Lived Experiences of Cancer and the Impacts on Well-Being Among Adolescents in Aotearoa New Zealand

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Abstract

Although advancements in cancer treatment have improved adolescent survival rates worldwide, it is important to recognise that an active cancer journey presents diverse well-being impacts, both positive and negative. Well-being impacts from cancer for adolescents often differ to those for other age groups because adolescents face a unique dual crisis: managing a serious illness while simultaneously navigating a volatile developmental stage characterised by identity versus role confusion. Existing knowledge emphasises the physical outcomes and the survivorship stage of cancer and is largely generalised from international adolescent and young adult studies. Consequently, knowledge of adolescents' lived cancer experiences, particularly regarding the holistic well-being outcomes is largely unknown. Interestingly, despite multiple reports in Aotearoa New Zealand (hereafter Aotearoa) documenting poor cancer experiences, unsatisfactory care, and substantial unmet well-being needs among young adults, adolescents, in contrast, have received limited research attention. In recent years, calls have grown for Aotearoa research to better understand adolescents' cancer realities and their developmentally situated well-being needs. Those calls have motivated this study, which explored the lived experiences of adolescents with cancer in Aotearoa and examined how their well-being was affected. Seven adolescents aged 16–21 years with an active cancer diagnosis participated in a one-off, individual semistructured qualitative interview lasting approximately 45 minutes. Reflexive thematic analysis was used to analyse interviews, enabling the identification and interpretation of shared patterns of meaning surrounding cancer experiences and well-being impacts. Participants described persistent emotional instability alongside diminished self-confidence, appearance changes, and disconnection to pre-cancer identities. Social dynamics often shifted as peers withdrew or struggled to engage, whereas family relationships frequently emerged as a strong source of support. Many participants reported unavoidable existential questioning, reflecting on purpose and meaning in ways hitherto unfamiliar to them. Critically, adolescents' in-between positioning within the Aotearoa healthcare system left some feeling out of place and overlooked. As the first culturally grounded exploration of Aotearoa adolescents' cancer experiences and related well-being outcomes, the findings of this study offer nuanced insights that can inform the creation of developmentally attuned cancer care and supportive healthcare environments.

Keywords

Aotearoa New Zealand, cancer care, adolescent oncology, holistic well-being, lived experiences of cancer, qualitative developmental research

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Chapter One: Background and Context

The World Health Organization (WHO, 2021) reported cancer as a leading cause of death among adolescents in Western countries. This is due to the cancers that adolescents are most often diagnosed with being biologically aggressive, and detection is often late because of low clinician suspicion and symptoms being normalised as growing pains. Adolescents were the population of interest in this thesis, defined by their distinctive developmental stage, transitioning from childhood to early adulthood (National Academics of Sciences, Engineering, and Medicine [NASEM], 2020). When normative developmental challenges coincide with a cancer diagnosis, adolescents face a unique dual crisis that may affect their well-being (Cameron et al., 2021; NASEM, 2020).

Globally, advances in treatment technology have improved adolescents' five-year survival rate of cancer; however, this survival-focused and clinical orientation has come at a cost (Hughes et al., 2024). Cancer is likely to shape adolescents' development across social, emotional, and physical domains, but there has been sustained neglect of research examining adolescents' unique lived cancer experiences internationally (McLoone et al., 2021; Quinn et al., 2015). The scarce international literature indicates that adolescents with cancer frequently encounter age-inappropriate healthcare environments, unmet psychosocial needs, and limited access to developmentally appropriate support services (Drew et al., 2019), highlighting persistent gaps in knowledge and care that affect their well-being outcomes.

In Aotearoa New Zealand (hereafter Aotearoa), research has similarly prioritised biomedical outcomes (Marsh et al., 2024), with comparatively little qualitative attention directed towards understanding adolescent lived cancer realities and well-being outcomes within the country's cultural context. During cancer treatment, adolescents in Aotearoa may experience strained relationships, disrupted daily routines, altered self-perceptions, and delays in developmental milestones related to autonomy and independence (Ballantine et al., 2018). The intensity of cancer-related experiences and well-being outcomes for adolescents is likely greater than those experienced by children or adults, given that their heightened developmental instability and cognitive awareness is not supported by adult emotional regulation capacities (Fleming et al., 2022; Moss et al., 2019). Adolescent cancer experiences are further shaped by Aotearoa's unique cultural, environmental, and systematic contexts (Pettit et al., 2023), yet these influences, including developmental positioning, remain underexamined in cancer research.

This thesis addresses these gaps in knowledge by exploring adolescents' lived experiences of cancer, with particular attention to how these experiences impact their well-being within Aotearoa's cultural context. This introductory chapter establishes the study's theoretical and contextual foundation. The first section defines key terms within the Te Whare Tapa Whā framework (Durie, 1984) and the Meihana model (Pitama et al., 2007), two culturally grounded well-being frameworks from te ao (the Māori worldview), as well as the adolescent age range adopted for this research. The second section outlines the international and national epidemiology of adolescent cancer, highlighting incidence, mortality, and inequities in prognosis outcomes. Relevant developmental theories, including E. H. Erikson's (1950/1964) Stages of Development Theory (SDT), are introduced and explained in the third section, which also critiques their potential application to the present study. The fourth section traces a shift from a biomedical perspective to a more holistic, culturally informed lens guided by the Te Whare Tapa Whā and Meihana models of well-being, illustrating the cultural progression of how cancer-related outcomes are understood. In the fifth section, international and national social and cultural contexts are detailed, highlighting how these landscapes may shape adolescents' cancer experiences. The chapter concludes by outlining the present study, including its research aim, and objectives, and outlines the overall thesis structure.

Definitions Guiding the Research Scope

The key well-being domains of the Te Whare Tapa Whā and Meihana model that are included in the discussion of this study's findings are defined below for conceptual clarity regarding the research scope. By drawing on models developed within te ao Māori, this study's discussion will foreground a holistic and multidimensional understanding of well-being, while also attending to how healthcare spaces and service structures shape adolescents' cancer experiences in Aotearoa. This section concludes with a brief outline of the age range for adolescents adopted in this study, providing contextual and developmental clarity of this research population.

Social Well-Being

In this study, *social well-being* is defined as adolescents' perceptions of and meaning-making in their social worlds, encompassing relationships, interactions, daily lifestyle practices, social milestones, and sense of peer belonging. Examples of social well-being outcomes from cancer may include strengthened friendships, loss of autonomy, and lifestyle changes related to increased dependency on family.

As Juth (2016) observed, existing literature often defines social well-being through objective quantitative measures, such as frequency of interactions; however, this approach fails to account for relationship quality, perceptions of belonging (or not), and subjective network connections (e.g., sport teams) that may significantly shape adolescents' social well-being. To support a wider research scope, this study defines social well-being beyond numerical indicators, privileging adolescents' meaning-making, moving past restrictive, culturally assumed outcomes of reduced peer interactions or increased social isolation when navigating cancer (Drew et al., 2019). This broader definition ultimately acknowledges that adolescents' dynamic, developmentally situated social norms—such as peer belonging and social agency—might come into conflict with their cancer experiences, potentially leading to paradoxical social well-being outcomes such as developed connection with friends but tension in family dynamics at home where they have lost their previously gained agency (Drew et al., 2019; Jones et al., 2011).

Psychological Well-Being

In this study, *psychological well-being* is defined as adolescents' cognitive and emotional responses to their cancer experiences (positive or negative), expressed through thoughts, feelings, and neurobiological functioning. For instance, given adolescents' developmental positioning, they may describe during the diagnosis process significant worry, anxiety, or mental strain about their future, as well as poor emotional regulation and turbulence while trying to cope with treatment demands. This study's definition of psychological well-being is intentionally broad, allowing space for unexpected or under-represented experiences, such as hope and perceived positive mental outcomes to be included. In most existing illness-based research, by contrast, the focus is on adverse mental states and trauma-related psychological outcomes (Drew et al., 2019).

