terms are the most commonly used terminology in Aotearoa (Veale et al., 2019). It should also be noted that the most commonly utilised terminology is rapidly evolving and may develop further beyond the publication of this thesis.

Community Psychology Lens

Community psychology is a sub-discipline of psychology, described as an applied social science. The discipline developed from a growing dissatisfaction with mainstream psychologists' tendency to view mental health and wellbeing as an individual level problem. Community psychologists believe this traditional approach fails to properly address the larger factors that significantly impact our health and wellbeing, such as social context and broader societal conditions (Prilleltensky, 2001). Community psychology highlights the interaction between people and their environments and acknowledges that people live within multi-level systems that always contextualise experience (Riemer et al., 2020). Accordingly, community psychology interventions advocate for multi-level, social and wider systematic transformation over individual change, aiming to address the root conditions of ill-health and shifting the focus to prevention over ameliorative treatment. This preventative focus enables a strengths-based over a deficit-based approach, by working with communities to build upon existing strengths and skills and increasing resource access to enable community agency (Trickett, 2009).

A defining feature of community psychology is that it identifies as a value-driven field (Riemer et al., 2020). Community psychologists argue that our perspectives and actions are always shaped by our assumptions and beliefs about the world, therefore our values are always reflected in the research and practice we conduct. Accordingly, community psychologists are critical of traditional psychology's belief that truly objective research can be conducted, arguing that the goal of objectivity reflects certain values and assumptions about the world in-itself. Thus, community psychologists maintain it is instead good practice to acknowledge the value-laden nature of research, and to account for those values within research and analysis (Prilleltensky, 2001; Riemer et al., 2020).

From conception community psychology has explicitly placed social justice as a guiding value, as improving broader societal conditions often necessitates responding to issues of inequity or oppression (Prilleltensky, 2001). Social justice is concerned with ensuring the rights of individuals and collectives are upheld, and aims for equitable distribution of opportunities, resources, and power within society (Riemer et al., 2020). Fundamental to community psychology and social justice is a contextualised approach. Situating the experiences of individuals within the circumstances that impact their lives is important, as there needs to be a nuanced understanding of the broader complex factors that shape social issues (Fondacaro & Weinburg, 2002; Riemer et al., 2020). Relatedly, respecting people's diverse identities, lives, and needs is important to ensure that the dignity and rights of all people are respected (Prilleltensky, 2001) Thus, diversity is also an important community psychology value for this research.

Social Determinants of Health

The social determinants of health, refers to how the circumstances and conditions of people's everyday lives affect health and wellbeing outcomes. Although individual factors do affect health, evidence shows our health is determined far more by the wider material and societal conditions outside of our individual control, such as social norms, economic systems, political systems, environmental factors, and social structures (Wilkinson & Marmot, 2003). Health inequities are systematic health differences between different populations and are a consequence of an unequal distribution of, and access to, the social determinants of good health. If a population has less access to the social, financial, and material resources needed for good health, more barriers and obstacles will exist to restrict health prospects (Wilkinson & Marmot, 2003). TNB people face societal conditions such as discrimination, prejudice, and stigma, resulting in social exclusion which disadvantages access to good health. Being a TNB person in-itself does not determine health, but the societal conditions related to being a TNB person have resulted in TNB populations experiencing lower levels of health and wellbeing compared to general populations, which is a critical element to consider in conversations about TNB health and experiences of healthcare (Pega & Veale, 2015).

Incorporating relevant context is important for combatting stigmatisation or stereotyping that can arise from overly deficit-based narratives. When health disparity is consistently linked to a specific marginalised population without wider social or systemic context, an association can occur between individuals within that community and illness or disparity (Hyett et al., 2019). This association may unintentionally contribute to the narrative that TNB people themselves are inherently connected to illness or disparity. TNB people have experienced a long history of being both pathologised and medicalised. Pathologisation/medicalisation refers to the process in which non-medical or non-psychological problems become defined and treated as a disorder or illness (Conrad, 1992). In this case, TNB individuals are viewed as a problem simply because existing in a non-normative body is seen as deviant and something to be ‘fixed’ or ‘controlled’. Thus, it remains important to ensure TNB cancer inequity is properly contextualised.

Intersectionality

Recognising the diversity and variety within TNB people’s experiences is critical for understanding TNB health. The TNB community is internally diverse, and TNB people can have different experiences of discrimination and oppression based on their own personal circumstances and levels of privilege. Thus, in understanding cancer care experiences we need to account for the variation in TNB people’s lives (Kcomt et al., 2020). Intersectionality is a theory which accounts for diversity of experience. Intersectionality describes the interconnecting relationships between multiple systems of oppression, which inform people’s identities and social locations within structures of oppression and privilege (Carastathis, 2014; Gopaldas, 2013). Intersectionality developed from the Black feminist movement, as a tool to illustrate how a person can experience multiple and simultaneous systems of oppression. Crenshaw (1990) who coined the term, discussed how poor Black women experience one of the most disadvantaged social positionings due to living at the axes of classism, sexism, and racism. It is important to note that these intersecting social locations of ethnicity, class, gender, sexuality, ability, or otherwise, are not exclusive, but often intertwine and compound together to provide a unique experience of the world.

Intersectionality also accounts for crucial differences within groups frequently perceived to be homogenous. For instance, even within TNB populations, those who also belong to marginalised ethnicity experience more barriers to healthcare access and are more likely to receive poor care during treatment than TNB people with non-marginalised ethnicities (Whitfield et al., 2020). Research that only accounts for a single social identity often erases the unique experiences of the most marginalised within that community. This is because when intra-group differences of privilege and oppression are not considered, the voices and experiences of those with the most privilege and power are often uncritically centred in the narrative of experience. Thus, it is important to not subsume all TNB people into an expectation of homogenous experience, and to account for unique experiences and barriers that can arise from different intersecting social locations (Carastathis, 2014; Wesp et al., 2019). Intersections to consider for TNB cancer care in Aotearoa might include people with disabilities and people with marginalised or minority ethnicities. Particularly as evidence suggests that these groups already experience disparities in health and healthcare access in Aotearoa (Te Aho o Te Kahu, 2021), which may be compounded in unique ways at the intersection of also being a TNB person.

Contextualising Cancer in Aotearoa/New Zealand

Cancer care is a critical component of the healthcare system in Aotearoa. Cancer is the leading cause of death in this country, and every year, around 25,000 people in Aotearoa receive a cancer diagnosis (Te Aho o Te Kahu, 2021). Reducing cancer incidence rates and improving cancer support and services, is recognised by the Government of Aotearoa as a crucial priority for ensuring the health and wellbeing of the people in this country (Ministry of Health, 2020).

Cancer is a disease that affects the cells of the body. Cells are normally produced in a cyclical way where they grow, eventually die, and are replaced by new cells. Cancer develops when cells begin to abnormally multiply and divide, with cell production no longer being controlled as it is in normal tissue. As these abnormal cells replicate, they can form lumps or growths in the body, known as tumours. As tumours grow, they begin to take up space within the body, causing compression to organs or surrounding structures. Tumours can also spread out from the original tumour and invade or destroy normal tissue throughout the body, causing significant impact on normal bodily function (Cancer Society, 2022a). Some of the most common forms of cancer in Aotearoa are breast, lung, prostate, and colorectal cancers (Te Aho o Te Kahu, 2021).

Treatment for cancer can include medications, surgeries, radiation therapies, and also chemotherapy (a drug that is administered through the bloodstream to stop or slow cancerous cells). Cancer treatments can come with severe side effects which affect patients in addition to their illness. Some of these side effects can include pain, nausea, insomnia, hair loss, mouth and eating problems, unusual bleeding, breathlessness, and more (Cancer Society, 2022a).

Quality Cancer Care

Quality cancer care is responsive to the needs of the people it serves (Te Aho o Te Kahu, 2021). As the nature of cancer is fairly complex, there is no completely universal treatment approach. Treatment plans are dependent on a number of patient variables such as diagnosis type, stage of cancer, previous medical history, and the patient's own desires and values. Additionally, multiple cancer specialists and services can be involved in treatment. Often, this complexity means the cancer care system is challenging to navigate for patients (Levit et al., 2013). A suggested approach for addressing the overwhelming nature of cancer care, is to prioritise patients' voices in conversations about potential care improvement. The current New Zealand Cancer Strategy suggests that services should be primarily informed by the voices of people experiencing cancer themselves, stating that "we need a cancer plan that is first and foremost about people rather than illness" (Ministry of Health, 2020, p.1).

Patient-Centred Care

Patient-centred care is the guiding concept for quality health care. Patient-centred care means clinical decisions are guided by the patient's needs and preferences and are informed by each patient's personal context (Epstein & Street, 2011). The patient-centred approach recognises patient experience as a critical part of treating illness. Providers work in collaboration with patients instead of viewing patients as merely passive receivers of care (Condon et al., 2021). Another aspect of patient-centred care is empowering people to have autonomy over their own health decisions. Patient autonomy encompasses patients being properly informed about potential care, patients being able to express opinions regarding treatment, and providers ensuring proper patient consent (Bond et al., 2021). Patient autonomy is a significant aspect of good quality healthcare. It increases treatment adherence (Husson et al., 2011), is linked to better health outcomes (Hibbard & Greene, 2013), and improves the monitoring of care services (Bond et al., 2021).

Cultural Safety

Interrelated with patient-centred care is cultural safety. The Nursing Council of New Zealand’s Code of Conduct defines cultural safety as, "respect for the cultural needs and values of health consumers" (2012, p.12). Cultural safety in Aotearoa was first brought to attention by Māori nurses/midwives in the late 1980s, who expressed concerns about the Pākehā dominated health approach in their training. The development of cultural safety practices allowed for nursing to move away from the traditional mantra ‘treat all people the same’. Despite positive intentions of removing differential treatment, this philosophy of nursing failed to accommodate the important differential needs of patients (Papps & Ramsden, 1996). The development of cultural safety was also a reaction to the Eurocentrism within healthcare itself, as the healthcare system was not built to be responsive to Māori needs or models of health. The failure to acknowledge Eurocentrism in healthcare allowed personal and institutional prejudice to remain unexamined, leaving Māori patients to feel alienated from the healthcare system that is supposed to support them (Richardson, 2004).

Current practices of cultural safety have developed to be responsive to differences such as age, gender, ethnicity, religion, sexual orientation, and disability status (Bond et al., 2021). Cultural safety is driven by the patient experience. Thus, the power to determine appropriateness or safety of the care provided, is held by individual patients themselves (Wi-Hongi et al., 2017). While cultural safety is determined through a patient’s subjective experience of care, it is also relational - established through the patient-provider relationship. Cultural safety relies on the provider's ability to *enact* culturally safe care. On behalf of providers, there must be recognition of the inherent power imbalance providers have in the care relationship, and awareness of how this dynamic can unintentionally impact patients. Providers must commit to reflecting on their own personal views and biases that may influence the care they enact (Medical Council of New Zealand, 2019). Failure to enact cultural safety is a violation of the conduct that health providers are expected to uphold in Aotearoa. (Medical Council of New Zealand, 2019; Nursing Council of New Zealand, 2012).

In order to successfully enact culturally safe care, providers need to have some basic knowledge regarding the inequities some patients may face and the sources of those inequities, to inform their self-awareness around biases they may inadvertently perpetuate. For example, it is required for doctors in this country to have basic knowledge of the history of colonisation in Aotearoa, as well as the resulting systematic biases and inequities that continue to impact Māori health (Medical Council of New Zealand, 2019).

Trans and Non-Binary Cultural Safety

Despite cultural safety expanding to be responsive to other cultural and social identities, there is still an unmet need for institutional change that supports providers in their care provision for TNB people (Baldwin et al., 2018). Wi-Hongi and colleagues (2017) discuss the need for a TNB model of healthcare safety in Aotearoa, pointing to cultural safety as a potential foundation for this development. The critique against the healthcare system being structured on Eurocentric ideals, highlights many parallels with the way the current healthcare system was designed by and for cisgender people, and how this has led to issues with healthcare equity for TNB people.

Work by The Professional Association for Transgender Health Aotearoa (PATHA) provides evidence-based recommendations for improving TNB healthcare in Aotearoa. In 2020, PATHA proposed the development of a targeted national approach for addressing TNB health equity. This strategy suggested action in three main areas: 1) Improving access to gender-affirming healthcare, 2) ensuring the wider health system has the resources and training needed to provide safe, equitable, and effective care for TNB people, and 3) addressing systemic and social harms impacting TNB health outcomes as social determinants of health. The second point is specifically where considerations related to patient-centred care for TNB patients is discussed. PATHA recommends that for a safer healthcare system for TNB people, firstly, the healthcare system should be resourced and required to incorporate training on how to provide respectful, responsive, and non-discriminatory care for TNB patients. In addition, they recommend that the Ministry of Health, in conjunction with PATHA and TNB community expertise, should review the current service design and health system responsiveness regarding TNB people. Lastly, they also recommend that targeted quality improvement programs for TNB people's experiences in healthcare be implemented (PATHA, 2020).

In PATHA's vision for transgender healthcare (2022), the development of a transgender healthcare resourcing hub was recommended. This Hub would assist with ensuring healthcare for transgender people is people-centred, equitable, accessible, and cohesive within new health system restructures. The resourcing hub would not provide care directly, but would concentrate on resourcing, co-ordinating, and supporting the healthcare system in the provision of good care for TNB patients. This hub would also help the promotion of TNB cultural safety and awareness within wider healthcare. This resourcing hub would also operate under a Te Tiriti o Waitangi framework, working in partnership with Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority), incorporating Māori co-governance, and supporting Māori and Pasifika models of care (PATHA, 2022).

Healthcare In Aotearoa/New Zealand

At the time of this research, the Aotearoa healthcare system is partly publicly funded, including some free inpatient and outpatient services, subsidised primary healthcare and prescription services, and disability support services. The healthcare system also identifies universal accessibility as a driving goal. However, issues with accessibility have consistently plagued healthcare in Aotearoa since implementation (Graham & Masters-Awatere, 2020).

In addition to longstanding equity issues, the current health system has undergone multiple instances of restructuring. In 1993, a neoliberal market-based health system was implemented (Goodyear-smith & Ashton, 2019). Public hospitals were reframed as a 'for-profit' business and patients as consumers. The introduction of a market-based system was expected to stimulate competition and increase economic efficiency. However, this system was criticised for both failing to achieve economic efficiency and causing complications to healthcare provision (Nicholls et al., 2020). In 2000, a government change introduced another major restructuring, intended to foster a more democratic and cooperative environment. Along with a commitment to improving primary care, twenty district health boards (DHBs) were established around the country. These DHBs would be responsible for procuring and providing care specifically for their local area, and for coordinating across regional and national levels to achieve integrated care for patients (Goodyear-Smith & Ashton, 2019).

Despite the optimistic intentions of these reforms implemented during the 2000s, many issues remained. The DHB system became overly complex, as integrating care across multiple DHBs and geographical locations is difficult to achieve successfully. Additionally, the effects of instating neoliberal ideology were only softened through further restructuring, not eliminated. Governmental priority is still given to reaching national performance targets and increasing financial efficiency (Goodyear-Smith & Ashton, 2019). As neoliberalism still exists as a hegemonic form of economic ideology, both the healthcare system and the wider economic ideals in society and of the government in Aotearoa are still significantly influenced by this thinking. A core belief of neoliberal ideology is that private markets over governmental control is better for society, as it purportedly creates better social gains and a more efficient allocation of resources. Accordingly, under neoliberalism social spending and welfare are heavily reduced, as these are considered as the state disrupting the law of the market and interrupting an individual's responsibility to be self-sufficient and make autonomous choices (Galvin, 2002; McGregor, 2001). The ramifications of this neoliberal thinking are reflected through the conditions of austerity within healthcare policy, which has been linked to healthcare strain. For example, cutbacks on frontline staffing and certain aspects of healthcare delivery (Goodyear-Smith & Ashton, 2019).

In 2021, another restructuring was announced in an attempt to remedy the inefficiency and fragmentation of the DHB system. The twenty DHBs were merged under one body named Te Whatu Ora, a single health service intending to provide consistent and high-quality services for all people in Aotearoa (New Zealand Government, 2022a). Given I only interviewed people whose cancer diagnosis and treatment had occurred in the past, the participants in this study received their care during the DHB system period. As the healthcare system is currently in transition, it is difficult to accurately know what cancer care will look like for future patients. Additionally, the current strain to the healthcare system has been compounded by the recent disruption to healthcare caused by the Covid-19 pandemic. Patients at this time likely experienced a different context of care than pre-pandemic patients, as new protocols were enacted to contain disease dispersion. Particularly notable changes being socially distanced care, limits on support people visitation, and a reduction of typically available supports like driving services and accommodation options (Gurney et al., 2021).

Disparities in Cancer

Marginalised groups within society often experience significant health disparities in comparison to the general population (Cleary et al., 2014). A particular concern for Aotearoa when it comes to addressing cancer, is how these overall health inequities are reflected in cancer diagnosis, survival rates, and access to care. Research has clearly documented that Māori in Aotearoa are disproportionately affected by cancer. Māori experience a general diagnosis rate that is approximately 20% higher than the general population, with a mortality risk that is double the general rate (Te Aho o Te Kahu, 2021). Disparities in cancer incidence and survival rates for Māori are recognised as being driven by the wider spectrum of social, economic, and political inequities Māori experience (Robson & Ellison-Loschmann, 2016). In the context of cancer, these conditions lead to an increased exposure to the risk factors for cancer, as well as barriers to healthcare access and receiving appropriate care (Te Aho o Te Kahu, 2020).

Other marginalised groups in Aotearoa also experience disproportionate rates of cancer incidence, high cancer mortality rates, and issues with accessing cancer care. Most notably, Pacific people experience high levels of cancer incidence, access barriers, and significant survival disparities. (Ministry of Health, 2020; Te Aho o Te Kahu, 2021). People with disabilities are also known to face inequitable access to cancer services in Aotearoa, although further research still needs to be done on this community's experiences with cancer incidence and survivorship (Te Aho o Te Kahu, 2021). Experiences of marginalisation, barriers to quality care, and decreased access to health services are common factors between groups with cancer and cancer care disparity (Ministry of Health, 2020; Te Aho o Te Kahu, 2021). As outlined in the next section, these experiences are commonly reflected in the lives of TNB people in Aotearoa (Veale et al., 2019), indicating that this topic is significant to explore.

Trans and Non-Binary General Healthcare Disparities

Too often, TNB people worldwide experience significant difficulty in accessing health services and in receiving adequate healthcare (Frohard-Dourlent et al., 2017; Kcomt, 2019). This is particularly concerning given that these communities experience high levels of wellbeing inequality. In Aotearoa, A 2019 report, Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand, found 71% of participants reported high levels of psychological distress. For context, this number is only around 8% for the general population of Aotearoa (Veale et al., 2019). The high levels of distress and wellbeing inequity is directly linked to the pervasive stigma and discrimination TNB communities face (Puckett et al., 2020). The Counting Ourselves study also found participants reported experiencing discrimination at a rate more than double that of New

Zealand's general population. Those who had experienced discrimination were also more likely to report very high levels of psychological distress (Veale et al., 2019).

The discrimination TNB people experience is part of wider social oppression resulting from cisnormativity (Bauer et al., 2009). Cisnormativity refers to the dominant cultural ideology surrounding gender and gender presentation, where cisgender people, those whose gender identity reflects the gender they were assigned at birth (Gender Minorities Aotearoa, 2020), are positioned as the unstated 'natural', normal, and dominant group in society (Frohard-Dourlent et al., 2017). An additional aspect of cisnormativity is the enforcement of the idea that there are only two legitimate genders, existing in a biological binary of either male or female (Ansara & Hegarty, 2014). These 'legitimate' genders are presumed to be static and unchanging (Bauer, 2009).

Cisnormativity creates the conditions for cisgenderism, referring to the privileging of cisgender people and the discriminatory practices that arise from this (Kcomt, 2019). Cisgenderism leads to the framing of those who fall outside of typical cisgender norms as socially or pathologically deviant. Consequently, prejudice, discrimination, and violence can arise from this othered framing, and may even unfortunately be seen as a justifiable response by those who perceive gender difference as a threat to the accepted norms of society (Lennon & Mistler, 2014).