Psychological well-being in this study also includes psychopathology and neurobiological functioning outcomes, which has been the traditional focus of this domain in international literature, recognising that cancer and related treatments can disrupt the rapid neurological development that occurs in adolescence (Jim et al., 2018). Cancer and its treatments have been correlated to outcomes including significant disruptions in cognition, decreased concentration, slowed thinking, memory difficulties, and neuroinflammation in adolescents, which—compounded with their developmental volatility—might contribute to heightened experiences of emotional reactivity, irritability, mood fluctuations, and reduced stress tolerance (Tometich et al., 2024).

The use of this broader, developmentally sensitive definition aligns with Aotearoa research by Marsh et al. (2024), in which adolescents' emotional complexity is explored without restricting responses to predefined biomedical assumptions, such as equating the level of mental distress to symptom presence. For instance, while reduced functioning from cancer may increase stress due to potential education disruptions and lead to treatment-related worry (Whitaker, 2020), cancer experiences may potentially serve as a catalyst for emotional growth, resilience-building, and mental strength, but this is currently underexplored in research. This psychological well-being—beyond solely pathological disorders and a distress focus—remains undertheorised in Aotearoa and wider adolescent cancer literature, but may provide a more comprehensive and developmentally grounded understanding of adolescents' inner psychological world.

Spiritual Well-Being

Spiritual well-being in this study is defined through adolescents' perspectives on their life's purpose and meaning, sense of self, and awareness of personal vulnerability to illness. Spiritual well-being outcomes may include disruptions to self-identity—for instance, adopting a cancer patient identity—alongside reevaluation of life priorities, existential questioning (e.g., "Why me?"), and moments of self-confidence as they build inner strength. The use of this definition challenges Western cultural associations that equate spirituality only to religion (Weaver & Wratchford, 2017), thereby supporting a wider spectrum of potential ways cancer affects adolescents' spiritual well-being.

Previous research indicates that restrictive, traditional definitions of spiritual well-being can marginalise adolescents without religious affiliations (LaRosa et al., 2017; Tirgari et al., 2022; Wei et al., 2025). In contrast, the definition adopted in this study aligns with Te Whare Tapa Whā's holistic conceptualisation of spirituality, which accommodates both religious and non-religious dimensions. This definition is suited to the Aotearoa context as it aligns with recent local evidence presented by McNeil (2016) and Tulip (2021) that many adolescents primarily experience illness-related spirituality through constructs such as self-perception, purpose, and identity *over* religion. For example, a cancer diagnosis and the demands of treatment may prompt significant reflection on life's meaning, creating an identity paradox between how adolescents saw themselves as pre-cancer and the new cancer patient identity they may come to adopt (Moss et al., 2019). The present study's inclusive and developmentally appropriate definition of spiritual well-being derived from cultural worldviews is consistent with contemporary Aotearoa research (McNeil, 2016; Moss et al., 2019), avoids restrictive cultural assumptions tied to religion, and comprehensively acknowledges the nuanced and diverse ways adolescents' spirituality may be affected by cancer.

Physical Well-Being

This study defines *physical well-being* as an adolescent's perceived capacity to engage in everyday activities, the bodily effects of cancer and related treatment, and visible changes in appearance associated with illness. Moving beyond an oversimplified traditional biomedical definitions that ties physical well-being to presence of adverse clinical outcomes, disease status, or symptom severity (Pina-Sanchez et al., 2021), this definition recognises the complex and heterogeneous physical impacts of cancer, encompassing both internal bodily changes and visible alterations in outward appearance that, in the adolescent developmental stage, largely impact wider well-being, including sense of social belonging (Syed & McLean, 2017).

Fertility is also included in the scope of this definition, as cancer and its treatments can affect adolescents' future reproductive functioning (Nelson & Levine, 2023). Fertility is often treated as peripheral within practice and traditional physical well-being definitions in adolescent and young adult (AYA) cancer research (LaRosa et al., 2017; McLoone et al., 2021; Nelson & Levine, 2023). However, given adolescents' developmental context includes future-oriented thinking and intimate relationship development, they may perceive treatment-related fertility risks, uncertainty about future reproductive ability, or limited access to fertility-related information (McLoone et al., 2021) as significant physical well-being affects. Including fertility, therefore, ensures that this study's definition remains developmentally inclusive to the full range of potential physical well-being outcomes.

The present study's definition acknowledges physical outcomes, including loss of strength, increased fatigue, and functionality concerns, as discussed in previous Aotearoa cancer research by Sligo et al. (2019). However, this definition also allows space to understand adolescents' developmentally situated meaning-making of their cancer-related physical outcomes. For example, while only being able to walk to the shower shows limited physical capability, it may be perceived positively, as the adolescent may perceive themself as still having some physical functionality. By allowing space for diverse interpretations of the same physical experience enhances analytic depth and supports a more nuanced understanding of the spectrum of adolescents' physical well-being realities.

Taiao: Environmental Well-Being

Within the Meihana model, *taiao* is defined as the physical environments in which individuals live and receive care, with opportunities (or lack thereof) in these spaces shaping illness experiences (Matenga & Westenra, 2022; Pitama et al., 2007). Incorporating taiao into this study broadens the research scope and acknowledges how healthcare environments may support or hinder adolescents' well-being outcomes during their cancer journey. Environmental contexts in this research may include hospital wards, treatment rooms, fertility clinics, and any other healthcare spaces encountered. For example, in Aotearoa, adolescents might describe patterns of feeling isolated from peers when placed in adult wards or feeling out of place in clinical spaces which are not age-appropriate for their developmentally situated well-being needs (Ballantine et al., 2018). Significantly, in Smyth's (2023) research on Aotearoa adolescents' lived experiences of chronic illness, incorporating taiao into the research scope was valuable for exploring how healthcare systems and contexts shaped their illness experiences by influencing their sense of comfort, safety, belonging, and social connection which could be applicable to cancer contexts.

Overall, the role of the physical environment in adolescent cancer experiences remains poorly understood in international and Aotearoa cancer literature (McLoone et al., 2021). Including taiao in this study's research scope enables original insight into how Aotearoa's unique healthcare environments (and the gaps within and between them) may affect adolescents' cancer experiences and related well-being outcomes.

Ratonga Hauora: Access to Health Services

Within the Meihana model, *ratonga hauora* is defined by the accessibility, appropriateness, and responsiveness of healthcare services and institutional support and how they may shape illness experiences (Pitama et al., 2007). For example, access to age-appropriate healthcare and support may influence adolescents' cancer experiences, support satisfaction, and opportunities to participate in decision-making.

Unlike much international cancer research that foregrounds clinical outcomes (Cao et al., 2024), this definition aims to acknowledge the pivotal influence of healthcare support, service policies, and resource protocols in shaping adolescent cancer experiences. This study's incorporation of ratonga hauora definition enables the research scope to include both negative and positive experiences. For example, insufficiently adapted services may create age-related isolation, while access to tailored, age-appropriate support could increase adolescents' adherence to treatment protocols. Including this Meihana domain widens the research scope, enabling nuanced insight into how systemic gaps in healthcare system supports and services may contribute to adolescents' experiences of stress and confusion within adult units, as explored by Nandakumar et al.'s (2018) international AYA research. Similarly, Ballantine et al.'s (2018) qualitative study concluded that often AYAs' intense discomfort and poor cancer experiences are partly driven by the lack of accessible, age-appropriate cancer support in Aotearoa. However, these systemic influences remain largely unexamined in adolescent-specific cancer research, making this well-being domain critical to include in this study.

Defining the Age Range of Adolescence

In this thesis, *adolescence* refers to the later phase of adolescent development between 16 to 21 years, with an acknowledgement that the full developmental scope of adolescence begins at 12 years (E. H. Erikson, 1970). Internationally, there is no universal agreement on the delineation of adolescence;

however, most epidemiological evidence generated is derived from large-scale AYA studies in the United States (Lehtimaki et al., 2019; Quinn et al., 2015). The American Childhood Cancer Organization defines the period of adolescence as 12–18 years, whereas the Teenage Cancer Trust in the United Kingdom and the Canadian Oncology Healthcare Centre adopt a wider span of 15–20 years, acknowledging a longer developmental period in adolescence (Taylor et al., 2019). Some international organisations, including WHO (2021), define adolescence as 10–19 years; however, the US National Cancer Institute and the Global Cancer Observatory (GCO), for example, use a broader AYA age bracket of 15–39 years (International Agency for Research on Cancer [IARC], 2023). The lack of international consensus has led to conflicting research scopes and inconsistent findings as key developmental differences between adolescents and young adults ignored.

In Aotearoa, the national AYA Cancer Network Aotearoa (AYACNA) and Canteen organisations define AYA as 12–24 years old, while the National Child Cancer Network defines adolescence as 15–21 years old, demonstrating poor alignment between these national cancer support organisations (Ballantine et al., 2018; Moss et al., 2019). Within Aotearoa's healthcare system, individuals aged 16 and older are considered young adults and are therefore placed in adult wards, with some transfers occurring as early as 12 years old (Ministry of Health [MOH], 2014). The mismatch of definitions across organisations has resulted in adolescents in Aotearoa being inconsistently placed in either paediatric or adult wards—neither of which is designed for their developmental or well-being needs. This exposes a disconnect between research definitions and clinical realities in Aotearoa (AYACNA, 2021; Moss et al., 2019).

Even within the adolescent age range, research and cancer services often overlook key intragroup differences, despite significant cognitive, emotional, and physical capabilities differences shaping perceptions of their cancer experiences (Pathrose et al., 2025). Early adolescence (10–14) is typically characterised by more concrete thinking and greater normative dependence on family (Vandermorris et al., 2020), which may minimise relational tension experienced when relying on family for daily support. However, late adolescence (18–24) is more commonly associated with norms of increased autonomy, stronger peer influence, and more advanced cognitive maturity, including abstract future-oriented thinking (NASEM, 2020), which may render these cancer patients more sensitive to the appearance social reliance changes during their cancer journey. To ensure developmental coherence, this study's research scope focuses on late adolescence (16–21 years), a period marked by relatively comparable cognitive, social, emotional, and physical development, enabling more meaningful and developmentally consistent conclusions (Drew et al., 2019).

In sum, clear and contextually grounded definitions of well-being and adolescence remain largely absent from both international and Aotearoa adolescent cancer research, despite them being crucial for enabling meaningful comparisons and conceptual clarity across studies. Given past definition inconsistencies, the use of clear Te Whare Tapa Whā framework and Meihana model definitions to guide the research is critical for establishing a clear conceptual foundation in discussing the research findings across social, psychological, spiritual, and physical well-being outcomes, while also accounting for the environmental and systematic influences that may shape adolescents' cancer experiences.

Adolescent Cancer Landscape: The Global Reality

This section draws on recent international and national epidemiological data to examine population-level trends in the adolescent cancer landscape. The subsections progress from global to national trends, highlighting data on adolescents' cancer burden, survival rates, and the inequities faced by Indigenous groups. It is important to note the frequent subsume adolescents within the AYA category (15–39 years) which may obscure developmental distinctions and results in only an approximate understanding of adolescent-specific cancer patterns.

International Cancer Statistics

Although there have been major advances in medicine and treatment technology, according to global population data cancer is becoming an alarming health burden, with the cumulative lifetime risk of developing cancer estimated at 20% in 2022 (International Agency for Research on Cancer [IARC], 2024b). In 2019, across the global total population, there were an estimated 19.3 million new cancer registrations and 9.9 million deaths, increasing to 19.9 million new cases in 2022, although mortality slightly declined to 9.7 million (Cao et al., 2024; WHO, 2024). Across the years 2018–2022, the most frequently diagnosed cancers worldwide were breast, lung, and colorectal, which together represented approximately 24% of all cancer cases (IARC, 2024b; WHO, 2024). According to the latest GCO data, cancer was the second leading cause of adult mortality in 2022, accounting for 27% of non-communicable deaths (World Cancer Research Fund International, 2024). Looking ahead, GCO data projects that, for the total population, the lifetime risk of cancer will increase from one in three to one in two by 2045, driven by the aging population, rising physical inactivity, and unhealthy lifestyle patterns (IARC, 2024a).

When population-level statistics are disaggregated, cancer emerges as a significant concern for adolescents (Ganz, 2019); however, due to the structure of epidemiological reporting, the most appropriate age bracket available for examining adolescent cancer statistics is 15–24 years. In 2022, approximately 1.3 million new cancer cases were registered globally among individuals aged 15–24—a 2.7% increase from 2020, likely reflecting improvements in cancer detection capabilities—with adolescents aged 15–20 comprising a substantial proportion of these cases (Bray et al., 2024; IARC, 2024b). During the same year, this cohort experienced approximately 380,000 cancer-related deaths worldwide, reflecting a 3% increase in mortality from 2021, likely driven by disparities in treatment support and healthcare access (IARC, 2023; WHO, 2024). Using GCO data, in 2022, the worldwide cancer incidence rate for individuals aged 15 to 24-year-olds was of 14 per 100,000, with a comparatively lower mortality rate of 3 per 100,000 in 2023 (IARC, 2023); however, according to Bray et al. (2024), the relatively small size of this age group means these figures are as concerning as those reported in adult populations.

Aotearoa Cancer Statistics

Consistent with international trends of high cancer mortality rates, data from the Aotearoa Cancer Registry, as reported by Te Whatu Ora – Health New Zealand (2024; hereafter Te Whatu Ora), indicate that in 2019, cancer was a leading cause of death in the general population, accounting for approximately 9,500 deaths. According to WHO (2024), the three most commonly diagnosed cancers across the total Aotearoa population in 2022—lung, colorectal, and breast—reflect international patterns, suggesting shared shifts in disease profiles and lifestyle-related risk factors, including increases in obesity and sedentary behaviours. Referencing the latest GCO data, in 2022, there were 38,157 new cancer cases and 11,301 deaths across Aotearoa's population, with an age-standardised incidence rate of 427 per 100,000, which underscores a significant national burden of cancer (IARC, 2024b). From 2013 to 2022, total population cancer registrations increased by 25%, while cancer-related deaths across multiple cancer types declined by 14%, with these figures attributed to advances in screening, early detection, and treatment technology (WHO, 2024).

Significant disparities exist in cancer outcomes between Māori and non-Māori (Te Whatu Ora, 2024). The Aotearoa Cancer Registry reported that, across the total cancer population, Māori had a 1.2 times higher cancer incidence rate and 1.7 times higher mortality rate compared to non-Māori in 2020 (Te Aho o Te Kahu – Cancer Control Agency, 2021; hereafter Te Aho o Te Kahu). This demographic disparity across the general population is driven largely by Māori being disproportionately diagnosed at later stages and by there being a persistent lack of culturally responsive healthcare systems, hindering their engagement with essential cancer services (Bray et al., 2024; WHO, 2023). A consistent trend reported from the national 2013–2022 general population dataset is that although Māori have lower absolute numbers of cancer cases than non-Māori, when adjusted for population size, their age-standardised incidence rates are 24% higher per 100,000, indicating they have a greater likelihood of developing cancer (Te Whatu Ora, 2024). Observations of disparities extend to mortality across the total population, with Te Aho o Te Kahu (2021) reporting that between 2015 and 2020 Māori experienced a 67% higher mortality rate than non-Māori. Such inequity likely reflects the compounding effects of socioeconomic deprivation, geographic isolation from treatment centres, limited access to travel support, and institutional racism more commonly experienced by Māori (Moss et al., 2019).

The latest Aotearoa AYA Cancer Incidence and Survival report indicates that from 2008 to 2017 Māori aged 15–29 had more than double the incidence rate for the most common adolescent cancers—leukaemia and lymphoma—compared to non-Māori, a disparity likely driven by broader social determinants and systematic inequities in Aotearoa (AYACNA, 2020; Chidobem et al., 2022). According to New Zealand Cancer Registry figures, in 2019 the incidence for Māori aged 15–29 remained stable at 285 per million, whereas incidence declined among non-Māori (Moss et al., 2019). However, this data masks persistent inequities in outcomes, with the five-year survival rate for Māori AYAs (78%) significantly lower than that for non-Māori (87%) (Te Whatu Ora, 2024). In 2022, Māori accounted for nearly 22% of all AYA cancer cases, with an incident rate 72% higher than that of non-Māori, a disparity further compounded by their disproportionate representation in high-deprivation areas (IARC, 2024b).