Cisgenderism operates on the interpersonal level but is also replicated institutionally. Most institutions uncritically centre themselves on cisgendered experiences, leaving TNB people unconsidered and invisible (Kcomt, 2019). Cisgenderism also operates within healthcare, resulting in systematic exclusion of TNB people within the healthcare institution (Bauer et al., 2009). TNB healthcare is usually discussed regarding two main areas: 1) general healthcare access, and 2) gender-affirming healthcare. Gender affirming healthcare refers to treatments, surgeries, hormone therapies, social transition, and other forms of support that allow for a person to affirm their personal sense of gender (Oliphant et al., 2018). Access to gender-affirming healthcare is quite significant to wellbeing for many TNB people. However, in Aotearoa there are extensive barriers regarding the availability and accessibility of gender-affirming services (PATHA, 2020). There is much to say about the issue of improving gender-affirming care access and prioritisation; however, cancer care is a subsection of general healthcare. As such, much of the focus for this thesis will be on the general healthcare system's responsiveness to TNB people. General healthcare refers to general health services, such as general practitioners and hospitals, which people access for a range of different health needs and illnesses, including cancer.

A significant way that cisgenderism is institutionally replicated within general healthcare is through informational erasure. Health research has historically relied on the assumption that research participants are cisgender. Only recently has health research begun to consider the experiences of TNB people, and there remains a significant gap in information regarding TNB people's health (Kattari et al., 2020). Consequently, general healthcare providers have little training or education regarding possible TNB health concerns. Providers frequently self-report a general lack of understanding around providing care to these communities (Carabez et al., 2015; Schabath et al., 2017). Commonly, TNB patients report their healthcare provider lacks relevant knowledge and are unable to provide requested information or help. TNB patients are then left with the burden of assuming the role of an educator, to ensure providers have even the basic necessary knowledge needed to provide proper care (Baldwin et al., 2018; Eliason & Dibble, 2015; Veale et al., 2019).

TNB erasure also impacts healthcare services. Healthcare services often lack the ability to sufficiently accommodate the existence of TNB people (Bauer et al., 2009). For example, intake forms usually have no capacity for recording gender outside of the male/female sex binary (Dolan et al., 2020). Additionally, changing names or gender information on health records can be a difficult or impossible process (Wi-Hongi et al., 2017). Misrepresentative 'sex markers' are then replicated on hospital records, prescriptions, referrals, and hospital armbands. Staff have no access to the information needed to respect TNB patients (e.g., preferred name, gender, and pronouns). The burden of correction is then imposed on TNB people themselves. These situations can lead to experiences of misgendering, "the use of gendered language that does not match how people identify themselves” (Ansara & Hegarty, 2014, p.261). Misgendering can also transcend language, with experiences of gendered patient attire and gendered healthcare spaces being assigned to patients. Experiences of discrimination can also be found in the use of language and attitudes by staff, which indicate unwelcomeness due to implicit and explicit cisgenderist beliefs (Alpert et al., 2021).

Consequently, TNB health is affected through pervasive systematic discrimination, identity invalidation, and poor treatment, that serves to deter TNB people from accessing needed care. Veale and colleagues (2019) found over one third of TNB respondents in Aotearoa avoid seeing a doctor, specifically due to anxieties around being mistreated or disrespected by staff. Ansara (2012) describes this as ‘structural violence’, where systematic inequality is built into the very structure of healthcare, which in turn inflicts harm or violence upon TNB people who need to access healthcare. This structural violence is directly related to institutionalised cisgenderism, where TNB people’s gender and bodies are treated as deviant and abnormal, whilst “simultaneously treating their oppression as ordinary” (Ansara, 2012, p.94). Thus, institutionalised cisgenderism turns a place that is trusted with supporting health, into a place that can further perpetuate harm.

Trans and Non-Binary Cancer Information in Aotearoa/New Zealand

There is little to no local research examining the experiences of TNB people accessing cancer care. One Aotearoa report, The State of Cancer in New Zealand 2020 (Te Aho o Te Kahu, 2021), provides a brief indication that TNB people may potentially experience health inequalities regarding cancer care. Its section on, ‘SOGIESC-diverse peoples’ (People of diverse sexual orientation, gender identity/expression, and sex characteristics) and cancer care states that, “there is a long history of SOGIESC-diverse peoples being criminalised and pathologised by medical institutions in this country” (Te Aho o Te Kahu, 2021, p.35). However, the report also acknowledges that limited research has been done into the actual cancer outcomes or experiences of SOGIESC populations in Aotearoa.

The limited research of TNB people's experiences of cancer in Aotearoa, focuses on the issue of cancer screening. Cancer screening is an important health initiative. Earlier diagnosis through screening improves a person's chances of cancer survival (Ministry of Health, 2020). The Counting Ourselves report (Veale et al., 2019), discusses TNB peoples' perceptions of cancer screening. The study found over one quarter of participants were unsure if prostate or mammogram screenings were applicable or relevant to their circumstances, and almost one in five were unsure about cervical cancer screening. TNB people also reported avoiding cancer screening services due to fears of mistreatment. Approximately 23% of those within recommended screening ages reported delaying their prostate screening, 15% delayed their mammograms, and 33% percent delayed their cervical screenings due to fears of mistreatment. Cancer screening is an issue, as internationally screening avoidance has been linked to TNB people being diagnosed at more advanced stages of illness, leading to more complicated treatments and lower survival rates compared to other populations (Haynes, 2008). Overall, further investigation into TNB people's experiences of cancer care in Aotearoa is needed for all areas of the cancer care journey.

International Research on TNB People and Cancer

Incidence and Survivorship

Internationally, the literature indicates that there are cancer and cancer care disparities specific to TNB communities. Actual incidence rates of cancer for TNB people remain mostly unknown, as current cancer databases/registries largely do not record TNB identity in relevant demographic information (Braun et al., 2017; Schabath et al., 2017). However, TNB people do have factors specific to their experiences that may increase cancer risk (Margolies & Brown, 2018). TNB people have disproportionately higher rates of psychological distress resulting from discrimination (Scime, 2019). Cancer patients who report higher rates of psychological distress are more likely to develop comorbid conditions (experiencing multiple illnesses simultaneously), have worse self-reported health during care, and have increased risk of mortality (Kamen et al., 2015a). Additionally, high rates of psychological distress could lead to higher rates of engaging with ‘risky’ coping mechanisms, such as smoking and excessive drinking (Gilbert et al., 2018; Hinds et al., 2021), which could be linked with increased cancer incidence (Connor, 2017; Hecht, 2006). While there is some suggestion that the discrimination and violence TNB people experience can increase risk for substance abuse, TNB people have been largely unexplored within wider substance abuse literature. Consequently, the actual prevalence of substance use among TNB people cannot accurately be determined. This is something that still needs to be comprehensively explored in further research (Connolly & Gilchrist, 2020; Dolcecore et al., 2020).

Inequitable social circumstances could also be linked to cancer risk for TNB people. TNB people experience discrimination in employment, housing, and education; consequently, leading to higher risk for homelessness, extreme poverty, and poor mental health (Baldwin et al., 2018; Veale et al., 2019). High levels of poverty are a critical area for cancer disparity, as low socio-economic status is significantly linked to cancer incidence and cancer mortality. Causation is complex, but people in poverty are more likely to delay accessing services due to service and transport costs, present with more advanced cancers, and are more likely to be exposed to carcinogens (cancer-causing agents) through occupational, recreational, and lifestyle exposures (Haynes et al., 2008). These issues listed are compounded by the previously mentioned low screening rates. Accordingly, TNB populations may be more vulnerable to cancer incidence and face decreased survivorship rates.

Discrimination in Cancer Care

Research suggests that issues for TNB people found in cancer care, reflect the issues TNB people experience in general healthcare. TNB cancer patients often delay and or outright avoid cancer services (Kerr et al., 2019; Scime, 2019). There are many factors contributing to this. TNB patients may be distrustful of cancer services if they have previous negative experiences with healthcare (Scime, 2019). Furthermore, the specific experience of cancer entails a level of engagement with the healthcare system that is significantly more extensive than general healthcare. TNB patients may feel uneasy at the thought of such prolonged and extensive contact with a system potentially insensitive and unwelcoming of their presence (Eliason & Dibble, 2015). Cancer patients are particularly vulnerable when accessing care. Thus, TNB patients may feel particularly concerned about experiencing discrimination in cancer care, as their survival is dependent on the treatment they receive from their providers (Kerr et al., 2019).

A large part of this distrust is due to fear of poor treatment. This fear may not be unfounded either, as interpersonal discrimination is reported by TNB people accessing cancer care (Kerr et al., 2019). Common instances of interpersonal discrimination include improper use of pronouns by healthcare providers, not respecting TNB people's non-familial support systems and partners, and derogatory remarks made by providers with cisgenderist beliefs (Boehmer, 2018; Kamen et al., 2019). Additionally, some TNB cancer patients reported being turned away from cancer services, such as seeing a specific surgeon or specialist, because their provider felt too uncomfortable to provide their needed care (Boehmer, 2018).

Informational Erasure

Structurally, cancer care also fails to support quality care delivery for TNB people. Providers are typically lacking in overall TNB cancer knowledge, particularly as TNB informational erasure extends to cancer research (Schabath et al., 2017). Taylor and Bryson (2016) found that most TNB cancer patients reported their providers are ill-equipped to answer questions about how cancer treatment might interact with gender-affirming healthcare. For example, a patient may want to know if they should stop taking gender-affirming hormones for their specific cancer treatment, but the provider does not have the knowledge to advise them on the correct course of action (Squires et al., 2022).

The scarcity of information not only means providers lack the knowledge or training necessary to advise TNB cancer patients (Scime, 2019), it also means that cancer information websites and cancer awareness campaigns often do not have relevant information for TNB patients (Taylor & Bryson, 2016). Kerr and colleagues (2019) found most of their TNB participants answered, “I don’t know” on provided statements intended to determine cancer-related knowledge specific to TNB people, such as “hormones can affect everyone’s cancer risk” and “people do not have any risk of developing breast cancer if they have had a mastectomy” (p.58-59). Overall, the research suggests TNB people are disadvantaged when it comes to having access to the knowledge necessary to enable informed decisions about what is best for their cancer care.

The lack of TNB cancer information also has implications on the political level. The exclusion of TNB people from population-based cancer research, creates the conditions for TNB communities to be overlooked in cancer health policies and in the allocation of funding and resources. Essentially, if there is no evidence documenting that TNB people are vulnerable to cancer disparity, there is no political incentive to prioritise addressing TNB needs in cancer care (Kerr et al., 2019; Whi-Hongi et al., 2017).

Lack of Support

Another issue is limited cancer support services available that accommodate TNB people. Additional support services are usually available alongside medical treatments to provide well-rounded care. For example, the New Zealand Cancer Society provides both practical and emotional support for current cancer patients, survivors, and their families, to work alongside medical treatment (Cancer Society New Zealand, 2022b). The problem is that most of these services do not consider TNB people in their design. A search of the same Cancer Society website offers no results for either TNB or general LGBTQI+ specific support information. In the international literature, Taylor and Bryson (2016) found their TNB participants were unable to find any additional cancer support reflective of their experience, in person or online. Often patients are recommended services that offer support to sexuality minorities, which are unhelpful in providing relevant advice specific to the TNB experience. Overall, the research indicates that support services are unprepared for TNB patients (Boehmer, 2018; Squires et al., 2022).

A lack of support services is troubling when you consider that TNB cancer patients may be more vulnerable to social isolation due to wider issues with social marginalisation

(Boehmer, 2018; Kamen et al., 2019). High levels of social isolation are a recognised determinant in higher cancer mortality (Fleisch-Marcus et al., 2017). Furthermore, social isolation affects the availability of informal support carers. This refers to the important practical and emotional support families, friends, or partners provide (Boehmer, 2018). Cancer is one of the 'top 10' illnesses that necessitates the support of a caregiver (Girgis & Lambert, 2017). Yet, despite an already high risk of isolation, there are also issues with non-familial support or non-traditional partners being disregarded in their attempts to support their loved ones with cancer. This is a particular issue with end-of-life care, where patients and their loved ones need extra support and quality time together (Cathcart-Rake et al., 2019). These support disparities indicate that improving external support services, as well as improving acceptance of non-biological 'found family' members and partners involvement in care for TNB people, may be an important area to explore regarding quality of life during cancer treatment (Boehmer, 2018; Cathcart-Rake et al., 2019).

Trans and Non-Binary Unique Experiences of Cancer

Cisgender Expectations in Cancer Care

Prevailing cisgender expectations and norms do exist within cancer care spaces. These expectations and norms are highlighted most explicitly with cancers typically viewed through a normative gender lens. For example, breast and gynaecological cancers are associated with cisgender women, and prostate and testicular cancers are associated with cisgender men (Squires et al., 2022). Cisgendered expectations about specific cancers can lead to TNB people feeling unwelcome accessing gendered cancer care spaces. TNB people may also face discomfort being forced into gendered spaces incongruent with their identity, such as gendered clinics or hospital wards. Additionally, TNB people can face scrutiny and discrimination from other patients and staff, who have not conceptualised that TNB people might need access to care (Alpert et al., 2021; Ansara, 2012). For example, a trans man accessing care for cervical cancer was turned away for their medical appointment, being told by the receptionist, "You are in the wrong place" (Bryson et al., 2020, p.348).

Often, TNB patients feel they have to present in certain ways that align with cisgender expectations to avoid negative healthcare experiences. Some TNB people report that providers seem more comfortable and provide better care when there is no disruption to their preconceived gender narratives (Paine, 2018). In one study, LGBTQ+ cancer patients described the experience of having to ‘turn off’ parts of themselves in order to navigate a cisheteronormative cancer care system without coming to harm (Waters et al., 2021). For TNB people, this could look like a non-binary person choosing to present themselves more within the typical binary, in order to avoid discrimination in care. Evidence shows that those who do not visually conform to expected binary gender embodiment are more likely to experience discrimination and stigma (Kcomt et al., 2020; Paine, 2018). Some TNB patients also experience resistance from providers when their care decisions, particularly surgical, challenge expected cisgender norms. For example, facing resistance for choosing not to undergo breast reconstruction after a mastectomy (Sledge, 2019; Taylor & Bryson, 2016).

Overall, cancer care and treatment for TNB people is fraught with challenges due to the prominence of normative gender expectations. TNB people present a challenge to the healthcare system, which is structured in such a way that maintains normative conceptions of sex and gender. This means that the cancer care environment is often unable to support TNB people, as providers are frequently unable to reconcile a TNB patient’s wants and needs with their own preconceived notions about gender embodiment. The problem of gender expectations has also contributed to the erasure of TNB people in cancer care. Particularly within typically gendered cancer services, where the possibility of TNB people needing access to that care is predominantly unconsidered. These expectations lead to unwelcoming and alienating cancer care environments for TNB people.

The Decision of Identity Disclosure.

The decision to disclose TNB identity to cancer care staff is difficult. On one hand, disclosure can support better patient-centred care and patients can be appropriately addressed and recognised as their gender (Ussher et al., 2023). However, a choice of disclosure can also expose TNB people to stigma and discrimination (Bryson et al., 2020).

To avoid this, some TNB patients may choose not to disclose their TNB identity. Some TNB patients may find it easier to avoid disclosure. For example, Ussher and colleagues (2022) found their non-binary participants were more often able to utilise non-disclosure and be incorrectly perceived as cisgender. Some TNB people who have transitioned and are living as their correct gender may also ‘pass’ as cisgender, and not feel comfortable disclosing that they are TNB, and may find it easier to let healthcare staff presume they are cisgender (Kcomt et al., 2020). However, non-disclosure is not always an option. Some types of care, such as a trans man accessing cervical cancer services, likely necessitate disclosure of TNB identity. This involuntary disclosure can sometimes cause TNB patients to avoid accessing care to prevent potential stigma (Kcomt et al., 2020; Paine, 2018). Many TNB people will utilise selective disclosure, where a provider’s attitude, the setting, or the relevance to medical need is used as context to determine whether it is safe or necessary to disclose identity (Kcomt et al., 2020). The decision of disclosure can be particularly overwhelming within the cancer care context as TNB patients are faced with potentially having to disclose to multiple cancer care staff along the cancer care journey (Margolies & Scout, 2013). Overall, the decision of disclosure is complex and relies on many personal and situational variables. Non-disclosure has been identified as a potential issue contributing to poor psychological wellbeing for TNB cancer patients, as it has been associated with feelings of dissatisfaction, stress, and invisibility throughout the cancer journey (Ussher et al., 2022). However, whether or not patients choose to disclose their TNB identity, they should be supported throughout their cancer journey (Alpert et al., 2021).

Unconsidered Treatment Effects

As mentioned, cancer treatments come with a variety of side effects impacting the body in significant ways. The limited research in this area suggests that these side effects can create additional challenges for TNB people. Some side effects cause changes to appearance, such as hair loss or physical body changes. Some treatments or specific cancers may necessitate cessation of hormone treatments. These changes can be distressing, particularly when they disrupt people’s ability to articulate their gender (Bryson et al., 2020; Taylor & Bryson, 2016; Ussher et al., 2023). This has important implications for a patient's care plan and determining what is best for that individual's wellbeing. Some TNB people may face an additional decision-making burden of weighing decreased cancer survival against living with the psychological distress treatments may cause (Alpert et al., 2021; Bryson et al., 2020; Sledge, 2019). On the other hand, some side-effects can also be an unexpected avenue of gender affirmation, as some cancer surgeries actually overlap with gender affirmation procedures. For some TNB people, cancer surgery could involve the removal of body parts they did not particularly care for anyway, allowing these patients to feel more positively about experiencing major surgery (Taylor & Bryson, 2016; Ussher et al., 2023).

Sledge (2019) found providers have little awareness about how a TNB person's felt sense of gender might affect treatment-decision making. Particularly for surgery, providers are inexperienced with the possibility of cancer surgery affecting TNB gender embodiment. As a consequence, TNB patients often have to self-advocate to receive preferred outcomes that coordinate their cancer and gender-affirming care needs (Sledge, 2019; Ussher et al., 2023). Providers need to be able to integrate all important elements that impact patient needs and care in order to provide quality cancer care (Conden et al., 2021). Without this awareness, providers are unable to coordinate between a TNB patient's cancer care and gender-affirming care. It would be helpful for providers to know about these possibilities to create better care plans for supporting and treating TNB patients with cancer.

Self-Advocacy and Resistance

A common thread seen throughout the literature, is how TNB people often enact self-advocacy when navigating a cancer care system that is ignorant to, or actively resistant to their needs. TNB people frequently speak of their experiences advocating for treatment decisions they feel are more appropriate for their needs, even against provider pushback or misunderstanding. TNB patients also enact self-advocacy in instances of misgendering or transphobia by staff and engage in acts of resistance when forced to take part in activities not respective of their gender, such as refusing placements in wrongly assigned gendered treatment spaces like hospital wards, and refusing gendered patient attire (Alpert et al., 2021).

Understanding TNB people's actions of resistance and self-advocacy can provide essential insight into where effective healthcare interventions are needed. Seelman and Poteat (2020) found that their participants frequently engaged in strategies to reduce negative health experience. For example, an emergent theme was 'doing one's own research'. This included searching for TNB knowledgeable providers and researching health needs and patient rights (Seelman & Poteat, 2020). That TNB people felt it necessary to engage strategies to improve their own care, is indicative of the wider issue of experiencing providers who are unknowledgeable and unhelpful. The study explains that approaching from the angle of assessing TNB people's responses and strategies, allows for interventions that not only reflects real life experiences, but also acknowledges the wisdom and knowledge already developed within the community.

Exploring TNB self-advocacy and resistance is also important for countering the hyperfocus on TNB disparity (Seelman & Poteat). Whilst it is still important to acknowledge issues of disparity and inequity, overemphasis on experiences of stigma and discrimination can lead to the impression that TNB people are simply passive receivers of oppression. The majority of literature about TNB people is focused on issues of risk and tragedy when there is far more nuance to TNB experiences. We also need to recognise TNB people's agency and achievements. Additionally, many TNB people do not just use advocacy to receive better healthcare for themselves, but also act to intentionally improve the experience and access to healthcare for future TNB people and other marginalised groups (Seelman & Poteat, 2020).

While promoting and fostering the strength of self-advocacy can benefit personal cancer outcomes and experiences of healthcare (Bond et al.,2021; Hibbard & Greene, 2013; Husson et al., 2011), it is also important to recognise it would be irresponsible to foster self-advocacy without actually addressing why TNB people need to self-advocate. TNB people are not obligated to take on a role of advocacy and not every TNB person wants to take on this responsibility, nor should it be required of them. Self-advocacy and resistance can also have negative consequences for TNB people. Challenging a provider's self-perceived expertise may cause negative consequences for the patient-provider relationship (Hagan et al., 2017). Challenging providers is particularly risky in cancer care when one is receiving help from a particular specialist and there may not be other options for care. Additionally, having to continuously self-advocate can add an additional layer of fatigue and stress, through having to undertake an additional burden of fighting for your own care whilst already experiencing serious illness. Acknowledging already existing strengths and wisdom is important, but we must also remember that the responsibility for ensuring that care is meeting people's needs, is that of the healthcare system and not the individual receiving care.