According to IARC's (2023) GCO dataset, Aotearoa ranked fourth-highest among Organisation and Economic Co-operation and Development (OECD) countries in 2022 for cancer incidence and mortality rates among those aged 15–19 years, with more recent figures yet to be released at the time of writing. The average survival rate for 15–19-year-olds across the three most prevalent adolescent cancers was 82% in Aotearoa in 2022, which is significantly lower than the averages recorded in Australia (87%), the United States (89%), and Canada (88%) (WHO, 2023). In 2019, the Aotearoa Cancer Registry recorded 190 new cancer registrations among 12–24-year-olds, an incidence rate of 15 per 100,000 (MOH, 2021), which had alarmingly increased by 2.7% in 2022 according to GCO data (IARC, 2024b). Relatedly, the AYACNA (2020) cancer action plan for 2020–2025 highlighted that in 2018, nearly 50% of new cancer diagnoses within the AYA population occurred among those aged 15–19 years, with lymphomas, bone tumours, and leukaemia the most common cancers. Ultimately, despite improving survival rates, adolescents in Aotearoa, particularly Māori, experience a significant cancer burden that warrants further attention and action.

In sum, adolescent age-specific epidemiological cancer data remains largely absent across international and Aotearoa contexts, creating challenges in accurately understanding adolescents' cancer burden, prognosis outcomes, and associated inequities. Of the datasets available, age-disaggregated AYA reports are the most useful for this study; however, more research is needed for a precise overview of adolescent-specific cancer trends.

The Context of Adolescent Cancer Experiences: Development Theories

Adolescence is a distinct developmental period marked by the maturation of biological, cognitive, emotional, and social capabilities (de Carvalho & Veiga, 2022; NASEM, 2020). To explore these age-specific complexities, the following subsections examine relevant developmental theories that may offer useful perspectives for understanding how adolescents' cancer experiences intersect with and are shaped by their developmental context.

Erikson's Stages of Developmental Theory

E. H. Erikson's (1950/1964) Stages of Development Theory (SDT) outlines eight stages of development, each defined by a central psychosocial conflict. Erikson believed the key conflict of adolescence was identity versus role confusion, with the overarching developmental theme being fidelity. According to his theory, adolescent identity is shaped by personal commitments, values, ideological beliefs, attitudes, and the relationships that reflect these orientations (Maree, 2021). E. H. Erikson (1950/1964) argued that adolescence represents a pivotal stage characterised by normative yet volatile transitions, including neurodevelopment, changing social roles, increased autonomy, and a heightened importance of wider social networks to their sense of belonging. Adolescence is viewed as a unique transitional period of becoming a separate entity—removed from the dependency and answerability of childhood while not yet attaining the relative stability and social norms of young adulthood (Degges-White, 2017).

Applying SDT to existing international and Aotearoa-based cancer literature is challenging, as research often conflates adolescence within the broader AYA category (Hughes et al., 2024). Consequently, most AYA research cannot confidently identify developmentally specific influences on adolescents' cancer experiences.

Within the limited body of adolescent-specific cancer research internationally, E. H. Erikson's (1970) concept of identity crisis is useful for understanding why adolescents in McLoone et al.'s (2021) study, for example, frequently self-reported identity disruptions and shifts in life perspectives following a cancer diagnosis. For adolescents, cancer may interrupt pivotal fifth-stage developmental tasks such as building independence and a stable sense of self-identity (Syed & McLean, 2017). SDT could be usefully applied in this study, providing a developmental lens for understanding reasons behind why adolescents with cancer may experience "dual identity" challenges (Weaver & Wratchford, 2017). An adolescent's normative identity formation may intersect with the imposed negotiation of a cancer patient identity, potentially disrupting their social roles and desired self-identity perceptions.

The age range used in this study to represent older adolescents (16–21 years) roughly aligns with the upper boundary of E. H. Erikson's (1970) definition of adolescence (ages 13–20). The study's age range was also intentionally selected to align with the limited Aotearoa-based adolescent cancer research (Marsh et al., 2024; Moss et al., 2019), as well as definitions used by AYACNA (Moss et al, 2019), supporting comparability across studies and the relevance of the findings to real-world healthcare contexts. Although the adolescent stage boundaries within SDT do not align perfectly with contemporary definitions of adolescence within Aotearoa healthcare settings, the theory may still offer a useful lens for interpreting how adolescents' stage-specific developmental context may impact their cancer experiences and well-being outcomes.

Other Developmental Theories

Various other developmental theories have sought to explain AYAs' experiences navigating cancer (Docherty et al., 2015; Vandermorris et al., 2020). Life course theory, for example, considers the significance of the timing, sequence, and social context of life events, proposing that experiences accumulate and interact over time to produce lasting effects on behaviour, relational pathways, and well-being outcomes across the lifespan (Cameron et al., 2021; Jones et al., 2011). Docherty et al. (2015) adopted a life course perspective and found that adverse experiences during AYA years can have long-lasting developmental consequences for autonomy, identity formation, and the negotiation of new social roles. Additionally, life course theory suggests that development is not an isolated event, but rather a dynamic, ongoing process affected by broader cultural and structural factors that shape individuals' opportunities, constraints, and life outcomes (Jones et al., 2011).

Life course theory could be relevant to adolescents diagnosed with cancer because it may explain how a major life event (cancer) could alter life trajectories in non-linear ways (Docherty et al., 2015). Cancer is suggested to disrupt adolescents' typical developmental progress, as suggested by self-reports made in a 2018 Aotearoa national survey, where many felt as though they were moving backwards compared with their peers (Moss et al., 2019). The sense of being out of step with peers is significant because, from a life course perspective, timing is critical: a cancer diagnosis during adolescence may derail key developmental milestones, including forming a social identity, sustaining intimate relationships, or achieving tertiary education, with consequences persisting into adulthood (Docherty et al., 2015; McLoone et al., 2021). If development is delayed because of cancer, it is plausible that identity formation may stall, accelerate, or shift in negative ways that may leave an adolescent feeling stuck to an unwanted cancer patient identity.

Although life course theory provides valuable insight into how the effects of adolescent cancer may unfold across the lifespan through its emphasis on timing and longitudinal trajectories (Docherty et al., 2015), it is less well suited to the present study's focus on adolescents' lived experiences and well-being outcomes within the immediate moment of active diagnosis. In contrast, SDT is more applicable for examining the immediate, stage-specific developmental context shaping adolescents' in lived cancer experiences, while also offering greater explanatory utility for understanding illness-related psychosocial and meaning-making processes than the more sociologically orientated life course perspective.

In sum, developmental theories are largely absent from international and national adolescent cancer research, despite their relevance for understanding the underlying reasons behind adolescent cancer experiences and well-being outcomes. Of the existing theories, SDT is particularly suited to this study's scope, offering a stage-specific lens tied to exploring identity formation, autonomy, and social integration—core developmental areas that may be disrupted by cancer.

How Cancer Experiences and Related Outcomes Are Understood

This section provides an overview of the evolution of perspectives used to understand illness, tracing the shift from traditional biomedical approaches to a more holistic biopsychosocial lens and the emergence of cultural models in contemporary illness research. The first subsection examines traditional Western biomedical perspectives and their limitations, including the tendency to reduce cancer experiences to clinical outcomes (Smith et al., 2019). The second subsection shifts to the biopsychosocial perspective, which extends recognition of illness through interconnected relational, psychological, and physical processes (Cameron et al., 2021), while also identifying drawbacks in capturing the full spectrum of potential well-being outcomes. The final two subsections introduce culturally grounded Māori models of well-being—Te Whare Tapa Whā (Durie, 1984) and the Meihana model (Pitama et al., 2007; Pitama et al., 2014)—that extend beyond biomedical and biopsychosocial constraints. These cultural models provide a rich, holistic, and culturally situated discussion of findings regarding the diverse ways adolescents perceive the impacts of cancer, while reflecting Indigenous values, contexts, and cultures often overlooked within traditional illness paradigms.

Biomedical Perspective

Recent systematic reviews illustrate that the Western biomedical model remains an enduring paradigm in both international and national healthcare research (McLoone et al., 2021; Moss et al., 2019; Quinn et al., 2015). Rooted in functionalist traditions, this perspective conceptualises illness as an independent biological dysfunction of the body, objectively measured and “fixed” through clinical approaches (Pina-Sanchez et al., 2021). The dominant biomedical focus has seen much of the international literature concentrate on clinical experiences, cure rates, and physical symptom management (Kestler & LoBiondo-Wood, 2012; LaRosa et al., 2017). Although the Western approach has driven major advances in disease detection and treatment technology, it reduces well-being to a clinical state of being viewed through bodily function capabilities, overlooking the psychological, social, and developmental dimensions through which illness is lived (Gillett-Swan & Sargeant, 2015).

In the context of cancer, biomedical perspectives have reinforced cultural constructs of cancer being a physical “battle” or a biological “invasion” to be eradicated (Barr et al., 2016). These cultural meanings of disease have shaped national priorities, directing cancer research towards clinical goals such as improving early detection accuracy and increasing survivorship (AYACNA, 2020; Ballantine et al., 2017). However, by prioritising physical outcomes, embedded systemic blind spots surrounding acknowledgement of other significant aspects of the cancer experience to well-being outcomes are reinforced (Pettit et al., 2023). Consequently, aggressive treatments such as chemotherapy, radiotherapy, and targeted therapies (immunotherapy and hormone therapy) are often rationalised for adolescents, with developmentally driven psychological, social, and spiritual well-being support resources frequently overlooked, which can affect their quality of life (Drew et al., 2019; Lehtimaki et al., 2019; Sligo et al., 2019). Large-scale national reports by AYACNA echo Sligo et al.’s (2019) findings: Aotearoa adolescents frequently self-report unmet non-physical needs, including lack of support in navigating peer relationship difficulties and coping with their heightened emotional distress AYACNA, 2020; Moss et al., 2019. These developmentally salient needs can profoundly impact adolescents’ interconnected well-being, yet they remain insufficiently addressed because they fall outside of the biomedical focus. This medical prioritisation constrains both the effectiveness of cancer care provided and clinicians' depth of understanding to adolescents' lived cancer experiences (McLoone et al., 2021). However, evolving cultural understandings of cancer recognise that survival alone cannot capture the complexity and holistic needs of adolescents throughout their cancer journey (Smith et al., 2019).

Biopsychosocial Perspective

The biopsychosocial model conceptualises well-being outcomes as resulting from dynamic interactions across interconnected social, psychological, and physical contexts, with illness understood through a holistic approach (Wickramasinghe et al., 2025). There has been a slow shift away from a biomedical focus to the biopsychosocial perspective in international illness research (Smith et al., 2019; Taylor et al., 2019). Illness experiences are understood as subjective and as permeating individuals' entire worlds, rather than as separate, mutually exclusive events (Zebrack et al., 2013). By incorporating contextual and environmental factors, such as community, culture, and socioeconomic status, this perspective situates well-being within the broader lived experiences of adolescents, enabling the development of healthcare support strategies that go beyond disease treatment to address the whole person (Drew et al., 2019). The biopsychosocial framework is particularly suited to adolescents, where developmental factors—rapid social changes, emotional instability, and neurological maturation—may influence their well-being (de Carvalho & Veiga, 2022).

In the context of cancer, while desired clinical outcomes are critical, positive psychological outcomes are equally important and cannot be separated from the primary goal (Smith et al., 2019). Worldwide healthcare systems fail to provide adolescents with developmentally attuned cancer care, lacking attention to the biopsychosocial realities of their cancer experiences, while reinforcing international evidence of adolescents' long-standing dissatisfaction with cancer healthcare systems, services, and environments (Pathrose et al., 2025). Similar to international research, in Aotearoa, a large-scale study by AYACNA (Moss et al., 2019) consistently shows that adolescents self-report dissatisfaction with cancer support and unmet well-being needs that, alongside physical symptoms, constitute the broader reality of adolescents' poor cancer experiences. These insights of low well-being satisfaction underscore that nonphysical well-being domains are deeply affected by cancer and cannot be considered secondary, aligning with the biopsychosocial model premise (Marsh et al., 2024). The biopsychosocial model, as highlighted by Moss et al. (2019), demonstrates how cancer patients experience a spectrum of holistic positive and negative outcomes shaped not only by individual factors, but also by social determinants such as socioeconomic status, sociocultural context, organisational systems, and environmental settings. For adolescents with cancer, determinants of cancer experiences and related well-being outcomes may include quality of family support, healthcare access, and the age-appropriateness of the Aotearoa healthcare environments (Moss et al., 2019).

Despite the biopsychosocial model representing important progress in recognising cancer as a multidimensional experience (Cameron et al., 2021), this approach remains limited by its exclusion of spiritual well-being—an area that, particularly within Aotearoa's context, may be meaningfully affected by cancer. Consequently, culturally grounded Māori frameworks, while largely absent in existing literature, may be essential for capturing broader well-being outcomes embedded within local values and sociocultural contexts.

Te Whare Tapa Whā Framework

Te Whare Tapa Whā is a widely recognised Māori well-being framework developed by prominent Māori psychiatrist and academic Mason Durie in 1984. The model is represented as a *wharenui* (meeting house) with four interconnected walls: taha tinana (physical well-being), taha hinengaro (psychological well-being), taha whānau (social well-being), and taha wairua (spiritual well-being). Durie (1996) proposed that positive well-being is achieved when all dimensions are in balance; however, if one or more is weakened (e.g., through injury or illness), the stability of the whole house, and thus overall well-being, is compromised. Importantly, Te Whare Tapa Whā privileges subjective experiences, supporting an open-minded discussion of new possibilities and alternative interpretations of well-being (Tulip, 2021). The Te Whare Tapa Whā framework acknowledges and enables the discussion of multiple culturally grounded realities and situates an individual's perceptions of well-being outcomes as valid truths within their embodied, relational, and cultural contexts (Huria et al., 2017).

Te Whare Tapa Whā is well-suited to the exploration of Aotearoa adolescents' cancer experiences and well-being outcomes because, as Tulip (2021) states, unlike the aforementioned models, this framework embeds the interconnected well-being domain within Aotearoa's cultural context—norms, environments, systems, and values—enabling greater contextual validity and rich findings. The Te Whare Tapa Whā framework challenges dominant Western biomedical narratives by positioning social, psychological, and spiritual domains as equally central to well-being as physical functioning (Huria et al., 2017).

Te Whare Tapa Whā provides a holistic framework for understanding the persistent unmet well-being needs identified by AYACNA (2021) by moving beyond identification to explain how systematic and multidimensional well-being imbalances can contribute to adolescents' cancer experiences. In essence, this framework's broader lens enables the discussion of multidimensional positive and negative illness-related outcomes spanning social, emotional, spiritual, and physical domains (Albert et al., 2024; Durie, 1985).

Additionally, adolescents' cancer experiences can amplify normative spiritual development by accelerating or causing disruptive shifts in self-identity, self-confidence, and self-perceptions (Barton et al., 2018; Dew et al., 2015). Such impactful outcomes are often overlooked or marginalised within dominant theoretical perspectives despite the key role spirituality plays in adolescent meaning-making and coping with cancer (Oyedele et al., 2024; Tulip, 2021). This reinforces the relevance of Te Whare Tapa Whā within the discussion of this study's findings, as it holistically recognises the developmentally situated impacts of cancer on adolescents' spiritual well-being.

In sum, Te Whare Tapa Whā provides a strong, holistic framework for understanding the interconnected well-being outcomes arising from adolescents' cancer experiences while enabling their unique developmental context to be considered (Dew et al, 2015). However, the exploration of well-being can be further extended through the Meihana model, which explicitly incorporates taiao (healthcare spaces) and ratonga hauora (healthcare services), positioning broader environmental, sociocultural, and institutional factors at the centre of well-being (Huria et al., 2017) and offering further depth to the discussion of this study's findings.

Meihana Model Perspective

Developed in 2007, the Meihana model incorporates the aforementioned psychological, physical, social, and spiritual dimensions of Durie's (1984) Te Whare Tapa Whā framework and recognises that knowledge is socially and culturally constructed (Pitama et al., 2007; Pitama et al., 2014). The Meihana model extends Durie's conceptualisation of well-being by including the domains of taiao and ratonga hauora (Huria et al., 2017). In this model, the well-being dimensions are represented as crossbars connecting two hulls of a *waka hourua* (double-hulled canoe)—one hull symbolises the patient, the other their social well-being connections (Pitama et al., 2007). The model proposes that well-being is a result of the intersection between personal experiences across the well-being dimensions and the broader environments, sociocultural systems, and cultural contexts (Pitama et al., 2014).