Chapter Summary

This chapter introduced the current knowledge around TNB people and cancer care and why this is a significant topic to explore for Aotearoa. Quality cancer care involves providing care, support, and information that is able to meet patient needs. However, the lack of information around TNB cancer care in Aotearoa makes it difficult to determine if the goals of quality cancer care are being met for TNB people. While TNB people do have diverse experiences, TNB people are more at risk of experiencing challenges relating to cisgenderism in Aotearoa, which negatively impacts access to the social determinants of health. Additionally, international research on cancer and TNB people has indicated that many general healthcare challenges for TNB people are reflected in cancer care. This suggests that TNB people in Aotearoa may also likely face additional challenges in getting the cancer care they need. As the type of care patients receive can make a difference to health outcomes and wellbeing during cancer treatment, exploring the experiences of TNB people in cancer care is important.

International research has identified issues and challenges for TNB in cancer care which may be important to investigate in an Aotearoa context. While actual incidence rates are unknown, there are some factors of TNB experience which may increase cancer risk and cancer mortality. Additionally, there are significant barriers to accessing cancer services and receiving quality cancer care. Namely, the discrimination and marginalisation that TNB people can experience is shown to discourage TNB people from accessing services, impact treatment adherence, and affect cancer outcomes. A further issue is the erasure of TNB people in cancer services and cancer research. Cancer care providers' ability to enact TNB responsive care is negatively impacted due to the lack of knowledge and training available. The knowledge gap also means that TNB people cannot access necessary information needed to make informed decisions about their care. Providers being unaware of TNB patients' unique needs also affects their ability to coordinate care, particularly when it comes to coordinating between cancer and gender-affirming care. Overall, the cancer care system itself operates within a cisgenderist structure that fails to account for the needs or existence of TNB people.

Current research on cancer and TNB people does have limitations. There is a major lack of large-scale longitudinal studies and recording of TNB identity in cancer registries, leading to a lack of information on actual incidence rates, risk factors, and cancer outcomes. Another major issue is with how TNB people are represented in the available research. A large amount of the research includes TNB experience only as part of the wider LGBTQI+ 'alphabet soup' (Ansara, 2015). The 'alphabet soup' represents how distinctive identities in the LGBTQI+ acronym frequently become flattened together in presumed homogeneity. In these situations, factors specific to TNB experience, as well as the complexities within TNB communities themselves become overlooked. Most TNB populations are also studied as if they are homogenous, with the intersectional and diverse experiences within TNB populations commonly being overlooked. Non-binary identities have also only recently begun to gain wide recognition within the academic research field (Clark et al., 2018). Thus, much of the research on this topic conceptualises trans people within the normative gender binary. Lastly, this topic is still a developing field and there are likely still aspects of TNB cancer care that could not be included, as they have yet to be explored.

The aim of this thesis is to address the current research gap through a qualitative exploratory study on experiences of TNB people in cancer care in Aotearoa. The following chapter will outline the theoretical underpinnings of the interpretive qualitative approach taken in this research, explain the use of narrative case studies, and outline the method steps taken to explore this topic.

Chapter Two: Methodology

This chapter firstly provides a discussion of the theoretical approach to this thesis. I explore why an interpretive qualitative methodology was chosen for this particular research, explain the theoretical underpinnings of this approach, and outline why a community psychology approach was important to the method of this thesis. The method procedure undertaken to engage with the stories the participants shared is outlined, and my use of narrative case studies is explained. The ethical considerations for this thesis are also defined, as this was important to the undertaking of this thesis. The chapter closes with a section explaining an unexpected complication that arose during my thesis and an account of how I addressed this, followed by some strengths, limitations, and considerations for this study.

Qualitative Research Approach

There is a growing body of research that asserts the usefulness of a qualitative approach to medicine and healthcare research (Beck, 2013). The power of qualitative research is the depth and richness of data it can generate, which allows us to look more deeply into the complex and nuanced experiences of people in ways that cannot be captured solely through quantitative measures (Al-Busaidi, 2008). Qualitative research is not concerned with the measuring of social phenomena, but with exploring underlying meanings, looking to understand people’s experiences, perspectives, behaviours, and the ways we make sense of the world (Merriam & Tisdale, 2015). Thus, qualitative research is common for exploratory studies and health research, as it can generate in-depth information about the perspectives and experiences of patients and is commonly used for developing patient-centred care initiatives (Isaacs, 2014). This thesis utilises interpretive qualitative research, which is more than just being language based over numerical data; it represents a particular theoretical positioning that differs to typical positivist studies (Moon & Blackman, 2014).

Theoretical Underpinnings

There is no universal prescriptive guideline when it comes to undertaking qualitative research. However, there are some underlying epistemological (how we know things) and ontological (what exists for us to know) principles that guide the qualitative researcher's methods, analysis, and overall approach (Merriam & Tisdell, 2015). The interpretive qualitative approach is underpinned by the theoretical position of social constructionism, the idea that knowledge and meaning are socially constructed. In social constructionism, meaning is not a passive thing waiting to be discovered as an objective universal reality. Rather, we construct knowledge and meaning through our interactions with the world around us. Meaning emerges from and is transmitted within the realm of the social world (Crotty, 1998). In contrast to the positivist/objectivist idea of an unbiased 'one truth' to investigate, social constructionism posits that there are a multitude of ways a phenomenon can be understood, as meaning is always mediated through our cultural, historical, and social contexts. Research drawing on social constructionism grounds an individual's experience in socially or culturally shared meanings, avoiding overly individualistic and non-contextualised approaches to understanding human experiences and meaning making (Harper, 2011).

There is some contention surrounding the accepted meaning of the term social constructionism. This contention is specifically related to where a researcher places their interpretation of social constructionism on the continuum between relativism and realism (Harper, 2011). Realism is an ontological belief that maintains that there is an objective reality existing independently of human perception. Realists typically claim that there is only one 'true' objective reality which can be discovered, studied, and understood (Moon & Blackman, 2014). In contrast, relativist ontology claims that reality is constructed through individual perception, and that any understanding of a phenomenon is relative to a particular framework or perspective (such as an individual person's perspective, a culture, or a historical era). Accordingly, there is not typically thought to be one 'true' reality (Baghramian & Cater, 2022).

Critiques against the use of social constructionism often come from a concern about the consequences of aligning too closely to relativism. The concern is that when social constructionists reject that one objective reality or truth exists, this could imply that we must accept that each perspective or standpoint has the same level of legitimacy (Andrews, 2012). This tension has important repercussions when arguing for change or social justice. If every perspective is equally representative of the world, or if every social issue is only a social construct, then it becomes difficult to argue for improvements or social change.

It is argued here that critiques of constructionism as an unsuitable approach for researching social issues, often confuse 'extreme' constructionism/fully relativist-leaning constructionism, with the actual general use of social constructionism by researchers. In actuality, general and practical use of social constructionism typically involves researchers aligning themselves with a more moderate approach - one that still accepts the prospect of an objective reality impacting human life (Burningham & Cooper, 1999). The argument that accepting a material reality in social constructionism is a theoretical inconsistency, is actually a conflation of social constructionism as an epistemology, with social constructionism as an ontology. Social constructionism is mostly utilised in an epistemological function, looking into what we can know about the world. In practice, most research within this tradition makes no ontological claims concerning the relative nature of the world itself (Andrews, 2012).

This thesis aligns itself with the moderate social constructionist position. It is aligned with the perspective that although we construct meaning through the social context, we are also constructing that meaning within the world around us, and our lives are still affected by our material reality (Harper, 2011). Thus, it is not an inconsistency to examine how people construct meaning within the social world, yet still accept that such things as illness or social disadvantage objectively exist and have very real effects on people's lives.

Community Psychology

Interpretive qualitative research is frequently used within community psychology, as the underlying theoretical positioning and methods align well with the discipline's approach. A major component of community psychology is a rejection of the notion that research is a neutral activity, where the researcher role is seen as an objective expert who acquires knowledge simply through scientific observation. Instead, community psychologist’s operate through a socially constructed lens, where the knowledge is co-created between researchers and the communities they work with, which we can see reflects the underlying approach within interpretive qualitative methods. Accordingly, community psychology approaches place value in a more participatory and collaborative dynamic between researcher and participants (Riemer et al., 2020). While the researcher still has an important role, they are reframed as, “only one player in the telling and interpretation of stories” (Wallerstein & Duran, 2017, p.35). This role reframing enables communities’ experiential or alternative knowledge to be respected as equally important to the research. A participatory approach is greatly valued within community psychology, as it ensures research is actually relevant and significant for the communities affected. Particularly for health research, this approach is effective for ensuring healthcare intervention strategies are properly tailored to community needs and are actually accessible to the communities addressed, through the inclusion of community expertise in the research itself (Wallerstein & Duran, 2017).

The turn from viewing research as a neutral project, also assists community psychology’s commitment to maintaining a critical consciousness of the researcher’s position. Community psychology does not view the researcher’s ‘self’ as separate from the research process. The ‘self’ is who is interacting with participants, interpreting participants’ words, and representing the information gathered. As such, the values, perspective, and subjective worldview of the researcher inevitably contributes to the research process. It is therefore argued that it is good practice for researchers to not only observe how they distinctly contribute to the research, but also makes their personal research approach transparent (Simons, 2009). In action, this process is referred to reflexivity, a process of ongoing, continuous reflection of ourselves and our assumptions throughout the research process (Soedirgo & Glas, 2020)

It is also important for researchers to be aware of their own positionality in relation to participants. Positionality includes the implications or perceptions around the researcher’s own identity, such as ethnicity, gender, education, and how these aspects might affect the dynamics of the research relationship. As community psychology often conducts research with marginalised communities, issues of unacknowledged power relations within research relationships can be problematic. The broader context of current and historical societal power relations is also relevant to research. Power dynamics not only impact on how personal privilege might affect the researcher's interaction with participants or interpretation of the research, but disciplinary or institutional history can also impact the research relationship. In particular for TNB people, the context of psychological research itself may carry negative connotations due to the discipline's history of pathologising TNB people's experiences. TNB people may be naturally wary of psychology researchers coming from outside of TNB communities and may be concerned that participating in psychology research might further contribute to this harmful narrative (Tebbe & Budge, 2016). Ignoring these valid concerns would only be detrimental to the research. Showing awareness and responsiveness to these concerns was an essential aspect of being able to work with TNB communities and apply the community psychology approach (Wallerstein & Duran, 2017). For example, it was important to be fully open about this research and the methodological approach to any interested parties, to ensure participants could make informed decisions about if they felt comfortable participating.

Method Procedure

Preliminary Research

In the early stages of planning, I contacted relevant TNB community organisations in Aotearoa for input on the topic choice to ensure the research was of interest and benefit to community needs. Importantly, contacted organisations also provided additional advice regarding best practice for working with TNB people that was used to shape the research approach. For example, I received and read articles on TNB research ethics from these organisations, which highlighted the importance of using participatory research models and ensuring consciousness of how cisnormative assumptions might shape research (Adams et al., 2017; Henrickson et al., 2020; Vincent, 2018).

Recruitment

I recruited TNB people, who were over 18, and had experienced cancer care in Aotearoa within the last ten years. Participants were recruited through online advertisement. Relevant TNB organisations in Aotearoa were contacted to ask if they would be willing to advertise the study on their social media platforms. This facilitated purposeful recruitment, where advertisement was directly posted where relevant people might view it. Contacting TNB organisations also allowed those organisations to review the study before recruitment, which is recommended practice for researchers outside of the communities in question (Thomas & Hodges, 2013).

Acknowledging the context of psychology research for TNB communities involved anticipating that some organisations would require more than a perfunctory email request to advertise the study. When approaching organisations, it was important to communicate my willingness for further communication and for answering questions and receiving feedback. Some organisations did request further details, such as viewing my interview schedule and requesting further information on my methodological approach, before agreeing to advertise the study. It was important to be willing to spend time with organisations discussing the study if needed, with no expectation of organisations accepting my request. After the study was advertised, participants contacted me by email if interested. From there, participants were emailed an information sheet. If they were happy to continue, the meeting time and place was arranged where the participant felt most comfortable.

Participants

There were three participants in this study. One non-binary person (age 40-50), one trans woman (age 50-60), and one trans man (age 20-30). The participants experienced a variety of cancer types. None were in active cancer treatment at the time of the interview, but all had received treatment in Aotearoa within the last 10 years.

Ethical Considerations

Before the commencement of the study, approval was granted by the Human Research Ethics Committee (Health) at the University of Waikato as HREC(Health)2022#13. For this particular project which involved both people from marginalised communities and people who may be experiencing serious illness, there were a myriad of complicated ethical issues that needed consideration to ensure participant safety and comfort was upheld.

TNB communities in Aotearoa are relatively small and only a limited number of people likely have the specific experiences discussed in this research. This limitation presented an increased risk to participant confidentiality. As TNB communities often experience stigma, confidentiality risk is a serious concern. Accordingly, it was necessary to be conscientious about what information was shared about participants. I restricted access to any identifying information to myself and the supervisors of this project. Tasks like transcription were done by me to avoid any third party access to participant information. I also removed any contextual information that could identify participants in published material. Certain details were withheld if they were too identifiable. All participants were sent their transcripts to review for any identifying context that was missed. Along with their transcripts, I also sent participants a summary of their interview. There were two reasons for this. Firstly, if participants did not read their whole transcript, they still had an opportunity to review the main topics discussed. Secondly, participants could read my own interpretation of their accounts, allowing them to point out any incorrect assumptions or highlight anything of importance overlooked.

I replaced the participants’ names with pseudonyms to protect confidentiality. An aspect of respecting participant input was to offer participants some agency in how they were represented. Participants were able to choose their own pseudonym. If participants did not want to choose their own, I offered a suggestion which the participant consented to before that pseudonym was used in the study (see Appendix A: Participant Consent Form, p.123). For any potential participant referred to me through a third party, such as a community organisation, additional ethical considerations were required. Being referred could lessen participant confidentiality, given that the referrer may find it easier to deduce identity knowing the person they referred could be a participant. To mitigate this, anyone who contacted me from a direct referral was made aware of this potential risk in our communications before any interview took place.

Every participant was fully informed about the topic and activities relating to this study before interviews started, allowing them to withdraw if they suspected the study would cause emotional distress or health burden (see Appendix B: Information Sheet, p.124). Having transparency was necessary for participants to make informed choices about whether this study would be beneficial for them to participate in. Due to the nature of the research topic, all participants were allowed to bring a support person to their interviews. One participant did accept this offer. Communication from the Human Research Ethics Committee noted this presented an additional consideration regarding confidentiality, as a third party would hear the interview. In light of this, a confidentiality agreement was designed for support people (see Appendix C: Support Person Confidentiality Form, p.127).

Participants were provided a $30 voucher for their contributions. Compensation was considered a matter of ethics in this study for two reasons. Firstly, because participants may be dealing with increased financial hardship that arises from cancer treatment, it may be unethical to expect these participants to travel for an interview or just give up their time without compensation. Additionally, ethics guidelines for working alongside TNB participants also highlight the importance of compensation to ensure that TNB expertise and time given to the study is recognised fairly (Hendrickson et al., 2020; William, 2018). Appropriately, compensation was advertised to participants to show their contributions were properly valued.

Narrative Case Studies

Participants were asked in interviews to broadly discuss their experience with cancer care in Aotearoa. One interview was conducted in-person, and two online using the videoconferencing app Zoom. Zoom was utilised due to geographical restrictions and the conditions of the Covid-19 pandemic, as many people preferred social distancing to avoid illness risk. An interview schedule was used for the purpose of these interviews (see Appendix D: Interview Guide, p.128); however, it was employed as a prompt rather than a strict guide. The interview was semi-structured with very broad and limited pre-planned questions. I wanted to employ a narrative based approach to interviewing, wherein the participant is able to frame their own story and direct the conversation to what they felt it was important to discuss (Anderson & Kirkpatrick, 2016). This was particularly beneficial in terms of this being an exploratory study, as having the participants steer the discussion lead to the discovery of unanticipated and previously underexplored areas of interest.

When it came to the stories shared with me in this research, I discovered that each person had a uniquely distinctive story and point of view to be communicated. I therefore found it more useful to attend to each participant's story as wholly important in their own right, rather than attending only to arising common themes. As such, narrative case studies provided the best fit for analysing and presenting the experiences of the participants in this study. The definition of narrative case study used in this research is an in-depth look into a particular case (or person's story), in order to gain understanding of a particular topic (Simons, 2009). Narrative approaches explore how people make sense of and ascribe meaning to their experience, whilst acknowledging that meaning is also always constructed and contextualised. Storytelling is a fundamental aspect of human communication. The stories we share provide insight into our personal experiences and identity, whilst also reflecting the wider social and cultural stories we draw upon to make sense of our experiences (Stephens & Brehenny, 2013).

My process of analysis began with journaling my thoughts and reflections post-interview and throughout the analysis process. Although, I had already been journaling in relation to what I had been reading and thinking prior to data collection and developing this thesis approach. Research journals are a common tool in qualitative research, particularly for engaging with reflexivity (Smith & Davis, 2010). Transcribing the interviews and preparing a summary for the participants, provided the framework for immersing myself in the data and developing ideas about the key aspects of each person's experience (McMullin, 2021). From there, I read and reread each participant's transcript to gain a thorough sense of a participant's narrative. Through this close reading, I identified particular issues and themes raised within each particular narratives, looking at where there may be differences and similarities in experience between the participants. The narratives of the participants were then situated within the wider research on this topic through my process of writing the participant chapters, looking at similarities, differences, and gaps in connection with the existing literature. As this approach acknowledges the role of the researcher (Murray, 2008), it is important to note that I did not include every aspect of the participants' experience of cancer, but highlighted parts that were relevant to the experience of being a TNB person within cancer care.

As there are multiple ways to approach narrative analysis, it is important to clarify that my approach did not focus much on the structure or emplotment of the narrative. I was instead interested in how these participants understood and gave meaning to their experience of cancer care, and how these personal narratives intersected with wider dominant narratives of the cancer patient experience. Narrative approaches are common when considering how to understand the experience of illness, as illness often presents a 'disruption' to people's previous life narratives and expectations. The way people make sense of this disruption and integrate their illness into their personal life narrative, can provide valuable insight into how people understand and give meaning to their experiences (Murray, 2008). I found it particularly valuable to frame my approach in terms of narrative case studies, as they can enable diverse, intersecting, and sometimes contradictory layers of meaning to be acknowledged within each person's experience (or case). As narratives reflect important aspects of lived experience, understanding the ways in which narratives can be constrained, accepted, or contested, can provide important in-depth insight into complex issues (Andrews et al., 2013). Therefore, this approach allowed for the diversity and complexity within each participant's story to be recognised (Murray, 2008).

Unexpected Complications

Approaching interviews with care to ensure participant comfort and safety was prioritised in this study. Due to the personal and sensitive subject matter, I felt I should be flexible in my approach to ensure participants felt at ease. However, the reality of conducting these interviews unearthed ethical and logistical issues that were both unanticipated and challenging. These challenges appeared from the first interview.

Although my first ‘participant’ requested a Zoom interview almost immediately after contact, they also required confirmation that I could provide them with an online Amazon voucher before they would commit, preferring compensation usable online. I felt I should provide compensation in a manner that most suited participants, so I agreed. In the interview, the participant was unwilling to have their camera turned on. I felt this might impact rapport, but ultimately thought it more detrimental to push a participant into something they were uncomfortable doing. The removal of facial communication, I felt, did impede communication, as there was a slight language barrier with the participant speaking in heavily accented English.

My second, third, and fourth participant followed a concerningly similar pattern. This included them wanting to meet quite quickly over Zoom, not willing to have their camera on, presenting with similar language barriers, similar accent, and also preferring Amazon vouchers. I also began to notice that the information I received from these participants was limited and used similar phrasing. I initially decided to trust that this was a coincidence despite my growing apprehension. I knew that similar phrasing and limited information could be a consequence of people having English as a second language. Similarity of voices could be that I was unfamiliar with this accent and unable to hear nuance. However, as I began to receive even more email inquiries, my suspicions heightened. After each interview, that same day I would receive an email from a new person requesting an interview. Although these emails were sent from different accounts, each email reflected the same specific writing errors and style as the previous emails of these suspicious participants.

I believed it might be a coincidence to have four participants follow this pattern, but to potentially have seven to eight participants with this unusual pattern was unlikely. Discussion with my supervisors led to the conclusion that these circumstances were suspicious, and for my own safety I needed to pause accepting interviews and change my approach for my own protection. Going forward, I added new regulations to accepting interviews. One important change was informing any people interested in participating that I would not accept interviews with cameras off. I also specified that I would only send vouchers usable within Aotearoa and changed my Zoom settings so only New Zealand IP addresses could access my meeting links.

Although this complication may not initially appear relevant to the thesis topic, it was pertinent to disclose why I only used the accounts from three participants in this study, even though more were interviewed. With the unverified participants, I could not know how much of their accounts were actually true to the topic, or if these participants were even in the country. As my intention was to learn from people with direct experience with the topic, I felt it would be a disservice to the study's purpose, and to the other participants, to include accounts I could not safely say were representative. Thus, only the accounts of participants where I was able to confirm eligibility are given precedence in this thesis.

Literature on researcher safety concerns for video-based interviewing is limited, as these technologies have only recently become so widely used. One older article on Skype interviews briefly theorises that online interviews might problematise identity verification (Lo Lacono et al., 2016), but their solutions were not applicable to my situation. Another article briefly mentions having cameras off might actually be beneficial for sensitive topics, but then referenced the aforementioned article, linking it to the concern of participant authentication. There was no given solution to this problem of authentication (Thunberg & Arnell, 2021). This experience taught me a lot about overcoming obstacles and adapting to challenges in the research process. It also presented a learning experience for me to take into my future research regarding protecting myself in online research spaces. It has highlighted further attention and consideration is still needed around the issue of ethical online-based interviewing for both participants and researchers, as we move into more frequent use of digital qualitative research technologies.

Strengths, Limitations, and Considerations.

A limitation that should be acknowledged in this study, is that the lead researcher in this study is cisgender. Conducting community research from a position of being outside of the community can have some disadvantages. Insider researchers likely have increased rapport and understanding of their communities' experiences and context (Henrickson et al., 2020). There is also the issue to consider that much of the existing research in this area has been inequitably investigated and constructed by cisgender people (Vincent, 2018). Responding to these considerations, it was important to be transparent about my social positioning as a cisgender researcher, and to be continually reflexive of what this meant for how I interpreted this research. Part of this involved acquiring relevant supervision for this thesis and connecting with relevant community groups in the early undertaking of this study.

Positionality requires researchers to acknowledge the particular social and cultural lenses which shape understandings in relation to the research process (Orr & Bennett, 2009). In this, it was also important to acknowledge that both researcher and participant, usually do not fit into a single, simple identity category. Thus, overly simplifying the insider/outsider dynamic as a simple binary can be problematic. To further reflexivity around researcher positioning, Cumming-Potvin (2013) advocates for considering this concept as a continuum that can often be complicated to untangle. Other aspects of my positioning regarding the research, being a queer, Pākehā, cisgender woman, and someone who has known people close to me who have experienced cancer, are also important to acknowledge and consider. All these aspects of who I am contributed to the lens I undertook the research with and my positioning in relation to the participants.

This study had a small participant pool, which does limit the ability to make broad statements concerning TNB cancer care as a whole. This also meant that some experiences were likely not represented in the study. However, this smaller-scale approach was also a strength in many ways, as it left room for the nuances and complexities within the participants' experiences. Instead of being subsumed into broader themes and patterns, the important contradictions and important differences between participants could be recognised along with commonalities of experience. This supported a community psychology approach, where the individual circumstance is present, and the interaction between individual experience and wider context and structure could be explored.

Another potential limitation is that this study took place not long before new health system reforms are to take place in Aotearoa. The participants in this study all received care within the old structure consisting of District Health Boards (DHBs). As such, some of their experiences may differ from those receiving care in the current health system context. Additionally, there may be aspects of the cancer care context TNB patients encounter in the future, which could not be captured within this study due to the differences between systems. However, this research remains important, as to achieve the reform's goals of a more equitable, accessible, and people-centred approach to health (Future of Health, 2023), knowledge of the kinds of experiences TNB people can have in the cancer system is still needed.

Chapter Summary

This chapter has introduced the methodological approach to this thesis, outlining why the interpretive qualitative and community psychology approach was chosen for this specific thesis, regarding the nature of this topic and the exploratory focus. The specific method procedure, ethical considerations, and analysis process were outlined. Additional complications within the study, and some strengths, limitations, and considerations were also explored. The next three chapters of this thesis present the case studies of each participant. Each chapter is dedicated to a single participant. In each chapter, a participant's personal narrative of their cancer journey is explored, in relation to their experience being a TNB person in cancer care. How each participant's narrative was situated within the wider circumstances that framed their experience, as well as the wider literature on this topic, will be explored in relation to each person’s story.

Chapter Three: Sarah's Story

This chapter recounts Sarah's experience in receiving treatment for colon cancer. Sarah (she/her) is a trans woman in her 50s and identifies as New Zealand European. An important part of Sarah's journey was the presence of a strong support system, with her close friend/chosen sister's involvement throughout their cancer treatment. Sarah was also the only participant comfortable discussing their trans identity with staff and had transitioned some time before entering oncology care. Sarah described the majority of her experiences with oncology staff as positive but did have some negative encounters, mainly during her pre-diagnostic stage. Sarah also experienced issues around the coordination of her care, which brought up interesting implications regarding when the burden of communication is placed on TNB patients. An interesting aspect of Sarah's account was her personal approach to interacting with oncology staff. Sarah felt it was important to approach staff from a place of understanding and was willing to provide education for staff lacking in knowledge about trans issues. Through this approach, Sarah was able to utilise her negative experience of enduring serious illness, as an opportunity to create positive change for future trans patients in oncology.

Pre-Diagnosis Experiences

Sarah's journey to diagnosis was difficult. Although she felt the majority of interactions with oncology staff were positive, there were a few instances where she felt poorly treated, particularly in the pre-diagnosis stage. Sarah first noticed something was wrong when she began experiencing symptoms of passing blood. She was booked in for a colonoscopy to determine the cause, however, she was misdiagnosed. Sarah felt staff at this appointment made presumptions about why she was experiencing these symptoms based on her being a trans woman, which contributed to her being misdiagnosed.

> **Sarah**: When I got to the hospital, they kind of judged me. They changed it from a colonoscopy to a sigmoidoscopy, the difference between twelve inches and one and a half metres – it's quite significant.

> I think they wrote me off as being a person that probably indulges in anal sex. Their belief was you're bleeding from there because you've got piles and one's been ruptured. Diagnosis came back as probably piles and they walked away from it.

This quote exemplifies the main issue Sarah experienced, that her concerns and comfort were written off due to presumptions about her person. Sarah continued experiencing symptoms but was not diagnosed until two years after her initial sigmoidoscopy. After another incident of profuse bleeding, Sarah knew she had to get re-examined, but feared being dismissed again. This led Sarah to wait overnight until her condition deteriorated before seeking help, and the blood had, as she described, . . . "gone off" inside her. She felt if she had gone immediately when the bleeding was less severe, she would not have been taken seriously. When she did seek help at her local hospital, she felt the doctor there was initially dismissive, and even extremely aggressive in his examination of her. It wasn't until he saw the severity of her symptoms, that he realised that she needed to be taken to a larger hospital with more extensive services for inpatient care.

> **Sarah**: The doctor at the [redacted, local] hospital was very, very rough in his exam. As in like painful you know. It was to be fair, brutal. He was very surprised when he discovered the dark coloured blood by the sound of his voice. He's like, "Oh shit! From there we're gonna shuttle you up to [redacted, larger] hospital".

Sarah's description of this encounter shows she perceived a sense of carelessness on behalf of the doctor towards both her medical concerns and her body. In contrast, Sarah's final colonoscopy before diagnosis was more positive. After hospitalisation, Sarah was called back for another colonoscopy. Sarah described this new technician as . . . "absolutely fantastic". She noted this colonoscopy was still lengthy and painful but was happy with the technician's more considerate and thorough approach. Sarah felt this technician was much more professional and appropriate compared to her previous technician encounters, as they did not make assumptions or dismiss her symptoms. This last colonoscopy was what finally resulted in Sarah's diagnosis of colon cancer.

Barriers to Colorectal Cancer Diagnosis

Aotearoa has some of the highest rates for colorectal cancer along with colorectal diagnosis occurring at later stages in comparison to similar countries (Blackmore et al., 2020). Colorectal cancers in general are at risk of late diagnosis. This is due to multiple factors; symptoms often overlap with other conditions and have non-specific presentation (vague, unobservable, difficult to determine causality) (Vega et al., 2015). Other diagnostic issues include poor GP and public awareness about symptoms, high age requirements for screening*,* and barriers to organising colonoscopies (Blackmore et al., 2020; Vega et al., 2015*)* As early diagnosis increases chances of survival, there has been effort to investigate why statistics for late diagnosis colorectal cancers in Aotearoa are so high (Blackmore et al., 2020; Firth et al., 2021).

One local study by Blackmore and colleagues (2020) found that a failure to perform physical examinations is a major barrier to diagnosis. Improving access to diagnostic procedures such as colonoscopies is also recommended, particularly as GPs in Aotearoa have comparably limited access to these procedures. What differentiates Sarah's barriers to diagnosis from what is explored in the literature, was she did receive physical examinations. The assumptions made about Sarah and the following dismissals of her symptoms, were the main barriers to earlier diagnosis. The aggressive treatment from the doctor in her physical examination at her local hospital may also be related to this. In Sarah's retelling, she emphasised the doctor's shock when her condition proved actually serious. His initial "brutal" treatment of her also indicates he may have also made unfavourable presumptions about Sarah, or at least did not feel she needed careful treatment. Sarah reflected on her long road to diagnosis stating that:

> **Sarah**: Another year and I probably wouldn't be sitting here. You know, I'd probably just be a statistic.

Sarah's statement effectively sums up the serious repercussions that can arise when people experience barriers to cancer diagnosis. The presumptions she experienced caused her unnecessary pain during her procedures and had potentially fatal consequences. Without Sarah jeopardising her health by waiting for her condition to become severe enough for hospitalisation, it is possible that she may never have been taken seriously and her diagnosis may not have been discovered in time to treat her illness.

Hospital Encounter

One of Sarah's worst negative experiences also occurred during her pre-diagnosis stage, during her period of hospitalisation. She described an interaction with the chief doctor of the ward she was placed in, which left her feeling . . . "like a lab rat". Essentially, a doctor came to visit her and brought along a crowd of intern doctors to view her case. Sarah usually enjoys helping people with their educational journey; however, in this instance she was not forewarned, nor had she given permission. Sarah also felt that the interest in her was not because of her medical issues, but that because as a trans woman she was an unusual patient.

> **Sarah**: He asked me a question and I answered, and then the curtain that had been pulled back slightly just got yanked right out of the way, and there's like another ten or so students behind there, and that was solely because of the depth of my voice. They were like, oh there's something interesting behind the curtain. Then it became like an old McDonald's petting zoo.

Sarah's language and the metaphors she employed in her description of the event, speaks to a sense of dehumanisation felt during this encounter. In this situation Sarah was treated as an object of interest without thought of her personal wants or feelings. Those considered 'other' (such as TNB people under a cisnormative society) are more likely to be objectified and be viewed through the lens of a spectacle. This is one way in which TNB people experience stigma and substandard care within the healthcare system (Wagner et al., 2016).

There is currently limited research on the pre-diagnostic phase for colorectal cancers in Aotearoa for all populations (Firth et al., 2021). What exists has yet to consider specific barriers to diagnosis TNB people may face. International research specific to TNB people and colorectal cancer diagnosis is also extremely limited. Sarah's experiences expose that stigma and presumptions towards TNB people are still experienced within healthcare and may be an underexplored barrier to colorectal diagnosis. The presumptions made about Sarah due to her trans identity directly affected the way her diagnostic procedure was handled. The callous treatment described by Sarah in her initial examinations, and the dehumanising experience with the doctor during her hospital stay, seems to reflect a lesser standard of care due to assumptions relating directly to Sarah's TNB identity. Experiencing poor treatment can dissuade cancer patients from accessing further oncology care, impacting diagnosis and treatment (Scime, 2019). Sarah was mainly happy with the care she received from staff post-diagnosis, so it is difficult to determine exactly why her experiences with staff pre-diagnosis were so difficult and if this is common for TNB patients. However, due to the direct link between stage of diagnosis and cancer survivorship, Sarah's experiences suggest the pre-diagnosis stage for TNB people with cancer may be an important topic in-itself to explore for future research.

Coordination of Care

Sarah lived on a boundary between two District Health Boards (DHBs), which often caused contestation around which district was actually in charge of her care. Sarah lived closer to one hospital; however, the other was larger with more extensive services. Depending on which service Sarah needed, she could be sent to either one. She was often unaware which hospital she would be sent to until the last minute and frequently had to phone different healthcare staff to find out what was happening with her treatment. Sarah described a situation where she was booked in for her cancer surgery, but there was no clarity about which hospital she was supposed to be attending.

> **Sarah**: We were two days out and didn't have anything, and nobody was getting a hold of us. But once again, that was a breakdown between the two DHBs. . . so, we had to do a lot of chasing around for that.

This quote highlights the breakdown of communication Sarah experienced regarding her care, both between the providers in charge of her care, and between the healthcare services and Sarah herself. Sarah also received chemotherapy late due to hospital miscommunication. Her chemotherapy was initially delayed due to Covid-19 lockdowns, but when the hospital opened again, no one contacted her about beginning treatment. Both hospitals had failed to communicate with each other and mistakenly thought the other was organising her treatment. Given the complexity of cancer care, it is common for patients to interact with multiple providers and services. Coordination of care is essential for patients to receive the proper treatment within the appropriate time frame. One of the most prominent barriers to coordination is poor communication between the healthcare team, which often leaves patients in the dark about their own care. This is further complicated by patients frequently not knowing who to call to get the necessary information (Walsh et al., 2010).

Failure to coordinate care for patients can significantly affect the provision of treatment. It also places a large burden on patients regarding the organisation of their care (Walsh et al., 2011). A pertinent issue with placing the burden of communication on patients, is that phone calls are where Sarah most often encounters instances of misgendering. Sarah explained that most staff in person always refer to her by her proper name and gender, but on the phone, she often faces pushback from staff about her identity. Sarah described calling one hospital to see if they knew why she had not received her chemotherapy treatment, and having the staff refuse to answer her questions because her voice did not match their perceptions about what she should sound like.

> **Sarah**: I tried ringing to find out what was happening, and they wouldn't talk to me, because I'm not me, because my voice is deep. So, they refused to deal with me, which made me upset.

This quote emphasises the frustration and distress Sarah experienced when she was denied necessary information about her care due to her voice. Sarah being turned away from the help she needed due to her voice, exposes an unconsidered aspect of TNB cancer service access. Having to search for answers about their care is already an unnecessary burden for sick cancer patients. However, phone calls also present additional complications for TNB people. Voice can be a significant aspect of gender presentation. Disconnect between a patient's voice and cisgender norms about what people should sound like, can expose TNB patients to instances of misgendering and discrimination (Zimman, 2018). Consequently, for Sarah, her identity was invalidated, and she could not access the necessary information about her care.

The breakdown of coordination around Sarah's cancer care reflects one of the major issues identified about the DHB system, namely the struggle to integrate care across different geographical boundaries and service providers (Goodyear-Smith & Ashton, 2019). This particular issue was likely exacerbated by the impact of the Covid-19 pandemic on the health system at the time of Sarah's treatment. Sarah's experiences also revealed an additional barrier to care coordination when the burden of communication was left to her. This barrier was specific to her identity as a TNB person, and reflected cisgender assumptions on behalf of staff who had not considered that TNB people may need access to their care.

"You Do It for The Ones Who are Going to be Following You".

Throughout her treatment, Sarah was conscious of the legacy she would leave behind as a patient. She was aware many oncology staff have not encountered trans patients before, which caused her to be mindful that her behaviour could reflect on the wider trans community. However, Sarah was also able to use her time in treatment as an opportunity to educate willing staff and make a difference for future trans patients.

Involuntary Representation

The patient/provider relationship is commonly thought to be mutually constructed (Nimmon & Stenford-Hayes, 2016). However, Sarah feels the role of the patient is often overlooked. Sarah noted that due to the history of mistreatment in medical care, many TNB people enter healthcare expecting negative interactions. Sarah explained that this can unintentionally contribute to a tense dynamic or cause TNB patients to be hesitant to speak up about their needs.

> **Sarah**: I learned that you have to advocate for yourself within the system. I think with trans people that's very hard for a lot of us because there's already a stigma around trans people, and there's so much past history where we've been treated like crap that a lot of trans people, they're gun shy. Or they've heard a lot of horror stories, so they're already frightened before they walk in the door, which puts them on the defensive.

This quote highlights Sarah's view regarding how TNB people may be more primed to interact defensively or reactively with cancer care providers. One reason this may be an issue is that due to the lack of external education, many staff rely on experiences with TNB individuals as their guide for TNB appropriate care. Thus, TNB patients can be involuntarily burdened with being representative of wider communities, and negatively perceived interactions between providers and TNB patients can affect other TNB patients' care. Sarah recounted a lung function test where her test results were skewed due to a technician's past experience with a trans patient. Sarah had been incorrectly tested against the spectrum for people assigned female at birth, causing tests to say her lungs were fine when she actually had difficulty breathing. Sarah noticed the mistake and asked the technician why she was not measured on the correct spectrum. She learned that this technician had a previous experience with a trans woman, who became upset and angered upon seeing the technician enter their sex information as male for the test, assuming malicious intent. This interaction made the technician hesitant to repeat the same actions, leading to her entering Sarah's information incorrectly to avoid upset. Sarah pointed out the implications this decision had for all following TNB patients.

> **Sarah**: I don't know how many other trans people between that woman and me she's seen, but she's done every one of them incorrectly because of it.

Sarah's quote shows the consequences of having no systems that consider the needs of TNB people. It was not necessarily wrong that this other trans woman was upset at how her information was entered for this test. A larger problem is that this technician had no interpersonal training, or technical ability with the test's design, to perform this test in a way that would have made their patient comfortable. Improving education and system procedures to consider the existence of TNB people, would relieve the need for TNB patients to perform as patient exemplars and improve the ability of staff to provide appropriate care.

Sarah also used this example to highlight why she likes to approach staff from a place of understanding and education. Sarah felt staff often come from a good place but are usually limited by experience or technical limitations. She felt the majority of staff she interacted with were caring and helpful, even if they lacked TNB care knowledge. She acknowledged it is often difficult not to assume the worst of healthcare staff due to personal and community history, and that some staff are obviously just discriminatory, but explained that her community needs to be more conscious of how they interact with staff.

> **Sarah**: As a community we also need to be looking inwardly at ourselves about how we treat the people that are going to be treating us. If someone gives you shit, fine dish it back, I've got no problem with

> that. But also, you know, don't be the person to actually dish it first, I think.

This comment shows how Sarah situates her approach to staff within a wider conversation about provider and TNB patient interactions. It appears Sarah picked up on an implicit narrative about TNB patient-provider relationships, where TNB patients must present as respectable TNB patients for the good of the community. Sarah seems to have established this narrative through her own experiences, and through hearing about other TNB people who were not so conscious in their approach to staff, and the negative consequences these instances had. Thus, Sarah feels this narrative should be communicated to other TNB patients in order to help improve wider patient-provider interactions and TNB healthcare. Sarah also internalised this narrative as part of her own approach, as she seemed to feel a certain level of responsibility to take on a more accommodating and understanding approach, in order to ensure quality care for following TNB patients. This brings up an interesting aspect of TNB cancer care, where TNB patients may face more pressure than cisgender patients to be seen by providers as responsible patients when accessing care.

Another interesting aspect brought up here, is that the line between an accepted level of self-advocacy and being perceived as a 'bad' patient is significantly reduced for TNB patients. Although the ways patients co-construct healthcare interactions are important to understand, it is also important to acknowledge that this relationship is unequal. Providers do hold a position of power through institutionally sanctioned medical authority and expertise, while patients are necessarily reliant on providers to give them access to the care they need (Nimmon & Stenford-Hayes, 2016). It can be a risk for patients to challenge a provider's authority as the care they need can be affected. 'Good' patients are thought to be polite, compliant, and knowledgeable, while 'bad' patients are difficult to care for and challenge medical authority. Those perceived as 'bad' patients are found to receive a lesser standard of care. (Kahlil, 2009; Sointu, 2017). With the cancer system structured to only consider cisgender patients, TNB people automatically present a challenge to providers' expectations and disrupt the typical power dynamic of the provider as the expert in care. Some providers have been found to enact interpersonal stigma and bias towards TNB people when this typical dynamic is challenged (Poteat et al., 2013). This places TNB people in a disadvantageous position within the patient-provider relationship. Not speaking up could mean not receiving proper care. However, being perceived as disruptive could also negatively impact care. The risk of being seen as disruptive not only impacts TNB patients themselves, but this can also affect the wider community due to issues with involuntary representation. Overall, Sarah's cautions about how TNB people must be conscious of their own actions during treatment, serves as a reminder of the interpersonal and structural pressures placed on TNB patients during cancer care.