Expanding on Te Whare Tapa Whā, the Meihana model identifies external societal and historical "winds"—marginalisation, racism, colonisation, and migration—as powerful forces shaping a person's well-being (Wilson et al., 2021). The direct inclusion of these wider determinants advances this model beyond the aforementioned frameworks by explicitly acknowledging how well-being is inseparable from the societal contexts that people inhabit (Huria et al., 2017).

Smyth's (2023) recent Kaupapa Māori research—research done by Māori, with Māori, and for Māori—on chronic illness shows how the Meihana model's winds may represent systemic inequities, inadequate healthcare environments, and a lack of age-appropriate institutional systems, all of which could contribute to significant negative well-being outcomes for adolescents with illness. Such influences could also be anticipated to shape adolescents' cancer experiences, which are not yet well understood in the literature. The winds emphasise how the environments and structures people occupy shape perceptions of safety, comfort, and access to resources, which can either support or constrain well-being (Huria et al., 2017). Reports of poor taiao experiences may signal that environmental change is needed, as inadequate or culturally misaligned settings can contribute to feelings of distress, sadness, and social isolation (Pitama et al., 2014)—negative well-being outcomes frequently reported in the 2018 AYACNA patient cancer experience survey (Moss et al., 2019).

Within adolescent cancer research, the inclusion of taiao and ratonga hauora in the discussion of findings may facilitate an understanding of how Aotearoa's unique system-level factors—such as ward placement, systemic inequities, and access to developmentally appropriate healthcare services—affect adolescents' lived cancer experiences and related well-being outcomes. By situating adolescents' cancer experiences within broader social, cultural, and systematic contexts, application of this model in the discussion of findings may support a more nuanced and contextually grounded understanding of how Aotearoa's context affects adolescents' multidimensional well-being.

In sum, the use of culturally grounded Māori perspectives in the discussion of cancer experiences and related well-being outcomes remains marginal within existing literature, despite their importance for understanding the multidimensional and meaning-laden ways adolescents experience cancer. Of the perspectives reviewed above, the Te Whare Tapa Whā framework and the Meihana model are particularly suited to this study's scope, as they provide holistic frameworks that foreground the contextual influences and provide an extensive spectrum of potential well-being outcomes, which are often overlooked in biomedical and biopsychosocial perspectives.

The Cultural Environment: Global and Aotearoa Contexts

The following subsections examine how adolescents' cancer experiences may be shaped by the broader cultural, institutional, and healthcare contexts they inhabit. Drawing on international contexts before narrowing to that of Aotearoa, each subsection identifies how cultural norms, healthcare systems, and access to age-appropriate services may shape adolescents' cancer experiences and related well-being outcomes.

International Context

Healthcare system designs, ward environments, and the accessibility of age-appropriate support services are culturally situated and reflect underlying cultural assumptions about care (Pathrose et al., 2025). For instance, Western biomedical-focused healthcare systems and support services in the United States are governed by the values of individualism, a focus on physical symptom management, and a separation of mind and body, whereas international holistic cancer support centres prioritise wider contexts, spirituality, and interconnected well-being (Islami et al., 2022; Quinn et al., 2015). It is important to consider differing cultural framings of cancer, as each country's viewpoint distinctly shapes what healthcare systems, service environments, and supports are valued, resourced, and delivered, which may contribute to why some international adolescents' self-report adverse cancer experiences and poor well-being outcomes (Wickramasinghe et al., 2025).

In high-income Western countries such as the United States, where healthcare is insurance-dependent, the foundational population-based Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE) study identified that one-third of adolescents delayed seeking medical care due to financial constraints, which contributed to a later diagnosis, adverse well-being outcomes, and a poorer prognosis (Smith et al., 2019). In this large-scale study, adolescents who did access care often relied on lower-cost, geographically distant support services, with 63% reporting inadequate age-appropriate support that contributed to unmet psychosocial needs, lack of developmentally supportive care, and intensified future-oriented worries (Drew et al., 2019; Taylor et al., 2019). Adolescents in minority groups and low-income areas with higher deprivation scores often face additional barriers, including resource scarcity, greater transport requirements, and challenges navigating fragmented services (Janssen et al., 2025), which collectively may contribute to poorer cancer experiences.

In contrast to private healthcare, the landmark BRIGHTLIGHT and STRONG-AYA population studies in the United Kingdom—operating within the National Health Service, a universal healthcare system—reported that even despite greater access to psychosocial support, cancer care is not developmentally age-specific (Janssen et al., 2025; Taylor et al., 2019; Wickramasinghe et al., 2025). Many adolescents placed in paediatric or adult treatment environments reported experiences of discomfort, isolation from peers, and difficulty navigating systems, reflecting cultural uncertainty around what constitutes adolescent-appropriate care, even in spaces that provide that support (Taylor et al., 2019). Although international research provides valuable insights, the direct applicability of their findings to Aotearoa is limited, as cultural contexts, including healthcare systems, services, and treatment environments, differ.

Aotearoa Context

Aotearoa's geographical size, small population, cultural context, and healthcare system present unique challenges compared to overseas counterparts regarding resources, service delivery, and care management, contributing to variation in well-being outcomes (AYACNA, 2020). Given Aotearoa's cultural context, some adolescents report not having immediate access to the healthcare services they require, while others do not utilise available support due to barriers including geographical distance, limited awareness of available services, and inadequate adolescent-specific support, barriers that are disproportionately experienced by Māori (Moss et al., 2019).

Aotearoa's Healthcare System. There are no dedicated adolescent cancer units in Aotearoa, and referral decisions to paediatric or adult units are made on an ad hoc basis, contributing to substantial variation in adolescents' cancer experiences and reported well-being outcomes in national surveys

(Ballantine et al., 2018; Moss et al., 2019). Although Starship Children's Hospital specialist paediatric oncology unit in Auckland is formally available only to those aged up to 15 years, some adolescents over this age may still receive treatment there, while others are transferred to adult units before age 15 due to resource or capacity constraints (Moss et al., 2019). International and national literature increasingly indicates that neither the adult biomedical-focused approach nor the paediatric family-based model achieves optimal well-being outcomes for adolescents (Freyer, 2010; Nandakumar et al., 2018), with many Aotearoa adolescents reporting feeling isolated from peers and uncomfortable within current healthcare environments (Moss et al., 2019; Sligo et al., 2019).

Recent reports highlight how geographical disparities and healthcare availability can limit access to timely, age-appropriate cancer care—particularly for Māori adolescent cancer patients (AYACNA, 2021; Moss et al., 2019). These healthcare system barriers contribute to delayed diagnosis and reduced access to supportive cancer care for both adolescents with cancer and survivors (Pettit et al., 2023). Although the healthcare system emphasises ideas of equity and universal care, Māori adolescents in these systems often face additional challenges, including transport barriers to treatment centres, which are frequently overlooked in support plans (Moss et al., 2019).

Interestingly, a nationwide project began in Italy in 2008 aimed to improve adolescents' access to healthcare systems that included developing age-appropriate treatment protocols and adolescent-trained staff, while also strengthening psychosocial supports, including the provision of dedicated age-specific hospital and community environments (Ferrari et al., 2020). Between 2010 and 2020, the project reported higher service satisfaction, improved well-being outcomes, and lower mortality rates compared with international peers. The project also shifted cultural attitudes by raising awareness of adolescents' cancer risk, encouraging earlier symptom checking, and promoting education about their unique needs, demonstrating that adolescent-specific cancer healthcare systems can be effective and offering a model that could be adapted for Aotearoa to address current gaps in adolescent cancer care.

National Service and Support Initiatives. In Aotearoa, there are only two national organisations dedicated to supporting AYAs with cancer. The AYA Cancer Network Aotearoa (AYACNA), established in 2013, provides national programmes and psychosocial support to AYA to improve care services for young people. Canteen—a national non-governmental organisation—also delivers psychosocial and peer support for 13- to 24-year-olds affected by cancer, whether as patients, survivors, or siblings, through counselling, connection, and advocacy (Moss et al., 2019).

Despite the important work of these services, Aotearoa has no adolescent-specific support services, leaving some adolescents feeling stuck in an in-between space while navigating cancer (Came & Kidd, 2020). Research mirrors this service gap, as no large-scale studies have exclusively examined adolescents' cancer experiences and well-being support needs. In 2019, AYACNA published *Whakarongo Mai: Listen to Me: Adolescent and Young Adult Experiences of Cancer Care and Support in Aotearoa New Zealand* (Moss et al., 2019), an analysis of its 2018 national patient experience survey. The report identified systemic issues—including poor service coordination, limited psychosocial support, and inadequate cultural responsiveness in well-being support, particularly for Māori—and called for greater attention to adolescents' developmental stage, cultural identity, and fertility concerns in cancer care services to improve their self-reported well-being (Moss et al., 2019).

Only recently has the MOH (2019) formally acknowledged that there is still much to learn about adolescent cancer experiences, with the *New Zealand Cancer Action Plan – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029* recognising that AYAs' well-being needs have been largely neglected in current cancer care services and that systematic gaps potentially contribute to inadequate and limited age-appropriate support services, as well as poor well-being outcomes. Similarly, in acknowledging current gaps in care, AYACNA's *New Zealand Adolescent and Young Adults Cancer Action Plan – Mahere Tautapa Mate Pukupuku Taiohi 2020–2025* stated that, by 2025, all adolescents diagnosed with cancer would receive high-quality supportive care, yet, according to the latest report, this is only supported by 53% of adolescents in survey responses (AYACNA, 2020). Even with clear policy statements aimed to progress cancer support, there has been minimal progression (Came & Kidd, 2020), highlighting how cultural context—shaped by biomedical dominance, structural inequities, and insufficient recognition of Indigenous perspectives—may continue to drive shortcomings in Aotearoa adolescents' cancer research and care.

In sum, adolescents' lived cancer experiences remain markedly underexplored within both international and Aotearoa research, resulting in an incomplete understanding of how experiences of cancer may be shaped by the cultural and structural contexts adolescents inhabit. Accordingly, this study foregrounds how Aotearoa's contexts, which include the limited availability of adolescent-appropriate services and culturally misaligned care spaces, uniquely affect adolescents' cancer experiences and related well-being outcomes.

Present Study

This study aims to explore adolescents' self-reported lived experiences of cancer and the associated holistic well-being outcomes within Aotearoa's cultural context. This section outlines the study's focus by presenting the research objectives alongside a brief overview of the study's design and research implications. To close Chapter One, an overview of the thesis structure is now presented.

Study Focus

This study's research aim is broken down into four main objectives:

1. To explore the self-reported lived experiences of Aotearoa adolescents with cancer.
2. To understand adolescents' perceived holistic well-being outcomes associated with their cancer experiences.
3. To explore how Aotearoa's broader context influences adolescents' cancer experiences and associated well-being outcomes.
4. To situate adolescents' cancer-related well-being outcomes within culturally grounded frameworks relevant to the Aotearoa context.

This qualitative study involved seven adolescents aged 16–21 who participated in a one-off, semistructured individual interview lasting approximately 30–45 minutes. Interviews explored adolescents' cancer experiences and how their holistic well-being was perceived to be affected. Open-ended questions listed in the interview schedule (see Appendix A) were used flexibly in interviews to support discussions. Participants were also invited to bring media to support discussions of their cancer experiences and well-being outcomes.

To my knowledge, this is the first qualitative study in Aotearoa to explore adolescents' self-reported cancer experiences and well-being outcomes exclusively, and the first to discuss its findings in relation to culturally grounded Māori frameworks. Research in this field may contribute to broader discussions around adolescent cancer care in Aotearoa and aid in the development of current services, resources, training models, and healthcare environments within healthcare organisations to make them more developmentally and contextually appropriate. A comprehensive understanding of adolescents' cancer realities and well-being needs could also help improve the support friends and family provide to their loved ones, fostering meaningful interactions and care that better align with adolescents' well-being needs during their cancer journey.

Thesis Structure

Following this introductory chapter, Chapter Two conducts a literature review that critically evaluates international and Aotearoa research on adolescents' cancer experiences, first examining factors shaping their cancer experiences and then reviewing literature on the holistic well-being outcomes associated with adolescents' cancer experiences. The chapter concludes by discussing the study's rationale and highlighting methodological gaps in existing research.

Chapter Three describes the study's methodology, beginning with the philosophical foundations underpinning this research, then detailing ethical and cultural considerations, data collection procedures, and concluding with analysis approach used. Chapter Four presents the main findings, organised into themes and subthemes. Chapter Five then organises the discussion of findings under the relevant well-being domains of the Te Whare Tapa Whā framework and the Meihana model. Findings are discussed in relation to existing literature and developmental theories. The chapter then outlines the study's strengths and limitations, identifies future research directions, and discusses potential implications of the research. Chapter Five concludes with final reflections and conclusions in relation to the research objectives.

Chapter Two: Literature Review

The chapter begins by presenting a critical review of international and national literature, examining key societal and personal factors that shape how adolescents make sense of and navigate cancer. The review progresses from cultural and healthcare contexts to developmental positioning, and concludes with the influence of diagnostic stage. The chapter then critically reviews international and national literature examining the current knowledge of how cancer impacts adolescents' holistic well-being, organised under Te Whare Tapa Whā domains (Durie, 1984). The chapter concludes by identifying key methodological limitations and persistent gaps within existing literature, establishing a clear rationale for the present study.

Factors Affecting Adolescents' Cancer Experience

This section examines how cultural context and systematic factors within Aotearoa New Zealand (hereafter Aotearoa)—relating to the taiao and ratonga domains in the Meihana model (Pitama et al., 2007; Pitama et al., 2014)—may shape adolescents' cancer experiences and the meanings they ascribe to illness. The final two subsections respectively explore how adolescents' developmental context—situated within the fifth stage of E. H. Erikson's (1950/1964) Stages of Development Theory (SDT)—and diagnostic stage may influence adolescents' meaning-making to their lived cancer experiences.

Cultural and Healthcare Contexts

Healthcare settings reflect a country's dominant cultural values and expectations, ranging from viewing cancer as a shared responsibility embedded within a public system to treating the disease via a privatised model (Jolidon et al., 2024). According to the American Cancer Society, the lack of accessible and age-appropriate healthcare services—particularly for Indigenous populations—is a leading contributor of current disparities in recent US adolescent and young adult (AYA) cancer incidence and mortality rates (Islami et al., 2022). International studies by Kirchhoff et al. (2024) in the United States and Janssen et al. (2025) in the United Kingdom further demonstrate that adolescents' access to culturally aligned healthcare, developmentally appropriate cancer supports, and inclusive care environments is a critical determinant of cancer experiences. Recent findings from the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study document racial disparities in the United States, where systematic and cultural bias within the privatised healthcare system disadvantages the provision of treatments and age-appropriate support for AYA cancer patients, with these outcomes heavily influenced by socioeconomic status factors of ethnicity and income (Smith et al., 2019).

The above findings are supported by research demonstrating that the absence of culturally representative cancer practices predicts mortality and persistent disparities in survival outcomes for Indigenous adolescents for some cancers (Bownes et al., 2018). Similarly, a UK BRIGHTLIGHT study suggests that the degree of healthcare accessibility strongly influences cancer diagnosis, treatment adherence, and survival outcomes for disadvantaged groups, with cultural barriers increasing risks of a late-stage diagnosis and less aggressive treatment (Taylor et al., 2019), suggesting that international cultural and structural contexts may shape findings on cancer experiences within AYA literature (McLoone et al., 2021; Pathrose et al., 2025).

Barriers within Aotearoa's cultural context, including cultural norms around illness and issues in healthcare structures, may play a significant yet under-addressed role in shaping adolescents' cancer experiences and well-being outcomes (Moss et al., 2019; Pettit et al., 2023). Comparing recent national research on adolescents' self-reported cancer experiences to global cancer reports, such as the AYA HOPE study (Smith et al., 2019), it could be suggested that Aotearoa adolescents face greater psychosocial adjustment challenges and have more limited access to age-appropriate services than their international peers. Differing psychosocial cancer experiences to international peers may be partly driven by the distinct features of Aotearoa's publicly funded healthcare system and embedded structural inequities, with many adolescents self-reporting feeling poorly supported due to their inconsistent placement across oncology units (AYACNA, 2020).