Education and Advocacy

Sarah is very open to answering questions and educating staff in . . . "trans 101", as she calls it. Most staff Sarah talks to are receptive to these conversations. Sarah explained that it seems to her the lack of education for staff is more to do with shortage of opportunity, rather than lack of interest.

> **Sarah**: Every time I go to hospital, I end up having at least one or two conversations with people and teach them a lot of stuff as well. A lot of them are just curious because they've never actually met a trans person before.

Sarah's comment highlights the frequency she engages in these conversations, indicating both a receptiveness and a need for more education. A United states of America survey on oncologists' attitudes and knowledge regarding LGBTQ patients reflects similar findings (Schabath et al, 2019). Only 36.9% of oncologists interviewed reported feeling confident in their knowledge of trans specific health needs, signalling that education gaps still need to be addressed. This same study also reports that around 70% of oncologists interviewed were interested in receiving education on general LGBTQ healthcare needs, showing a willingness from oncology staff to learn (Schabath et al., 2019). Sarah sees that most staff are open to learning more, and that is promising because education is key in ensuring the provision of better care (Bond et al., 2021).

Sarah's efforts to educate staff follows a long tradition of leadership and activism within TNB communities. Sarah noted much of the improvement regarding TNB healthcare she's seen is due to the actions of previous TNB patients. However, it should be acknowledged that while some TNB people are naturally drawn to these positions, many acquire these roles out of necessity. The challenging circumstances many TNB people face often means activism is required in order to obtain even basic rights and needs. Particularly in healthcare, in the absence of formal help many TNB people have taken it upon themselves to make the necessary changes for their communities. In spaces such as healthcare, this activism can be essential for survival (Arnold-Renicker, 2020).

There is some contention in the wider literature around the circumstances of this activism. On one hand, many TNB people feel burdened with the expectation they should be educating people on trans issues. TNB people are often expected to engage in discussions about TNB issues for others' learning, which can often include extremely personal and emotional topics. In reality, it should not be required that people must explain or justify their identity in order to receive respect or proper care, particularly when the same is not expected of cisgender patients (Wagner et al., 2016). On the other hand, Sarah personally spoke quite positively about her experiences providing education and took pride in her ability to make a difference. It can also be said that some people feel a sense of agency and accomplishment from the ability to create change for themselves and their communities (Arnold-Renicker, 2020). In this way, Sarah was able to build on the legacy of those who had improved the system before her and show care for her community.

This contention around people's feelings towards TNB activism within healthcare highlights that the universality of TNB experience should not be assumed. There is a large distinction that should be noted in Sarah's experiences versus those who feel that having to educate healthcare staff is burdensome, which is the difference between voluntary and involuntary engagement. Sarah personally felt comfortable taking on the educator role, but this is not always the case. Particularly with cancer, this added responsibility can be unwarranted stress for patients during a time where people are overwhelmed with serious illness. Sarah's circumstances may also play a role in her more positive feelings about her educator role. Sarah was the oldest participant in the study and had been out as a trans person within healthcare longer than the other participants. Although she acknowledged work is still needed, Sarah had personally witnessed positive improvements over time for TNB health and had seen that change can be possible through action.

> **Sarah**: I mean it can be difficult within the system, and I'd like to think they're getting better. I mean, my DHB I know from when I first started till now, they have got better. A lot of that is because the trans people they've seen, they're speaking up for themselves as well.

This quote highlights how Sarah's personal experiences influenced her more positive feelings towards education and advocacy as a patient. Another aspect of Sarah's experience that may have facilitated her educator role, was her consistent support person throughout her treatment, as she had someone whom she was confident would be on her side. Positive social support is a protective factor for cancer patient wellbeing, particularly that provided through close relationships (Helgeson & Cohen, 1999). Sarah's position as an older New Zealand European woman may have also afforded her some relative privilege in her ability to take on the educator role. Even within TNB populations, there are those who are more likely to face pushback from staff when the knowledge and authority of a provider is challenged. For example, research shows that Māori patients often face bias within healthcare (Houkamau, 2016). Discourse from healthcare providers often frames Māori patients as 'non-compliant', particularly when they challenge doctors' normative western perceptions about appropriate care (Penney et al., 2011). This often leaves Māori TNB patients more at risk of being categorised as 'bad' patients when attempting to educate or self-advocate (Sointu, 2017). While Sarah was able to maintain an accepted level of self-advocacy, this may be harder to achieve for TNB patients facing other intersectional oppressions. Other TNB patients may not wish to engage in the same type of educator role as Sarah due to the increased risk it may present to their care.

Overall, Sarah's approach to staff tells us some important things. Firstly, Sarah's consciousness around involuntary representation aligns with previous findings that TNB people often contextualise their healthcare experiences within a big picture account. The wider picture of TNB discrimination and stigma within healthcare and society in general plays an important part in how TNB individuals situate and make sense of their experiences (Wagner et al., 2016). Secondly, the way Sarah connected her personal philosophy to her more positive experiences, suggests there may be strengths and protective factors that TNB patients can develop to support wellbeing during cancer. Some of Sarah's approach already mirrors strengths identified by cancer patients as beneficial to their wellbeing, such as the ability to make actionable change, finding value in their experience to help or educate others, and drawing on positive social relationships (Rotegård et al., 2012). There may be some issues to consider here. For example, promoting self-advocacy without addressing both the negative consequences of TNB self-advocacy and the wider structural issues. There may also be intersectional issues, as some TNB patients who are additionally stereotyped as a challenge to healthcare may experience more risk when engaging in advocacy or educator roles in their healthcare interactions. However, supporting a patient's strengths, capabilities, and personal resources is also crucial for improving health behaviours and upholding wellbeing during cancer. The majority of attention on the topic of TNB cancer care centres around negative experiences when this is not the totality of TNB experiences. Sarah's story shows that there are other aspects to the cancer care experience that are important to explore.

Chapter Four: Alim’s Story

This chapter discusses Alim’s story of cancer care. Alim (he/they) is an Asian trans man around 20-30 years old. Alim’s specific cancer diagnosis is not given for privacy, but for context their cancer was unrelated to any gender specific anatomy. The most significant element that shaped Alim’s experience of cancer care was his status as a migrant at the time of treatment. Alim’s experiences unearthed many underexplored barriers that people who are migrants/refugees/asylum seekers can experience accessing cancer care in Aotearoa. Other topics brought up in our conversation include considering TNB people in cancer care services and improving oncology knowledge regarding gender-affirming hormone use.

Considering Trans and Non-Binary People in Cancer Care

Early in our conversation, Alim expressed difficulty in completely linking their experience of cancer care to their experience of being a trans person. This disconnect was due to an amalgamation of factors. A major component was that Alim had not yet started their transition and was not as open about being trans at the time. Alim explained that most issues related to being trans occurred in follow-up treatment, after he started his transition journey.

> **Alim**: It’s kind of like cancer care itself is actually quite straightforward. It’s the wrap around care and the after, I don’t know, the follow up that got really difficult for me around trans stuff. Because of how I started transitioning afterwards.

This comment displays that Alim felt that his gender was not a prominent aspect of his direct experience with treatment, particularly as their specific cancer and cancer treatment were unrelated to gender. This feeling of unrelatedness contributed to Alim not bringing up their TNB identity to staff. He explained that he felt it was not really necessary to bring up his identity and add additional stress to his situation.

> **Alim**: I just felt like there was already a lot of things to address, I didn't want to add even more to it. I just felt like it was a lot already. I was already getting a lot of attention and I didn't feel like I could do more.

This quote highlights Alim's feelings that disclosure of identity would not necessarily have made things easier for them in terms of dealing with his cancer treatment at that time. Just trying to survive their illness took precedence over everything else. What also stands out is the overwhelming and draining nature of cancer treatment. His treatment involved undergoing surgery almost immediately after discovering his diagnosis, and then undergoing chemotherapy. Alim also described not really being in an emotional or physical state to have additional conversations with staff about their gender, on top of everything else they were going through.

Although Alim felt disclosing his identity to staff was not really something he was comfortable doing at that time, there are still some instances where simple considerations for TNB people would have improved his experience. Alim expressed feeling uncomfortable in situations such as when they were assigned female designated hospital garments, gender specific support services, and when they were misgendered by staff. At one point, they mentioned to their oncologist they might be trans, but this was brushed aside by the oncologist and not really acknowledged. Alim never felt comfortable pushing back against these instances. Another element to this was Alim's migrant background. Coming from an environment that was more conservative and not as accepting of TNB people, Alim still felt some shyness and did not feel comfortable being out with staff. Alim was also alone during treatment and had no family in the country and relied on cancer support groups for social support during their treatment. He was first sorted into a support group that focused on feminine coded self-care, which made them feel uncomfortable rather than supported. They then found a non-gender specific group, which they found really supportive and helpful. However, even then, this group still commonly separated activities out by gender. In reference to their preferred cancer support group, Alim comments that just some basic awareness around TNB people potentially needing their services would have improved his experience further.

> **Alim**: It would be really good if they could be more conscious about it. Like no one asked me, oh do you have a preferred name or a preferred gender? Or like which group, like we have a gendered group, are you okay with going to this gendered group? Things like that.

This quote highlights how even small acts of consideration for TNB patients could make a large difference. The discomfort Alim experienced was not due to a single large instance they could necessarily point to, but rather a series of small careless moments on behalf of cancer staff and services, such as cisgendered assumptions and the assignment of gender segregated services. A significant element to Alim’s experiences here, and part of considering TNB people in cancer care, is that TNB people should be comfortable accessing services without having to come out to staff and request consideration for their existence. Accounting for the presence of TNB people should be something already within the structure of cancer care itself. Alpert and colleagues (2021) found that similarly their TNB participants preferred the concept of ‘inclusiveness’ over the concept of ‘accommodation’ in cancer care. To aim only for accommodation merely furthers the othering of TNB patients and fails to challenge why accommodation is necessary in the first place. Truly inclusive healthcare would have the needs of trans people considered from the beginning as a normalised aspect of healthcare, not treated as an anomaly or ‘add on’ requirement that needs reacting to. To act otherwise only implies that cancer care spaces have to know that a TNB person is present for TNB people to be respected within that space (Alpert et al., 2021).

As we can see from Alim’s story, there are many reasons why someone may not be in a position to discuss their gender during cancer treatment, or why someone might feel that their TNB identity is not always something that is relevant to the treatment they are receiving, particularly when their cancer care and treatment have nothing at all to do with gender. Ensuring some consideration of TNB people within these spaces may have reduced the instances of discomfort Alim experienced, without him having to disclose his identity and ask for accommodation.

The Acceptable Standard of Health

Being a migrant was an extremely significant aspect shaping Alim's experiences of cancer care. Alim explained that the regulations around healthcare for migrants produced many struggles throughout most of his cancer care journey.

> **Alim**: I am a migrant as well, and that kind of affected the whole cancer and trans experience as well. Mostly because of the eligibility to public health and certain things. Um, and problems with immigration and stuff. There's a huge thing in the immigration policy called the Acceptable Standard of Health, that if you do not meet that they will cancel your visa and kick you out of the country pretty much. Pretty much throughout the entire time I was having problems with immigration because of the cancer, and also because of being trans.

Alim's comment highlights the extent to which their fear of repercussions from the immigration department amplified stress around their cancer treatment and disclosing their trans identity.

Most visa applications for immigration to Aotearoa are required to meet the Acceptable Standard of Health (ASH) regulations. Applicants must submit their health status and provide a medical certificate if intending to be in the country longer than twelve months. The purpose is to determine if applicants will cause 'strain' to the healthcare system. Immigration New Zealand is determining whether someone poses a risk to public health, presents a significant cost/burden to public health services, and if they can work/study if that is their visa's purpose (New Zealand Immigration, 2022). One way to fail the ASH is if someone has/had any illness or disability that is on their extensive list of banned health conditions. Another circumstance in which someone can fail even without a condition on the list, is if they require health services that will exceed NZ$81,000 within five years of their assessment, or if the current demand for that service is not being met (Lane Neave Immigration Lawyers, 2022). Essentially, those likely to fail ASH are typically migrants who require hospitalisation, home care, expensive medications, or disability services. Particularly affected by ASH are migrants with disabilities, health conditions, and health needs. Even some refugees/asylum seekers are subjected to ASH processes and TNB people can be affected by this policy as well (Kelly-Costello, 2022).

Importantly for Alim, the list of banned health conditions includes “malignancies of organs, skin, and haematopoietic tissue, including past history of, or currently under treatment” (Immigration New Zealand, 2021, A4.10.1 section). Malignancy is a medical term for the presence of cancerous cells. This meant that by accessing cancer care, Alim risked having his right to stay in the country revoked. For privacy, Alim did not go into specifics regarding his struggles with immigration services in determining whether he would be able to stay in the country and access necessary cancer care. However, they did make it clear that their experiences in dealing with this policy had a profoundly negative effect on their experience of cancer treatment.

It is possible for migrants to apply for a medical waiver if they have/had a condition on the banned list (although some conditions are non-waivable), in order to avoid visa cancellation. Applicants must justify why they should be able to stay in the country, so that immigration officials can “consider the circumstances of the applicant to decide whether they are compelling enough to justify allowing entry to, and/or a stay in New Zealand.” (Immigration New Zealand, 2018, B section). Considerations include ties to the country, degree of potential service cost, and whether that person’s contribution to the country is ‘significant’ enough to outweigh the cost (Immigration New Zealand, 2018). However, applying for/appealing a waiver is an extremely lengthy and exhausting process. It is also a huge financial burden, often requiring expensive immigration advisors and lawyers. Many applicants become stuck on particular visa arrangements during this time, limiting what they can do, for example, not being able to work for extended periods (Kelly-Costello, 2022).

The entire process of ASH is likely to negatively impact people's mental and physical health. The distress people experience waiting for results that determine significant life circumstances, cannot be underestimated (Kelly-Costello, 2022). Additionally, migrants/refugees/asylum seekers can experience significant stress from the fear of authorities discovering their health status and revoking residency, which can act as a barrier to healthcare access (Kelly-Costello, 2022; World Health Organisation, 2023b). This leads to abysmal conditions for patients fighting cancer. Patients are likely to experience constant stress and may postpone or avoid treatment, delaying diagnosis and reducing chances of survival. Even if migrants are able to access treatment, many are not in the position to rest or recover when their visa conditions necessitate they must continue to work or study to maintain visa eligibility. For example, one migrant undergoing cancer treatment was forced to continue full-time study throughout their treatment, due to their visa conditions being tied to their study. The conditions of being unable to properly rest and recover from their intense treatment, severely impacted their already ill-health at the time (Migrants Against the Acceptable Standard of Health, personal communication, December 2, 2022). In addition to this being awful conditions for cancer patients, this also undermines the universal right to the highest attainable standard of health (World Health Organisation, 2023a). The World Health Organisation (2023b) specifically states that as part of this right, migrants and refugees should have equitable access to quality health care, regardless of migration status. Yet, in practice the Acceptable Standard of health policy directly excludes migrants with disabilities, health needs, and TNB migrants from citizenship specifically because of their perceived healthcare needs, and consequently obstructing access to needed healthcare.

The Acceptable Standard of Health and Trans and Non-Binary Migrants

Alim also experienced fears around the ASH due to his identity as a trans person. Alim had heard of other TNB migrants having their visas denied/revoked due to presumptions about TNB people needing expensive healthcare. Although not on the published list of banned health conditions, the cost of gender-affirming treatment, and surgeries in particular, places TNB people at risk of exceeding the ASH price limit for required services (RainbowPath, personal communication, October 21, 2022). Alim explained this was another significant reason why he was uncomfortable disclosing his identity as a trans person to cancer care staff.

> **Alim**: They [immigration] assume that you will want the most expensive treatment, the most expensive surgery for transgender healthcare, regardless of if you actually want it or not. And then they deem you are causing a really high cost on the health system and that you are not meeting the ASH, and then they will cancel your visa and kick you out. So, that has happened to a lot of transgender migrants, they unexpectedly get kicked out because of being trans related. . . . and because of that I was really scared of being found out.

This statement shows that the stress Alim experienced around the precarity of his cancer care access as a migrant, was further heightened by the way TNB people are additionally discriminated against under the ASH policy. There is evidence of TNB people being targeted by the ASH policy. A report by the organisation Migrants Against the Acceptable Standard of Health (MAASH) to the United Nations Committee on the Rights of Persons with Disabilities, details how the ASH policy directly discriminates against migrants on disability and health grounds. The report also states that TNB migrants are also often made to undertake the ASH process, due to the assumption that they will need expensive gender-affirming healthcare (Kelly-Costello, 2022). Not all TNB people are interested in surgeries or other gender-affirming healthcare. However, at the time Alim was receiving cancer treatment, there was some indication that immigration was operating under a blanket ban towards TNB people. Any evidence of inconsistent name or pronoun use in someone’s personal history could risk residency, regardless of any actual disclosure of TNB identity or wish to access gender-affirming healthcare (MAASH, personal communication, December 2, 2022). For Alim, this meant he felt he could not discuss anything to do with his identity with staff, as this posed a risk to his already precarious ability to stay in this country and access cancer care. The fear of discovery also contributed to the stress Alim experienced during his cancer and significantly disrupted his wellbeing and state of mind during treatment.

Currently, whether TNB people fail the ASH is determined on a case-by-case basis. However, TNB migrants must now prove to immigration that they do not need gender-affirming care, including seeing a specialist to obtain a letter of proof. Whether someone wants to access gender-affirming healthcare is a personal journey for each person to decide for themselves. However, this policy obviously places pressure on TNB people to say they do not want this care. Some TNB migrants do want to access gender-affirming healthcare but cannot access it without risk (MAASH, personal communication, December 2, 2022). There are current issues in Aotearoa regarding the provision of gender-affirming care. For surgical procedures in particular, there are quite significant issues with both funding and availability (Veale et al., 2019). However, needing access to gender-affirming care should not be a criterion for determining a person’s worth. TNB people in Aotearoa should have the right to access gender-affirming healthcare. Access to gender-affirming healthcare is integral to elevating the mental and physical health of TNB people. This is why the New Zealand Guidelines for Gender Affirming Health maintains that “withholding gender-affirming treatment is not considered a neutral option” (Oliphant et al., 2018, p.26), because to do so can cause significant personal distress.

In terms of cancer care in Aotearoa, migrants in general are likely to be undergoing additional stress, anxiety, and potentially financial burden. They may be fighting for their right to receive treatment or may be delaying treatment to avoid risk to resident status. The unique challenges TNB migrants face, such as fear of identity discovery, barriers to disclosing needs to staff, and additional issues with immigration on grounds of their TNB identity, only serves to further complicate the already adverse circumstances of oncology care for migrants. What has been exposed by the issues Alim highlighted, is that the intersection of TNB healthcare access and migrant healthcare access is incredibly important to consider for future conversations around improving TNB cancer care.

Citizen or Burden?

Regardless of citizenship status, everyone has the right to access healthcare as part of the universal human right to health (World Health Organisation, 2023a). However, in practice, the current healthcare system in Aotearoa is struggling to achieve a balance between the stress of public health costs and maintaining adequate health rights for migrants. Despite public discourse extolling universal rights, often implicit moral considerations exist regarding who is 'deserving' of these limited resources, which still act to justify who exactly is included or excluded from these rights (Willen, 2012). These moral considerations are reflective of the surrounding societal context, particularly in this case, the current local political context of neoliberalism, and the neoliberal principle of individual responsibility. A significant aspect of neoliberal governance is the requirement of citizens to be independent, responsible individuals, who do not rely on the state for provision of their needs (Hache, 2007). Undesirable circumstances then, are framed as resulting from poor choices or irresponsible citizens, rather than a consequence of structural inequity or wider social context (Juhila & Raitakari, 2016).

Individual responsibility in this sense, is linked to ideas of material self-sufficiency and one's ability to contribute to economic life (Galvin, 2002). This has important implications for perceptions of health. Health is seen as a matter of individual responsibility which signifies someone who makes good choices (Hache, 2007). Health is also connected to the ability to perform as a responsible citizen and contribute to the economy. This framing affects those who are limited in their ability to work or economically contribute due to illness or disability. It also affects those who are stereotyped as needing extensive access to health services (such as TNB people), as they are perceived to be a 'burden' to society who 'drain' health resources (Harjunen, 2021). A migrant's fundamental rights and access to healthcare is connected to their ability to enter and stay in the country. The ability to stay in the country is then dependent on their perceived ability to perform this productive, responsible, 'good' citizenship (Oliveri, 2015). Those who are instead perceived as a negative cost to the country due to extensive healthcare needs, are directly oppositional to the perceived 'good' citizen. In this context, policies that use health status to determine citizenship exclusion are seen as justifiable governance (Burns, 2017).

It is also important to note that perceptions of value or productivity versus costs to society are often based on an assumed understanding of health and healthcare access that is “read from the body” (Harjunen, 2021, p.7). In an autoethnographic article, Pausè (2019) discusses their experience fighting Immigration New Zealand’s denial of their residency due to their body mass index. They relate this to their wider experiences of fat oppression and the perception of people with high body mass index as burdens who overly consume health resources. They draw connections between current neoliberal context and the hostile environment that people perceived to be a ‘drain’ encounter, and how this environment contributes to stigma against ‘othered’ bodies. Pausè (2019) feels that there is a common perception that citizenship is a concept that has no relation to personal bodies. However, their experiences show that this distance between citizenship and bodies is only true for those considered normative, “other bodies, including bodies of colour, bodies with disabilities, and fat bodies, have long been positioned as public concerns and sites of surveillance, legislation, and regulation” (Pausè, 2019, p.45). In many ways, these observations parallel the treatment of TNB people under ASH. Under the conditions of cisgenderism, in which people are expected to conform to cisgender body norms and those who deviate are penalised, gender-affirming healthcare is often framed as cosmetic, despite the immense evidence showcasing the importance of providing access to this care and proving its medical necessity (Coleman et al., 2022). The positioning of normative bodies as an implied condition of citizenship, sits alongside neoliberal notions of self-responsibility. Consequently, the framing of TNB care as a burden can be used as a justification to portray TNB people as ‘bad’ potential citizens and revoke their right to access healthcare.

This framing of citizenship under ASH ignores the value humans have beyond economic worth and discounts the immense knowledge, enrichment, skills, and strengths that people have to offer. What becomes overlooked is that migrants are not responsible for the issue of limited healthcare resources, rather, ensuring adequate funding for key social services, such as healthcare (including cancer care) would be a better step forward in maintaining adequate access for all (Kelly-Costello, 2022).

Administration Structure and Migrant Trans and Non-Binary Identity.

Proof of identity presents another barrier for TNB migrants/refugees/asylum seekers accessing cancer care. Cisgender assumptions around sex and gender are embedded in current medical administration practices, with gender variance and TNB identities often being overlooked in favour of simple binary understandings of sex and gender. Thus, health record systems are not usually set up to account for TNB patients (Albert & Delano, 2022). Consequently, TNB people who have a different name/gender marker than what may be on their current legal identification, may experience issues around patient identification and proof of identity in their medical records (Deutsch & Buchholz, 2015; Samuels, 2018). Migrants are particularly affected by this, as they cannot legally change their name or gender on Aotearoa government records without full residency (New Zealand Government, 2022b). Some DHBs and GP practices in Aotearoa will accept name changes in their database without a legal name change, however this is not consistent across services or districts. Alim was able to change his name with his local DHB, but their GP and other DHB referrals did not accept the change. He explained how this caused inconsistency in his records and contributed to many practical issues in accessing care.

> **Alim**: It would keep changing back and forth. Every time after I would change it at the DHB, they [GP practice] changed it back. And then when I would get referred to another DHB, they got really confused because they kept getting referrals from two different people.

This comment demonstrates Alim's difficulty trying to get his medical records to show their correct information. As a migrant, he did not have access to the process of legally changing his documentation. This was not only frustrating, but his inconsistent records also had serious implications for his care. At one point, their oncologist requested frequent blood tests to monitor Alim post-treatment. However, the oncologist never received their results, despite Alim undergoing the test. Their lab test forms were rejected as the label was inconsistent with the name on the blood sample. These issues were consistent across most services, including the pharmacy where he sometimes struggled to receive his necessary medication.

Another aspect to this issue is that Alim was often asked to provide proof of his identity in public reception areas. Reception staff would often question Alim's inconsistent records, asking him to explain this discrepancy and prove they were the same person. This process sometimes included staff reading this documentation out loud, including reading out his previous name. Deadnaming, or the use of a TNB person's legal or birth name they no longer associate with, is a common microaggression experienced by TNB people when accessing healthcare. Deadnaming can have a profoundly negative effect on TNB patients' experience, as it is an invalidation of identity and personhood. This can be a significant barrier to continuing care, as for some, the experience of deadnaming is not worth seeking treatment (Freeman & Stewart, 2018). Further complicating Alim's situation was that this broadcasting of personal information was not just an interaction between the patient and receptionist, but occurred in front of whomever was in the public reception room. Alim stated he wished that reception staff were equipped with some sort of privacy protocol, such as a private space to show personal documentation or share sensitive details.

> **Alim**: A lot of time I had to do it in a really busy reception area, and everyone could hear that I am saying that I am transgender. . .There was just no privacy, and sometimes the reception person was really rude. . . I just – it was quite scary for me.

This comment emphasises the distressing nature of having these conversations in public, and with staff who are unprepared and sometimes unsympathetic to this issue. In these situations, Alim felt forced to out themselves as both a trans person and as a migrant in front of staff and whomever was in the reception area. This was "scary" as they not only had to disclose personal information publicly, but due to the stigma that both TNB people and also migrants can face, these conversations made Alim vulnerable to judgement and discrimination from surrounding people. Disclosing personal information in public could also be an issue of safety. Research from the United Kingdom (Kang et al., 2019) finds that migrants, especially refugees/asylum seekers, also experience discrimination and stigma in the reception space. Particularly for refugees/asylum seekers, this can be an issue as they have to disclose all the above information and must also prove their refugee/asylum seeker status in public to gain eligibility for public health services (RainbowPath, personal communication, December 2, 2022).

Alim's experiences demonstrate that there are issues with current healthcare administration practices regarding how to properly account for TNB patients. For people who are migrants, there are additional barriers to consider. In particular, issues around ensuring the right to medical records that accurately reflect a TNB patient's name and gender when there is no access to legal name changes, and no reception protocols around privacy and proof of identity.

Health Provider Knowledge about Hormones and Cancer

Sometime after he finished chemotherapy, Alim took steps towards beginning hormone therapy. Alim's oncologist was concerned about his plans, due to his history of cancer. Alim discussed that although they felt their doctor was coming from a good place, it was difficult for them to have to justify their decisions to medical staff.

> **Alim**: It's unrelated, but my cancer doctors were a bit unsure about it. Like they were like, "Oh you should wait, it's known to increase the risk of cancer. Like you just got cancer, like why do you want to do that"? It would be great if I didn't have to explain that to them.

This comment highlights the judgement and scrutiny Alim felt from medical staff in relation to their decision to take gender-affirming hormones. This was particularly frustrating as their doctor seemed unsure about the actual links between hormone use and cancer risk. Many cancers are sex hormone-dependent, such as breast or prostate cancers, and there is some debate about the use of hormones and cancer risk. However, there is limited research regarding TNB populations and hormone use, and further comprehensive research is very much required (McFarlane et al., 2018). Most importantly, Alim's cancer was not sex-hormone dependent and was thus unrelated to the use of hormones. As such, their oncologist's concern about their hormone use appears to have been misplaced.

The staff at the clinic where Alim received his hormone therapy were also initially hesitant, but after learning Alim's cancer was not sex-hormone dependent, they gave the okay to go ahead with hormones. They were also able to answer his questions around what the concerns regarding hormone use are, which the oncologist was unable to do. It seems the clinic providing gender-affirming care had more up to date knowledge on the implications of cancer for TNB people, while the oncology department was further behind. Alim explains it would be helpful if cancer care providers also had more up to date knowledge about the use of hormones and cancer risk.

> **Alim**: Like more training for cancer doctors and the GPs, so that it's not being all put on me to think about, oh, am I gonna get more cancer when I should be thinking, am I ready to transition yet? Instead of thinking is this going to increase my cancer risk, like, do I want to sacrifice, do I want to risk my life for this? Just more accurate medical knowledge, that would be good.

This observation from Alim highlights how this gap in knowledge can negatively impact TNB cancer patients. Because their oncologist could not properly advise him on how their gender-affirming care could be coordinated with their cancer care, the burden mainly fell on Alim to figure out what steps they could safely take. This experience is consistent with existing literature, which reports TNB people often have to possess a higher level of health literacy than cisgender patients (Hostetter et al., 2022). This is due to the lack of training and education around TNB issues for providers, which often burdens TNB patients with having to educate staff in order to receive proper care (Bauer et al., 2009). Regarding cancer care, many oncologists are unprepared for answering concerns and helping TNB patients coordinate between their oncology and gender-affirming care (Squires et al., 2022). Having to educate providers is further complicated by the lack of quality TNB health information available. This means TNB patients often have to put a lot of effort into locating relevant information accurate to their healthcare needs (Hostetter et al., 2022). Additionally, the lack of comprehensive research around TNB cancer limits the extent of education available and knowledge that providers can accurately learn at present (McFarlane et al., 2018). Patient-centred cancer care should mean that providers can work alongside patients to find the best care pathway. Usually, providers should be able to present all available options and provide evidence-based information on the benefits and risks, so that patients can make informed decisions about which options are best for them (Kane et al., 2014). However, Alim's case supports existing research that TNB patients are particularly disadvantaged in this aspect of care, due to the lack of knowledge accessible for providers on TNB cancer issues. This knowledge gap means that it is particularly difficult for providers to properly coordinate between cancer care and gender-affirming care.

Chapter Five: Alex's Story

The following chapter explores Alex's narrative. Alex (they/them) is a Pākehā/Tauiwi non-binary person around 40-50 years old. Alex underwent cancer treatment relatively recently and was still in the midst of processing their experience when we met. However, they felt it was important to share their story to help others who might be experiencing something similar. Alex's story highlighted an important aspect of TNB cancer research that has received limited attention: the external pressures some TNB people face from friends, family, or intimate partners during treatment. This issue was not raised by Sarah or Alex, but for Alex this was their foremost concern.

Alex discovered their illness after noticing their breast was inflamed and painful. They contacted their GP, who referred them to their local breast clinic where Alex was diagnosed with breast cancer. Alex's specific circumstances with their tumour meant their treatment involved receiving chemotherapy first, and later undergoing surgery for tumour removal. The main conflict in Alex's story revolves around their cancer surgery decision. For breast cancer, depending on tumour size and stage, different options for surgery treatment can be available. The least invasive is a lumpectomy (sometimes known as breast conserving surgery/partial mastectomy), where only the tumour and minimal surrounding tissue is removed, preserving the breast shape. Another option is a mastectomy, the removal of all tissue from the breast. Breast reconstruction surgeries can be performed during or after a mastectomy to recreate the breast shape (Breast Cancer Foundation NZ, 2013).

Early in the process, Alex felt that a bilateral mastectomy (both breasts removed) without reconstruction was their best option. They felt that a mastectomy provided the best chance for removing their tumour and for preventing future cancer incidence. Removing only one breast would likely require reconstruction or other procedures to maintain symmetry, which would significantly increase surgery and recovery time; thus, a bilateral mastectomy was preferred. Further, Alex felt comfortable with the choice to stay 'flat', as non-reconstructed mastectomy bodies are colloquially called (La et al., 2019). However, Alex described feeling an intense internal hesitancy about articulating their surgery decision. Alex confessed they were concerned that others, particularly their partner, would assume they only wanted a bilateral mastectomy because they are non-binary, as an unintentional consequence would be a more androgynous body.

> **Alex**: I think the surgeon could see that that was what I really wanted to do, but I had such a hard time saying it. I think it was because subconsciously I knew my partner didn't support that decision.

This statement shows how Alex's internal fears and apprehensions around others' reactions to their surgery choice affected them throughout their treatment. Although Alex's partner knew of Alex's gender exploration before entering the relationship, Alex feared their partner was not truly comfortable seeing them as a non-binary person. Being confronted with potential mastectomy due to Alex's illness, brought these worries to the surface in an unexpected and sudden way. In the end, Alex went through with a bilateral mastectomy, although it took a while for them to feel comfortable enough to communicate this with staff. Unfortunately, Alex's fears were confirmed, and their decision resulted in the dissolution of the relationship soon after surgery. The stress of the relationship tensions leading up to the surgery, and the emotional withdrawal Alex experienced from their partner post-surgery, significantly affected Alex throughout their cancer journey.

Support Networks and Trans and Non-Binary Disclosure in Cancer Care

Alex's partner was present for most of their oncology and surgery appointments for support. However, while their partner's presence was in some respects comforting, it also complicated Alex's feelings about being fully open about their needs with staff, both in terms of their surgery decision, and also in terms of their gender. Alex already felt uncomfortable sharing that they are non-binary with staff. Knowing that talking about their gender could bring tension into their personal relationship, ultimately left Alex feeling any benefits from disclosure with staff, would not outweigh the potential interpersonal distress it may cause with their partner.

> **Alex**: Knowing his issues made it even harder for me to say anything in these appointments because I kind of felt like, well I’m going to have to deal with him, and I also potentially have to deal with the people who are trying to give me medical care.

Alex’s statement here highlights how their partner’s presence further complicated their already apprehensive thoughts around identity disclosure. Fears of experiencing stigma or substandard care from staff as a barrier to disclosing gender identity is well documented within TNB healthcare research (Kcomt et al., 2020; Paine, 2018). Less explored is how a patient’s extended network (such as friends, family, or partners) may also contribute to this disclosure barrier. We often think of support people as a purely positive presence in a patient’s cancer journey. However, Alex’s story indicates that for some TNB people, relationship dynamics within their support network may be more complicated, particularly when their cancer decisions impact gender embodiment. TNB people can experience condemnation or rejection from within their own relationships when those around them are unaccepting of their gender (Allen et al., 2022). It may be that many TNB people cannot disclose their needs to cancer staff if their accompanying person is unsupportive or unaware of their personal gender information. For some TNB people, disclosing gender information could cause the loss of the emotional, social, and practical support cancer patients usually rely on to cope with their illness (Margolies & Scout, 2013).

There is very limited exploration of how TNB people may experience complex support dynamics during cancer treatment. The closest example is young people seeking gender affirmation care. The New Zealand Guidelines for Gender-Affirming Healthcare (Oliphant et al., 2018), states routine practice should include at least one instance seeing the young person on their own. This is to provide an opportunity for patients to discuss their needs and desires without family members present, as some patients have complicated relationships with their families. This situation is not directly comparable, as identity disclosure is a routine part of seeking gender-affirming healthcare, whereas cancer providers are not necessarily aware of their patients' TNB identities. Nevertheless, these guidelines highlight that the presence of support people can be more complicated for TNB people in healthcare appointments than is generally acknowledged in conversations about cancer support.

Regarding intimate partners specifically, research on cisgender women's experiences of breast cancer explores how relationship dynamics can complicate a patient's cancer experience. Cancer is a significant life event, which naturally shifts relationship dynamics as people come to terms with their loved ones experiencing serious illness. While some cisgender women report feeling increased closeness with their partners after diagnosis, many others report their diagnosis caused relationship strain (Sprung et al., 2011). This strain can result from feelings of loss and anxiety, shifting relationship roles, and changes in physical body (Ussher et al., 2011). A patient's ability to cope with their diagnosis is connected to the quality of the emotional and practical support available. Thus, when significant relationship distress is present, a patient's cancer outcomes and overall quality of life can be severely impacted (Valente et al., 2021). However, relationship distress commonly goes unnoticed by providers, being referred to as a patient's 'silent suffering.' As such, research suggests that identification and response protocols for potential couple distress may be significant for quality of life during cancer treatment (Sprung et al., 2011). This research is limited however, as these relationships are only explored through a cisheteronormative and intimate partner exclusive lens. Thus, TNB specific issues remain largely unexplored.

Not disclosing identity and needs has been linked to worse cancer health outcomes for general LGBTQI+ populations (Kamen et al., 2015b). Although it is naive to assume that identity disclosure is always beneficial, since disclosure can lead to very real negative consequences for TNB people, it is conceivable that distress from issues being misgendered or feeling limited in surgery decisions could impact wellbeing during treatment. Alex's story highlights that support network dynamics are something that needs more consideration in conversations about ensuring TNB people are able to discuss their needs regarding cancer care. Although this issue and how to address it likely needs further exploration, it would be helpful for providers to be aware that these potential complications beyond the patient exist.

Support During Cancer

Throughout our conversation, Alex mentioned feeling isolated and lonely during treatment. Alex came to an interesting insight as they began to talk through the different forms of support they had. Alex did talk to friends about their cancer. However, the person Alex expected to rely upon the most, was not there for them how they anticipated.

> **Alex**: I felt very lonely throughout this process. Even though I had friends that I saw, and my partner was there, the decisions really boiled down to me. And that felt like a really lonely place to be.

Alex's comment highlights how the lack of support from their partner at such a crucial time affected them significantly during their treatment. Although Alex had some forms of support, they felt alone when it came to the tough decisions about their cancer surgery, contributing to a sense of isolation. Alex acknowledged that their partner did provide some forms of support. They were present at appointments and provided physical care when Alex was sick from treatment. However, Alex explained that emotional support remained a critical missing element.

> **Alex**: He fed me, he looked after me, he – I thought he was emotionally supporting me. But then after surgery, it was like he reached the end of his capacity to even pretend that he could handle my decision or support me in my surgery decision. And that was when our relationship just really fell apart. But um yeah, I would definitely say his expectations, or his lack of ability to support me in my decision, even though that was what he said that was what he was doing, yeah that had a huge effect on me.

This comment highlights the importance of emotional support specifically when dealing with cancer. Emotional support involves receiving support, care, communication, and reassurance from loved ones, and is usually critical when experiencing distressing life events such as cancer (Leung et al., 2014). Social processing, which involves talking through cancer related thoughts and feelings with loved ones, is also a critical dimension of emotional support during cancer. However, experiencing social constraint, or the restriction or modification of thoughts, feeling, and actions to avoid negative responses from others, can invalidate potential benefits of social processing (Lepore & Revenson, 2007). Patients who experience distance, denial, criticism, or negativity when disclosing cancer-related feelings, generally have worse emotional wellbeing during cancer (Lepore & Revenson, 2007; Schmidt & Andrykowski, 2004). Alex clearly experienced social constraints in their relationship with their partner. Fearing a negative response, they were hesitant and unable to fully voice their feelings about their surgery.

Alex’s case indicates that potentially, TNB cancer patients may have a unique risk of social constraint and barriers to receiving emotional support from loved ones, particularly when their cancer has implications for gender embodiment. Although more research is still needed, one Australian study (Ussher et al., 2022) similarly found that low levels of support was a unique predictor of distress for LGBTQI+ cancer patients. Additionally, they found that TNB people report lower access to support during cancer, even compared to other LGB populations. Ultimately, responding to these issues will require furthering the awareness within cancer providers and support services of the various situations TNB people may face regarding support networks. Correspondingly, for TNB patients suffering from low social support, it may be important to facilitate access to external support services (Power et al., 2022).

One way Alex was able to combat feelings of loneliness was by connecting with breast cancer communities online. Alex was unable to attend a physical cancer support group as they found the meeting times unsuitable. However, they did find comfort and support in an online breast cancer forum. Specifically, Alex discussed how helpful it was to read accounts of people who had gone through similar experiences.

> **Alex**: That was a really important part of keeping myself sane during the experience, just being able to read what other people were going though.

This remark demonstrates how instrumental it was for Alex to find support from this external source. It also seems for Alex, the forum being breast cancer specific was also a huge benefit. When discussing the in-person Cancer Society support group they considered attending, they mentioned this service did not provide support groups for specific cancers. From Alex's tone, I felt they perceived this to be a drawback. Research into online breast cancer support groups found many patients are keen for advice and support specifically from others with similar experiences (Sillence, 2013). Connecting to others and sharing experiences is beneficial for reducing feelings of isolation and loneliness. Finding that their struggles are shared by others and hearing how others coped with illness, can help patients feel less alone and more hopeful about maintaining a good quality of life (Vilhauer, 2009).

Alex also explained that reading other's stories also helped them learn more about what they can expect from a breast cancer surgery. Additionally, this helped them feel supported in their choice and feel more confident about advocating for their surgery decision. Alex specifically explained that reading other's experiences with their partners after a bilateral mastectomy, helped them realise they were not abnormal for expecting more support from their partner.

> **Alex**: I know that other people's partners don't have reactions like this, because I've read about them online in breast cancer forums. I know that there are partners out there who don't care about if their partners have breasts whether they're male, or female, or other genders. I think I

> had an unfortunate way of finding out that he couldn't accept me for who I am through this.

Alex's comment shows how important it was for them to experience validation for their surgery decision. This shows that a significant aspect of this external support's helpfulness was the relatability of experience. Whilst Alex found their support online, they also mentioned that they would have liked an in-person support group that was breast cancer specific for this reason. However, although Alex did not bring up this issue themselves, it should be noted that many TNB people accessing formal in-person cancer support groups tend to find them unwelcoming towards TNB people (Taylor & Bryson, 2016). Additionally, cancer support groups can struggle to recognise important issues that specifically relate to TNB experience, such as how treatment can affect gender embodiment (Ussher et al., 2022). At this time, there is no data evaluating whether cancer support groups in Aotearoa are TNB inclusive. However, due to the findings in the international literature, in addition to how significant the relatability of experience was for Alex's external support, it may be important to consider if cancer support services are accessible and inclusive for TNB people.

Something important to note regarding external support, is that Alex's treatment partly took place during a Covid-19 lockdown. This meant that their feelings of isolation may have been exacerbated by the limited in-person interactions due to lockdowns (Edge et al., 2021). Lockdowns would have also meant in-person support groups unavailable even if Alex were able to attend. These circumstances may have intensified feelings of isolation during Alex's cancer treatment.

Cisnormativity and Breast Cancer

The heart of the issue Alex experienced while receiving cancer care was the scrutiny they faced around their surgery decision. A bilateral mastectomy did not alter Alex as a person, only their physical appearance. However, as this specific anatomy is assigned as essential for normative gender presentation, this surgery places Alex's body outside of accepted societal binary gender norms. Breasts are strongly ascribed with social meaning. Although dominant understandings of the difference between ‘sex’ and ‘gender’ have improved over time, it is still common for gender to be conflated as dependent or resulting from sex characteristics. Breasts, being anatomically a secondary sex characteristic, exemplify this conflation between anatomy and gender, as they are significant signifiers of womanhood and femininity (La et al., 2019). Thus, bodily deviations from these norms, even if they are a result from unavoidable medical intervention, can elicit rejection or critique from others. This stigma and scrutiny TNB people may face around their surgery decisions are upheld by underlying cisnormative beliefs about ‘right’ and ‘wrong’ ways to embody gender (Sledge, 2019; Taylor & Bryson, 2016).

Alex’s experience highlights how the community around cancer patients can also contribute to scrutiny and critique TNB people may face regarding their treatment decisions. The literature largely focuses on how the actions and opinions of medical providers affect patients, and obviously this topic is critical in conversations about TNB cancer care. However, Alex’s story shows the reactions of others in a patient’s life also impacts experiences in relation to cisnormative expectations in cancer care. Alex particularly noted that their partner’s issues with their surgery decision was the most influential factor in their cancer experience.

> **Alex**: There’s plenty of women out there who make this decision who are straight and cisgender. I kind of feel like, If I hadn’t been dealing with my partner and his feelings about things, I probably wouldn’t have had a lot of the issues I did around this with regard to gender.

This comment highlights how significantly Alex was affected by their partner’s issues with their surgery. Alex had no internal struggle accepting a bilateral mastectomy as their best option. In fact, although they had never seriously considered any gender-affirming surgery before diagnosis, Alex stated their mastectomy did help them feel more comfortable with their body, although this is something that they are still processing for themselves. This experience is not uncommon for genderqueer or non-binary breast cancer patients who opt for mastectomy without reconstruction (Brown & McElroy, 2018). However, despite no internal struggle, their surgery decision still caused them strife throughout their treatment due to their partner's reactions.

Their partner's assumptions around why Alex might be choosing a bilateral mastectomy overlooked the very important context that their surgery was a medical necessity. Any other surgery option meant Alex would have to endure follow-up mammograms, close monitoring, and prolonged medications and treatments. Alex explained a major reason for their decision was that it allowed them to move forward in their life beyond cancer.

> **Alex**: My main goal was to get as much of the cancer machine out of my life as possible. I just did not want to deal with all of that stuff, and I didn't want the anxiety and all of that. And it just seems mad to me that, I don't know, he couldn't empathise or understand that those things to me were far more important. Like the gender thing just kind of meant that, actually this kind of thing is probably less difficult for me than it would be for a lot of people. But that was just a footnote to me to the whole thing, rather than being what it was all about.

Alex's comment shows how the gendered aspect was the most scrutinised and focused on element of their surgery. This was distressing as it led to their true reasoning being dismissed. Alex's story highlights that even people close to TNB patients may carry these underlying cisnormative beliefs, which can cause conflict when TNB people are faced with surgical decisions that could affect gender presentation.

The persisting association of breasts as signifiers of womanhood is reflected in clinical settings, where the 'cosmetic crisis' of breast cancer often overshadows important medical aspects of dealing with this serious illness. A significant portion of breast cancer research is dedicated to understanding the psychosocial impact of breast cancer on cisgender women’s feelings of femininity, attractiveness, and sexuality, with reconstruction framed as necessary to quality of life (Bryson et al., 2020). The true path to wellness for breast cancer is often presented as becoming ‘whole’ again and reconnecting with the ‘feminine’ self that is thought to be lost during this illness (La et al., 2019).

Research into TNB people’s experiences of cancer reveals TNB people often face challenges in surgical care due to wider cisnormative gender expectations. There are many stories of patients fighting to have surgeons agree to perform a mastectomy. In two separate studies, patients reported receiving a psychological referral for choosing to stay flat. Having breasts is seen as an ‘essential’ element of embodying a feminine perceived body, thus those who do not comply with this narrative are thought to be misguided and are assumed to likely regret their decision (Sledge, 2019; Taylor & Bryson, 2016). An additional complication for TNB patients, is that some TNB people may experience increased scrutiny when their surgery carries a resemblance to gender affirmation procedures (Sledge, 2019; Taylor & Bryson, 2016). A large reason why some TNB patients may face more criticism for choosing a bilateral mastectomy, is that this surgery features many similarities to top surgery undertaken by some trans men and non-binary people to masculinise the chest area (Puckett et al., 2018). One breast cancer patient’s provider denied their choice of surgery option, as they assumed that they wanted a mastectomy as a ‘cheat’ for gender affirmation surgery. The patient was forced to argue that their choice was necessary for their cancer treatment in order to get their preferred treatment decision (Sledge, 2019).

Alex also experienced gendered assumptions in their encounter with their cancer surgeon. They recounted how their surgeon automatically assumed that they would prefer reconstruction or otherwise would prioritise options that preserve the breast shape. Alex explained that this contributed to their hesitation in communicating their decision to the surgeon.

> **Alex**: I think that because I felt like that was the assumption, and then with what I was dealing with at home, and of course the experience of chemo, that part of it was quite difficult.

This comment highlights the unintended consequences of unquestioned cisgender presumptions about preferred surgery. The surgeon's presumption only added to Alex's existing fears around their decision, leaving Alex to worry they would have to deal with a negative reaction from their surgeon, on top of the reaction from their partner, whilst also being emotionally and physically exhausted from treatment. Fortunately, Alex did not experience resistance from their surgeon after sharing their decision for a bilateral mastectomy. Alex even felt at some points their surgeon had guessed which option they wanted and was encouraging them to voice their decision. However, it still took a long time for Alex to feel comfortable enough to actually communicate their decision. Alex reflected that if the provider had presented all options neutrally from the beginning, they may have felt less hesitancy in voicing their decision.

> **Alex**: It was just assumed it would be mastectomy and reconstruction, or a lumpectomy and radiation, and potentially some kind of balancing surgery or something. But I think I would have felt more comfortable with the surgeon if there had not been that assumption.

Alex's comment here shows how the surgeon's assumptions served as an indicator to Alex that they could not trust their surgeon to respect their decision, even if the surgeon stated otherwise. Although Alex's surgeon was open to respecting their surgery choices, the surgeon's underlying assumptions interfered with their ability to reassure Alex they could provide their preferred surgery, and a critical chance to ease some of Alex's anxiety about their surgery decision was missed.

Overall, Alex's experiences show that cisnormative ideas about acceptable body presentation can cause unique challenges for TNB patients experiencing cancers that are strongly associated with a specific gender. This is particularly evident when cancer surgery is involved, and the possibility of non-normative body presentation arises. Reducing the assumptions within cancer surgery may help TNB patients feel more comfortable voicing their surgery needs and improve the patient-provider relationship. Additionally, examining the role of support networks in supporting or inhabiting patient issues around cancer surgery may be something significant to explore further.

“The Kind of Acceptance I Was Hoping For”

Alex discussed another encounter with a cancer care provider, which stood out to me as encapsulating something quite significant about the wider narrative of Alex’s experience. This encounter occurred during their final pre-operation appointment and involved their breast clinic nurse. Alex wanted one last conversation about their surgery in attempts to convince staff they made the right decision; they had some anxieties that they would face resistance for their decision all the way leading up to the surgery. Alex was preparing to recount all the reasons justifying their bilateral mastectomy, to ensure staff would respect their decision. However, the nurse stopped them, and reassured Alex that they trusted them to know what was best for their life.

> **Alex**: She said, “You don’t need to tell me”. I was already crying, but I just kept crying and she said, “We just want to know that you’re sure, and that’s enough”. And I suppose that was the kind of acceptance that I was also hoping for from my partner.

This excerpt shows that even simple validation around their surgery choice had an immense emotional impact for Alex. Alex faced a lack of support from their partner for their decision, constraint in expressing their feelings about their cancer treatment with both their partner and with staff, and scrutiny for their surgery decision from their partner throughout their treatment. What Alex needed during this time was acceptance for their decision, the trust that they knew best about their own body, and the reassurance they were making the right choice for themselves. The affirmation from this nurse that their surgery decision needed no justification was something Alex needed to hear. This nurse had no knowledge about Alex’s non-binary identity but could still tell this surgery was the right choice for them. The message the nurse was able to convey to Alex affirmed what they had been trying to communicate to their partner throughout their experience; that Alex was making a fully informed decision about what was right for them, and there was no medical reason why they should not have their chosen surgery. We can also see from contrasting this experience with Alex’s experience with the surgeon, that the way providers respond can make a huge difference to patients, even for something seemingly small such as an initial assumption about what a patient ‘should’ want to do with their body.

Chapter Six: Discussion and Conclusion

This thesis was undertaken to address the lack of information on trans and non-binary (TNB) people's experiences of cancer care in Aotearoa. Information regarding TNB people and cancer is limited generally, and little to no known research has been published specific to Aotearoa. The scarcity of information has meant that cancer care providers are limited in evidence-based guidance to refer to for treatment and care of TNB patients. Existing international research suggests that TNB people experience challenges in accessing cancer care and receiving care that meets their needs. Additionally, TNB people experience general healthcare inequalities in Aotearoa. These factors suggest that this was an important topic to explore. The research question for this study was, what are the experiences of trans and non-binary people during cancer care in Aotearoa? To answer this question, I interviewed three TNB people who had experienced cancer, who were over 18, and had experienced the cancer care system in Aotearoa within the last 10 years. Narrative case studies allowed for the complexity and diversity within the participants' experiences to be embraced and recognised.

Summary of Key Findings

This thesis provided new insight into the experiences of cancer care for TNB people in Aotearoa and highlighted some barriers TNB patients can face in receiving quality cancer care. The findings are laid out in three sections. Firstly, the issue of constraint on TNB people's agency is explored. Issues of constraint highlight how cisgenderism within health systems and wider society interrupts TNB patients' ability to define their own narrative of illness and move forward through cancer in ways that are personally meaningful. Secondly, the ways in which TNB patients find ways to maintain agency within cancer care is noted, as this provides significant insights into the experience of cancer care and where change for TNB patients may be needed. Lastly, this section will argue that the diversity of the participants' experiences was an important finding itself and explore what this means for TNB people's cancer care.

Constraining Agency

A cancer diagnosis is a major life event that often challenges people to re-evaluate existing self-narratives. Aspects of serious illness such as changes to the body, to agency, and to relationship dynamics, can present a stark new reality that people are forced to incorporate into understandings of their life and expectations for the future. Such changes can significantly impact emotional and psychological wellbeing (Mathieson & Stam, 1995). Part of maintaining wellbeing during cancer is enabling patients to make sense of their illness and find ways to move forward in a manner that is meaningful to them (Le Boutillier et al., 2019). However, individuals are always situated within a context that frames experience (Mathieson & Stam, 1995). This study found that for TNB cancer patients, cisgenderism within cancer care and wider society, can disrupt the ability to reconstruct their life in the face of cancer in ways that respects TNB identities.

The clearest example of a disruption to the sense of self, is Alex's experiences of cancer surgery. Alex's had a clear view of themselves and their optimal treatment plan. However, Alex suffered critique and scrutiny, as their decision conflicted with dominant understandings of what restoration looks like after experiencing breast cancer, and particularly after surgery. The dominant narrative around breast cancer frames this illness as a 'threat' to womanhood, and preserving the breast aesthetic is assumed to be a patient's priority in cancer surgery (La et al., 2019). This narrative was communicated to Alex by their surgeon through their initial assumption that Alex would prioritise breast preservation. Alex's understanding of their best surgery option was also challenged by their partner. Although Alex framed their decision of a bilateral mastectomy in terms of medical necessity, Alex's partner attributed their decision as a desire to further their non-binary identity, which was negatively perceived. This was particularly interesting, as it showed that cisgenderist assumptions from people in support networks can also have a significant impact on TNB patients' cancer experience, and act to constrain their ability to make decisions that best suit their needs.

In some ways, Alim also felt constrained in his ability to receive care that was considerate to his needs and identity. His account can be linked to the invisibility of TNB people within the cancer care structure. Although gender was not a salient part of his experience of cancer treatment, his comfort was impacted by cisgendered assumptions within cancer care and the threat of immigration issues. In most interactions, the possibility of TNB existence was unable to be expressed or was overlooked, and his identity was invalidated. This highlights the harm that can arise from simply interacting with a cisnormative structured care setting. Alim's case also highlights that not all TNB patients will want to disclose their gender to staff. This non-disclosure may be due to irrelevance to care, or due to the risk posed to personal safety and access to care, or a mixture of both. There is a narrative within healthcare research that disclosure of identity is somewhat necessary for providers to be able to provide TNB patient-centred care. The main argument of this narrative is that work needs to be done to ensure a safe environment for patients to disclose, in order to improve service delivery (Kamen et al., 2015b). Ensuring people can safely disclosure their identity is important, however Alim's case shows that consideration for TNB people accessing cancer care must extend to the structure of cancer care itself, and proper care should not be contingent on disclosure.

A lack of access to training and research for providers also impacted the ability to receive care that was supportive of the participants' needs and identities. Both Sarah and Alim spoke about needing to educate staff about TNB related issues in order to receive proper care. For example, Alim's oncologist lacked knowledge around the use of gender-affirming hormones and the actual risk it posed to his specific type of cancer. This meant that the oncologist was unable to properly work with Alim on how to coordinate their gender-affirming care and cancer care.

Patient-centred care should be responsive to patient values and needs. Part of this involves ensuring patient involvement in care decisions and respecting patient preferences (Health Navigator, 2023). When considering how to best provide patient-centred care to TNB cancer patients, wider inequities and the context of healthcare and health policy also need to be considered. We can explore this further by looking at the concept of agency, defined here as a person's capacity to exercise individual power (Ocloo et al., 2020). Cancer patients enact agency through making sense of, coping with, and making decisions about cancer and what it means for their life. Thus, enabling patient agency is part of being responsive to patient-centred care (O'Hair et al., 2003). However, agency is always enacted within social circumstances. Thus, patients can find that their agency to define their own narrative of their illness and their best path forward is constricted by wider socially constructed forces (Ocloo et al., 2020). We can see this in cancer care in the way that cisgenderist healthcare systems and the erasure of TNB people within health research, impacts TNB peoples agency through the way that it positions patients as automatically cisgender, and the way it constrains how patients position themselves (Hunter et al., 2015).

Maintaining Agency

In response to the healthcare system's failure to meet needs, participants developed personal strategies to have their requirements met and retain a sense of personal agency. Sarah provides a clear example of this. Her case highlighted how TNB people can be uniquely constrained within the patient-provider relationship, through involuntary representation and challenging providers' cisgender expectations. By taking on a role of educator/advocate, Sarah was able to obtain a sense of personal agency and mitigate some of these constrictions for her and future TNB patients' care. Sarah viewed issues in the provision of her care as something that could be changed, and she was able to improve the quality of her care and have her needs met (such as ensuring the right test results) through her approach. Sarah was also conscious of how being perceived as overly disruptive or rude in her approach towards staff could affect future trans patients. Thus, Sarah was careful to employ her advocacy in a way that did not compromise her tenuous position as a 'good' patient as a way to manage this risk.

Another example of maintaining agency was Alex's use of information and community seeking online, in response to a lack of support and acknowledgement regarding their surgery decision. Online sites and communities for breast cancer patients helped Alex by filling gaps in knowledge around bilateral mastectomies and how others had advocated for this surgery option. This also enabled them to feel more capable to advocate for themselves regarding their decision. Connecting with other people’s experiences of breast cancer and surgery also helped alleviate some of the gaps Alex experienced regarding support, both in terms of their personal support network and the lack of external support services available that related to their specific needs.

Alim’s case is particularly complicated in terms of maintaining agency. Alim’s ability to feel supported in his cancer care was impacted not just by how the healthcare system responds to TNB patients, but also by wider immigration policy that affected their healthcare access. One way that Alim could maintain a small amount of agency was through managing identity disclosure. Not disclosing his trans identity provided two important benefits during his initial cancer treatment. The first benefit was emotional protection. Alim was already dealing with a lot of overwhelming issues with just experiencing cancer, receiving treatment, dealing with immigration, and other life challenges. Choosing not to discuss gender with staff meant he could avoid unneeded stress and the risk of discrimination that could potentially come from identity disclosure. Secondly, due to the issue with Immigration New Zealand potentially targeting TNB people, not disclosing identity was also a form of protection in terms of maintaining his access to cancer care.

These three case studies highlight a range of barriers that TNB patients can experience while accessing cancer care. Whilst it is important to acknowledge that TNB patients are not passive in the face of receiving inadequate care, it is also important to acknowledge that the reason these strategies exist is because the current cancer care system is failing to support quality care for TNB people. Thus, highlighting where the participants had to work to maintain agency, provides direct insight into where TNB patients are undermined and where change is needed.

All the participants experienced constraint due to cisnormative restrictions in cancer care; however, there was variability in the participants’ ability to maintain agency in the face of constraint. Personal context and social positioning played an important role in the ability to maintain agency. This can be seen in the contrast between Sarah and Alim's response to the lack of TNB training/education for providers. Sarah as an older New Zealand European woman, who had been out as a trans person within the healthcare system in Aotearoa before, and had a strong support system, was able to take a larger role in pushing back when her agency was constrained by cisnormativity within the cancer care system. Alim's agency was much more limited by his circumstances. Alim was unfamiliar with the healthcare system in Aotearoa, had no social support, was still early on in their transition journey, and could also potentially face additional stigma in healthcare as a migrant and person of colour. On top of this, his actions were further controlled by external forces, as he could not discuss anything to do with his identity without placing their access to care at risk. Alex too, faced an additional level of constraint on top of what existed within cancer care itself, due to their circumstances with their partner. Overall, this variability in the participants' ability to maintain agency, speaks to the importance of context and intersectionality when considering the cancer experiences of TNB people.

Diversity of Experience

The diversity of the participants' experiences also presents an important finding in-itself. Whilst there are some clear commonalities across these patients' experiences, this research has highlighted that the experiences of TNB cancer patients are not homogenous. The clearest example of this is Alim's case, for whom being a migrant at the time of cancer care, presented an additional layer of complexity on top of the issues the other participants experienced. In the beginning stages of this research and from my preparatory readings of academic literature on this topic, I anticipated that the experiences of TNB cancer patients would differ from that of cisgender patients. What I did not anticipate was the extent in which the participants' experiences would vary between each other. This significant finding brought up the consideration that for some TNB people, the fundamental ability to access cancer care may be an issue that precedes concerns about the quality of cancer care. To subsume this experience in with the other participants, may have overlooked the weight and significance of this aspect of their cancer experience.

The diversity within these participants' experiences showed the necessity of an intersectional and contextualised lens when researching TNB issues. It became clear through the process of this research, how a person's unique identity, life experience, and position within interconnecting social systems, played a significant role in their experience of cancer care. Diversity and context are important values within the community psychology approach, particularly in the ways they support the overarching goal of social justice. There is clearly no one standardised experience of cancer for TNB people, and this variation in experiences has particularly important implications for cancer care, as a 'one size fits all' approach to quality TNB cancer care will not be suitable. To equitably support all TNB people receiving cancer care, there must be room for different TNB people's voices and experiences. An intersectional and contextualised lens can disrupt one-dimensional categorisations of TNB people's experience, through recognising how social context, and positionality within axes of intersecting systems of domination and marginalisation (such as cisnormativity, colonisation, heteronormativity, and neoliberal citizenship) differentially impact TNB people's experiences. To uphold an equitable social justice approach within TNB cancer care, these intersections need to be recognised and appropriately addressed, because to ignore these aspects would further silence and subordinate those most affected by intersecting axes of oppression and marginalisation (Bailey et al., 2019).

The interpretive qualitative approach for this research, enabled me to acknowledge the diversity of participants' experiences. Rather than seeking a single objective reality for TNB cancer patients, this approach allowed room to acknowledge that each participant had their own reality of cancer care unique to their circumstances (Delucio & Villicana, 2020). A qualitative interpretive method approach also enabled flexibility in finding the analysis method suited to this research, allowing me to determine that narrative case studies would provide the best fit. Through narrative case studies, the in-depth exploration of different individuals meant the nuanced differences within this group of participants could be addressed, even when important similarities in experience were present. Thus, through this approach, each participant's lifeworld, context, and positionality could be explored in a way that allowed varying axes of intersectionality within TNB experiences to be uncovered.

Suggestions for Trans and Non-Binary Cancer Care

The experiences of these participants strongly support the need for a patient-centred approach for TNB patients. Each TNB cancer patient will likely have diverse needs and individual patient circumstances, available support, and personal priorities will be different. It is also clear from this study, that wider issues of cisnormativity and gender binaries within cancer care act to constrain the implementation of patient-centred care for TNB patients. For TNB patients to be able to express their needs, and for providers to feel prepared to address these needs, a shift away from these cisnormative constraints within the wider structure of cancer care is needed. In addition, intersecting constraints affecting TNB agency and ability to receive patient-centred care (such as citizenship, ethnicity, socio-economic status, or otherwise) need to be considered in order to achieve equity for all TNB cancer patients. This aligns with PATHA's (2022) recommendation that person-centred care for TNB people, should consider diversity and uphold obligations under Te Tiriti o Waitangi, as part of supporting health equity for all TNB people in Aotearoa.

Much of what the participants identified as important for TNB care aligns with existing literature on this topic. Notably, the participants' cases suggest that even small modifications to cancer care settings could make a significant difference. Common recommendations include removing gender-based segregation in cancer care, providing gender neutral garments and bathrooms, and implementing processes that ensure correct names and gender are used across all medical encounters (Alpert et al., 2020; Griggs et al., 2017; PATHA, 2020). Including TNB people within information material for cancer patients, such as websites and brochures, is also an important suggested consideration (Kerr et al., 2019; Pratt-Chapman & Potter, 2019). Overall, health systems and services should be designed for TNB inclusion (PATHA, 2020). Changes to administration procedure particularly would have made a difference for the participants, specifically around privacy protocols, ensuring consistent names and gender across medical records and services, and addressing identity invalidation over phone calls. The participants felt that just dealing with their cancer was already a significant aspect of their experience. Furthering the consideration of TNB people in cancer care contexts, would have allowed the participants to focus their energy on dealing with illness, and overall improved their experience of cancer care.

Additionally, Alim's case brings up important considerations regarding the development of procedures for respecting TNB people's identities in cancer care. Migrants/refugees/asylum seekers are not able to access official name or gender changes on their identity documentation. As some health services only accept legal identity in their records, this creates an additional barrier for correct identity information being reflected in medical records and service systems. When considering how best to implement any further changes and expansion of services, it will likely be important to ensure that the benefits are accessible for all TNB patients.

A lack of knowledge and training for staff around TNB issues supports current recommendations for the development of TNB cultural safety guidelines and increasing access to TNB education for providers (Griggs et al., 2017; Kerr et al., 2019; PATHA, 2020). An interesting aspect of this study was that each participant had unique issues throughout the different subsections of the cancer care journey, related to a lack of staff knowledge/training. For example, there were issues with treatment by screening technicians, difficult interactions with reception staff, experiencing cisgendered assumptions in cancer surgery, oncologist knowledge about hormones and cancer risk, and TNB invisibility within cancer support services. These issues support existing critiques that cisgenderism and the invisibility of TNB people, is a pervasive problem throughout the structure of healthcare (Ansara, 2012). However, this also suggests that cisgenderism may play out in unique ways within each cancer care setting, which is something to consider in the development of TNB cultural safety guidelines within cancer care.

The experiences these participants discussed also provided insight into areas of cancer care which have not received much attention in the literature. Alex's case brings up interesting implications regarding support networks for TNB patients. Their experiences suggest some TNB patients may have more complicated dynamics with their support networks than is typically discussed, particularly when family or partners struggle with a patient's TNB identity. There is a need for further exploration of this issue within TNB cancer research. Additionally, improving providers' awareness of this issue may be pertinent, particularly as it may affect the ability to disclose care needs to staff, and suggests that access to external support services will be important for some TNB patients struggling with this issue.

Alim's experiences of being a migrant during cancer care brought up many underexplored issues. Researching this topic was particularly difficult due to the lack of academic literature. Alim personally felt it was important to discuss their experiences of cancer care, given that the voices of migrants/refugees/asylum seekers are missing from this topic. This is specifically because the issues discussed (being a TNB migrant or experiencing serious illness like cancer) place a migrant's residency status at risk. Most publicly available information on the Acceptable Standard of Health (ASH) comes from government websites outlining official policy regulations, and the personal impacts of such policies is largely invisible. Interaction with non-traditional information sources, such as news articles and personal communication with local migrant community organisations, was essential to obtain a more complete picture. This was a particular issue regarding the topic of migrants and the intersection of also being a TNB person, as there was very limited published information available on this topic at all. Alim's experiences show there are clearly barriers for migrants accessing cancer care. However, it is also clear that the issues brought up in this study are only the surface of what is known about this topic. The actual scope of the effect on migrant cancer patients, TNB migrants, and others impacted by ASH remains largely unexplored. Investigating these issues further will be difficult, as speaking to the people affected places them at risk. However, Alim's story shows that it remains critically important for TNB cancer care to consider the intersection of TNB people who are migrants at the time they are accessing care.

Directions for Future Research

There are many issues and questions that have arisen in the process of this research regarding TNB cancer care. Much of what the participants talked about could be extended upon and explored further in future research, including potential strengths and protective factors for TNB cancer patients, TNB inclusivity within in-person support groups, and how support people can inhibit or support TNB identity disclosure. One significant topic which requires further investigation, is the pre-diagnosis experiences of TNB people with cancer. Sarah's experiences of discrimination and substandard care in her pre-diagnostic care, suggested that there may be significant TNB specific barriers to cancer diagnosis, particularly for colorectal cancers. This is a particularly important issue to investigate and address further, due to the link between stage of diagnosis and cancer survivorship.

Additionally, there are aspects of the cancer care experience that were not able to be covered in this small study, for instance palliative care and experiences of preventative cancer screening. Further research could also address the perspective of oncologists and other cancer care staff who form the other side of the patient-provider relationship. Exploring providers' perceptions of TNB cancer care may generate useful insights regarding where gaps in knowledge exist, and for identifying potential barriers affecting cancer providers' ability to implement better care for TNB people.

Future directions could also include the incorporation of more large-scale research and information gathering regarding cancer and TNB populations within Aotearoa, and internationally. This could include furthering accurate recording of cancer incidence diagnosis, and survivorship rates among TNB populations. Additionally, quantitative research could be employed alongside further qualitative explorations of TNB people's cancer care experiences, to help to address the lack of a wider perspective regarding TNB cancer care. Further, it may also be useful to examine differences in experience between different types of cancer. For example, people interacting with cancers involving typically gendered body anatomy may have a different experience, due to gender being more salient to the experience of care. TNB patients who also have existing comorbidities (having another health condition in addition to cancer), may also have a different experience of cancer that could be considered in future cancer research.

Conclusion

Overall, this is a significantly under-researched topic, and further work is still needed to improve the knowledge around cancer and cancer care experiences in relation to TNB people. This study has shown the value of utilising a broader range of methods within psychology, particularly for attending to diversity within TNB people's experiences. Mainstream approaches to methods within psychology have typically valued the more generalisable and 'objective' approach of quantitative research. This research has shown that qualitative methods can also deliver equally valuable in-depth insights, which have particular use when considering the complexity of human experience (Delucio & Villicana, 2020). A particular benefit of the qualitative approach in this research, was the flexibility to discover new underexplored areas of interest on this topic. Within many quantitative methods, the researcher pre-determines much of what is expected to be important to investigate or measure (Murray, 2008). By utilising a less structured qualitative approach, the participants were able to steer the research to topics which I could not have predetermined, such as cisnormativity within support networks, the cancer experiences of TNB migrants, and discrimination as a barrier in the pre-diagnosis phase. This method allowed for new important insight into this topic to be obtained, and new areas of further inquiry to be opened.

Community psychology values acknowledging diversity and context in approaching social issues (Banyard & Millar, 1998), which presented an important lens for understanding the experiences of my participants. I wanted to find a methodological approach that could reflect this diversity and context. Even within qualitative methods, a more typical thematic qualitative approach, where the participants' experiences are subsumed into universal themes, may not have been able to capture this diversity. Narrative case studies enabled depth and variety within the experiences of participants to be respected. Thus, demonstrating the value of a narrative case study approach for exploring the specificities of experience, and creating more space for the lived experiences and agency of the participants to be included. Due to the importance of acknowledging diversity and context within even this small study, future research in this area could also find it useful to explore how to acknowledge and attend to the diversity of experiences within TNB populations within their methodological approaches.

To summarise, this research has contributed new insights into the topic of TNB cancer care in Aotearoa. The findings demonstrated that there are access and quality of care issues for TNB cancer patients. These inequities are related to broader structural inequity related to cisgenderism, where TNB identities are marginalised, pathologised, and erased within society. We can see this through the scarcity of information and research regarding cancer within TNB populations, the lack of training for providers, and the invisibility of considerations for TNB patients throughout the structure of cancer care itself. Improving the cancer patient experience for TNB people will require addressing the systemic issues and power relations that constrain TNB patients from attaining quality patient-centred care and constrain providers from providing quality care. To ensure that all TNB cancer patients can be supported throughout the cancer journey, from pre-diagnosis to follow-up treatment, consideration of intersectional structural inequities TNB people may experience is also needed.

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Appendices

Appendix A: Participant Consent Form

UNIVERSITY OF WAIKATO
DIVISION OF ARTS LAW, PSYCHOLOGY & SOCIAL SCIENCES
FACULTY OF ARTS & SOCIAL SCIENCES
PARTICIPANT CONSENT FORM

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, and that I can withdraw my participation at any time up to three weeks after the interview, or up to three weeks from receiving my transcript.

During the interview, I understand that I do not have to answer questions unless I am happy to talk about the topic. I can stop the interview at any time, and I can ask to have the recording device turned off at any time.

When I sign this consent form, I will retain ownership of my interview, but I give consent for the researcher to use the interview for the purposes of the research outlined in the Information Sheet.

I understand that my identity will remain confidential in the presentation of the research findings.

Please complete the following checklist. Tick the appropriate box for each point.	Yes	No
I wish to use a pseudonym. If yes, I would like to use the name: ____________________		*
I wish to receive a summary of the project's findings (provide email)		
I wish to bring a support person to my interview		
I am currently undergoing cancer treatment - Please provide support/emergency contact below if yes		

Participant :	____________________	Researcher :	____________________
Signature :	____________________	Signature :	____________________
Date :	____________________	Date :	____________________
Contact Details :	____________________	Contact Details :	____________________
Emergency /Support contact	____________________		____________________

*If you do not wish to choose your own pseudonym, one will be offered by the researcher in consultation by you. No pseudonym will be used without your permission.

Appendix B: Information Sheet

UNIVERSITY OF WAIKATO

Participant Information Sheet

You are invited to take part in a study on **Trans and non-binary people's experiences of cancer care in Aotearoa/New Zealand.** Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive.

This Participant Information Sheet will help you decide if you'd like to take part. I will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. You are also welcomed to bring a support person to the interview.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

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

Tēnā koe, my name is Keziah Brown. I am a postgraduate student with the University of Waikato undertaking this project for the requirement of my masters in community psychology.

This study explores trans and non-binary people's experiences of cancer care. Cancer is the largest cause of death in Aotearoa/New Zealand. A cancer diagnosis can be a life changing and emotionally distressing time for people and their loved ones. Current research proposes patient-centred care is recommended during this time. Patient-centred care means patients are treated with dignity, personal contexts are acknowledged and respected, and patients are empowered to be involved in the decisions about their own care. However, there is a lack of research into trans and non-binary people's experiences with cancer care in Aotearoa. The purpose of this study is to address this gap in knowledge and explore perspectives on what quality and patient-centred care for trans and non-binary communities might look like.

Who will benefit from this study?

Participants can benefit from this study by having their perspectives heard about this issue and by contributing to the knowledge base for improving services for future recipients of cancer care.

I am looking to talk with people who have had a diagnosis of cancer and have had experience with the cancer healthcare system in Aotearoa/New Zealand within the last 10 years. Preferably participants would not be in active treatment, in respect to not wishing to further burden people during this already difficult time. However, if you are currently in treatment and still wish to share your story, I will leave the option available for you to participate, but please be aware that if participation would negatively affect your mental or physical wellbeing, it may not be of benefit to you to commit to this study.

What does the study involve?

This study will involve participating in a semi-structured interview (approximately 60-90 minutes long) regarding your experiences of cancer care in Aotearoa/New Zealand. You will be sent a copy of your interview transcript and a small interview summary for you to review. You do not have to read and make amendments to the transcript if you do not wish to. You will receive a voucher at the value of $30 in compensation for your valuable insights. If after receiving your transcript, you would like the opportunity for a single follow-up interview to discuss anything further, I will leave this option available to you. You can do this through contacting me and we can arrange something further. This is entirely up to you; you do not have to request a follow-up interview if you do not wish to.

Are there any risks involved?

Discussing the subject of this research may be an emotional or experience for some.

I will ensure that you have the opportunity to take breaks or end the interview at any time if you need. You do not need to answer any questions you feel uncomfortable with.

You have the option to bring a support person to the interview with you if you feel this would be more comfortable. Support people must agree to sign a confidentiality agreement.

If you are currently undergoing any form of treatment for cancer, please be aware that participating in this study may cause you additional taxation or burden. If you are in treatment and still wish to participate, you will be asked to provide a person of contact for support or emergencies.

If you feel that participating in this topic choice will cause you to experience distress, or participation would be a significant burden on your heath, it may not be in your best interest to participate in the study.

What are your rights as a participant?

As a participant, you have the right to stop the interview at any time. You can also ask to have the recording device turned off at any time.

You also have the right to withdraw from the project for up to three weeks from receival of the interview transcript. You can do this by contacting myself as the principal researcher, or you can contact the supervisors for this project if you feel more comfortable. You do not have to provide any reason for withdrawal.

Likewise, if you have any concerns or complaints, please contact the supervisors for this project.

Will my information be identifiable?

Information will be anonymised, and all data collected will be privacy protected. Information that identifies you (e.g., your name, date of birth, or address) will be removed from any published information. Only the researcher and my supervisors will have access to your identifiable information.

You will have the opportunity to use your own pseudonym, or I can offer one with your approval. I may potentially use general identifying information (e.g., trans man, age 18-25) In order to give context to the information provided, but only if you feel comfortable sharing this information. Likewise, I may also ask for general information about your diagnoses, again this is totally up to you how much you are comfortable sharing. I will consult with you regarding how I best protect your confidentiality in this research, and you will get the chance to review your interview transcript.

What will happen with my information?

The information collected in this study will be used for completing a thesis that will be submitted to the University of Waikato. This thesis will be available on the Waikato University research commons, accessed through the Waikato University library website.

Participants can also request for a summary of the findings to be sent to them upon completion of the project if they wish. The project is intended to be completed in March 2023.

Security and storage of your information.

Your information is held on a password protected computer during the study. After the study it is transferred to a secure site at the University of Waikato where it is stored for a minimum of 5 years, then destroyed.

Where can I get more information about the study?

For more information about this study, please contact the primary researcher using the contact information provided below.

This research project has been approved by the Human Research Ethics Committee (Health) at the University of Waikato as HREC(Health)2022#13. Any questions or concerns about the ethical conduct of this research may be sent to the Secretary of the Committee, email humanethics@waikato.ac.nz, postal address, Human Research Ethics Committee (Health), University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240.

Contact Information

Primary Researcher

Keziah Brown

Email Kmem1@students.waikato.ac.nz

Supervisors

Dr Ottilie Stolte

Email ottilie@waikato.ac.nz

Dr Jaimie Veale

Email jveale@waikato.ac.nz

If you wish to seek additional support about any of the topics covered in this research:

OutLine is an all-ages rainbow mental health organisation providing support to the rainbow community, their friends, and their whānau. OutLine provides nationwide, free, and confidential support line and online chat service at 0800 OUTLINE and outline.org.nz/chat between 6pm and 9pm every evening, for people who want to speak to a trained volunteer from the rainbow community.

Appendix C: Support Person Confidentiality Agreement

UNIVERSITY OF WAIKATO
DIVISION OF ARTS LAW, PSYCHOLOGY & SOCIAL SCIENCES
FACULTY OF ARTS & SOCIAL SCIENCES

Support Person Confidentiality Agreement

This confidentiality agreement is for the support people of participants in the study **Trans and non-binary people's experiences of cancer care in Aotearoa/New Zealand.** During your role as a support person, you will be in a position to hear or see personal information. Whenever someone other than the researcher is accessing a participant's personal data, an appropriate Confidentiality Agreement is required. This is in order to protect that participants have the right to privacy and confidentiality. By signing this document, you are agreeing to keep any information provided by the participant or the researcher (written, verbal, or otherwise), obtained at any point during your participation confidential, and ensuring this information is not shared or discussed with anyone outside of the participant or researcher. The expectation being the supervisors for this project, who you can contact for any further concerns or questions regarding the interview. This also means that the identity of the participant you are supporting, must also remain confidential and is not to be revealed. If you need to take notes during your role as a support person (written or recorded), I will need to be aware of this, and any information you record is also part of the information you are agreeing to keep confidential.

☐ I understand that all the information provided during the course of the interview is confidential.

☐ I understand that the contents of the interview can only be discussed with the researchers or supervisors of this study.

☐ I give consent to be a support person in this study and agree to the conditions of this document.

Name	
Signature	
Date	
Researcher Signature	

Primary researcher
Keziah Brown Kmem1@students.waikato.ac.nz

Project Supervisors
Dr Ottilie Stolte ottilie@waikato.ac.nz
Dr Jaimie Veale jveale@waikato.ac.nz

Appendix D: Draft Interview Schedule/Topic guide

Personal introductions **-** Hi, thank you so much for agreeing to meet with me (explain a bit about myself e.g., my name is, I'm from here, what I do etc). Establish preferred pronouns.

Introduction and explanations about the research –

The goal of this study is to document the experiences of the trans and non-binary participants who have had cancer, in order to inform the care provided for these communities.

Explaining the interview process

I am interested to hear about your story with cancer care, however you want to tell it, in your own words.

This interview will be recorded for transcription purposes, is that alright with you?

Take some time to read through the info sheet with participants and sign the consent form.

The questions/the participants' narrative - This section will mostly be for the participant to share their story with some guidance on the topic.

- Can you tell me about your experience of cancer care?
- Potential prompt if necessary – "maybe we could start at the beginning of your experiences?"
- If you think back over your experiences, what is one situation or moment that particularly stood out to you?
- How do you view quality cancer care for trans and non-binary communities?

Potential prompts:

- What was your access to knowledge regarding your situation and how it might affect you specifically?
- Do you feel that you were given the opportunity to be involved in decisions about your care?
- Did you have any access to any support networks during this time?
- Are there any other experiences or matters you would like to share with me?

Concluding Statements

Thank you so much for sharing your story and taking the time to meet with me today. Just before we close this interview, we'll just cover the next steps that will be taken with this project and what might be expected of you from here.

Firstly, the information you provided today will be transcribed and any identifying information will be removed. This information will be used to inform a master's thesis on this topic that should be completed in early March of 2023.

You will be sent a copy of your interview transcript and a summary of the interview in case there is information you wish to be changed or removed. You do not have to read or edit your transcript if you do not wish. You will have up to three weeks from receiving the transcript to withdraw from the study if you wish. (Otherwise from the interview, if not reviewing transcripts). If after receiving your transcript or summary, you would like the opportunity for a single follow-up interview to discuss anything further, I will leave this option available to you. You can do this through contacting me and we can arrange something. This is entirely up to you; you do not have to request a follow-up interview if you do not wish to.

It would also be helpful for me to collect some basic demographic information from you (e.g., age, gender, diagnosis if yet unmentioned). This will be useful for me to give context to your accounts. It's up to you how much information you are comfortable sharing, even if that means you don't wish to share any information at all.

- *Discuss in consultation with participant the best way to protect any identifying information based on their specific circumstances*.

If you would like to contact me further about any questions or concerns, you can find some contact information on the bottom of your information sheet.