Aotearoa's healthcare system, while equitable in theory, does not consistently deliver culturally responsive care, particularly for Māori and Pasifika adolescents[1] (Albert et al., 2024; Dew et al., 2015). Survey data from AYACNA show that only 40% of Māori adolescents felt they had access to culturally appropriate support services that matched their cancer experiences and well-being needs during treatment, raising concerns about cultural invisibility and indicating significant gaps in current cancer care provisions (Moss et al., 2019). The clear disconnect between the design and delivery of cancer care and Indigenous collectivist and equity-focused cultural values may explain factors behind reported patterns of lower treatment adherence and reduced engagement with support services among Māori adolescents (AYACNA, 2021). The *New Zealand Cancer Action Plan 2019–2029* (MOH, 2019) also highlighted persistent inequities in cancer incidence and outcomes for Māori AYAs, acknowledging that the current healthcare system inadequately addresses Māori cancer needs. Te Aho o Te Kahu (2021) and Pettit et al. (2023) further conclude that inequities reflect structural-cultural failures to integrate Indigenous cultural values, contributing to a biomedical-focused healthcare system that leaves Māori adolescents experiencing disproportionate barriers to timely diagnosis and unmet psychosocial needs.

It is important to consider how perceptions of cancer experiences for adolescents who are raised in a Western cultural context may differ from those in non-Western settings, given their differing values and beliefs (Albert et al., 2024). Dominant biomedical models guiding adolescent cancer care in Aotearoa prioritise clinical outcomes which often fail to account for the culturally significant roles of family, social connections, and cultural practices (Moss et al., 2019). Neglect in cancer care has contributed to higher rates in adolescents of negative cancer experiences, greater feelings of peer isolation during treatment, and disproportionally higher mortality rates among Māori and Pasifika (Albert et al., 2024; MOH, 2020; Moss et al., 2019). In essence, rudimentary international and culturally grounded Māori research indicates

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[1] "Pasifika" has been used by the New Zealand government to describe the ethnic make-up of people who have migrated from the Pacific Islands to Aotearoa New Zealand (Chu, 2016).

that cancer is not experienced solely as a biological disruption but also through holistic channels of social and cultural roles, family dynamics, and spiritual connection (Matenga & Westenra, 2022; Smyth, 2023). The lack of whānau (family)-inclusive care and limited integration of Indigenous models of well-being may be some of the factors that are exacerbating these well-known Indigenous adolescent cancer inequities (Albert et al., 2024).

Ultimately, the limited attention to contextual influences in cancer research has contributed to an under-theorised, fragmented understanding of how Aotearoa's sociocultural context and healthcare structures may shape adolescents' meaning-making processes in relation to their cancer experiences. This omission constrains cross-study comparisons, as evidence generated in international cultural and healthcare contexts cannot be confidently generalised to Aotearoa populations where values, systems, and care structures differ and might meaningfully shape cancer experiences (Cameron et al., 2021). In response, the present study discusses the findings of adolescents' cancer experiences through the culturally grounded Māori frameworks of Te Whare Tapa Whā (Durie, 1984) and the Meihana model (Pitama et al., 2007; Pitama et al., 2014), enabling a holistic and contextually grounded discussion of factors, including healthcare environments, cultural systems, and social structures that may affect their lived cancer experiences within Aotearoa. Without such an inquiry, continued reliance on poorly translatable international research risks limiting the capacity of local research and practices to adequately respond to Aotearoa adolescents' actual cancer realities and diverse needs.

Adolescents' Developmental Stage

According to reports drawing on data from the US National Institute of Health (NIH) and the World Health Organization (WHO), clear links exist between adolescents' developmental stage—particularly their neurobiological maturation—and cancer experience perceptions (McDonald & Patterson, 2015; NASEM, 2020). Core experiences identified in SDT's fifth stage of development, such as identity formation, shifting relational roles, increasing autonomy, and expanding reliance on wider social networks beyond family, can intersect and conflict with the demands and constraints of cancer, likely shaping how adolescents interpret, navigate, and experience illness during this developmental stage. Findings from the AYA HOPE study highlight how cancer may delay, disrupt, and reshape adolescents' normative development trajectory, often leading to identity and role confusion (Smith et al., 2019). Given adolescents are actively forming a sense of identity and social position, many struggle to incorporate cancer into an emerging self-concept, experiencing heightened uncertainty about social roles, aspirations, and future directions relative to healthy peers (Juth, 2016). At the same time, still-developing cognitive flexibility—further reduced by treatment-related demands, stress, and fatigue—may hinder adolescents' ability to adapt to abrupt lifestyles changes and shifting expectations during their cancer care (Fladeboe et al., 2023). In contrast to adolescents' limited development, young adults in the UK BRIGHTLIGHT study, whose cognitive and psychological development was comparatively more advanced and stable, showed greater resilience and flexibility in adapting to rapid changes (Wickramasinghe et al., 2025).

A formative Aotearoa study by Cameron et al. (2021) exploring the psychosocial effects of cancer among AYA survivors further demonstrates that developmental stage is a major determinant of how AYAs understand, experience, and respond to cancer—shaping diagnosis experiences, treatment engagement, and psychosocial adjustment. Moreover, WHO (2021) emphasised that adolescents' developmental stage plays a critical role in shaping how cancer is experienced. When interpreted through SDT, normative developmental processes for adolescents, including identity formation, striving for autonomy, and negotiating belonging, intersect with illness in ways that influence how adolescents make sense of cancer and navigate treatment-related challenges (Fladeboe et al., 2023). As cognitive capacities expand, adolescents become increasingly capable of understanding complex clinical cancer information; however, growth in abstract thinking (without similar maturation in resilience and self-regulation) may amplify distressing experiences of existential questioning and anxiety surrounding their prognosis compared to children, who show more concrete thinking (Smith et al., 2019; Taylor et al., 2019). Complementary findings from NIH research (NASEM, 2020) and earlier foundational work by Zebrack et al. (2013) suggest that cognitive immaturity, combined with heightened emotional reactivity and a still-developing prefrontal cortex, may adversely affect how adolescents experience and engage with cancer treatment plans, interpret mortality risk, and identify unmet needs within oncology environments. Critically, evidence from Ferrari et al.'s (2020) Italian study demonstrated that when support services are developmentally attuned, adolescents report more positive cancer experiences, including smoother well-being adjustments, increased treatment adherence, and better prognosis outcomes.

Similarly, many adolescents in Aotearoa struggled to feel that support provided in healthcare settings fully addressed the broader ways cancer had affected their lives, with developmentally situated needs (autonomy and social belonging) poorly considered compared to direct medical concerns (Moss et al., 2019). Although the MOH's (2019) *New Zealand Cancer Action Plan 2019–2029* briefly acknowledges that adolescents face distinct development challenges, this recognition is not translated into concrete strategies or actionable plans for the developmental of adolescent-specific cancer care practices in Aotearoa. Aligned with E. H. Erikson's (1970) conceptualisation of distinct developmental stages across the lifespan, adolescents' age-specific developmental challenges, existing independently of illness, fundamentally shape how cancer is experienced. This reinforces the need for the MOH to recognise young people's developmental needs within the design, resourcing, and delivery of adolescents' cancer care.

Relatedly, the AYACNA (2020) action plan identified disparities across AYA cancer experiences related to the limited extent in which developmentally situated needs have been acknowledged in their care plans, suggesting a relationship between age, developmental needs, and cancer experiences. Similarly, Sligo et al. (2019) found that adolescents' developmental context shaped how cancer was experienced in Aotearoa, with ill-suited care spaces failing to support normative development, contributing to experiences of heighted role confusion and removal from age-typical norms, including a focus on future planning. Together, these Aotearoa studies suggest that positioned between dependence and emerging autonomy, and within the negotiating the conflict of identity versus role confusion, adolescents often face challenging cancer realities (Ballantine et al., 2018).

In sum, there is a growing international consensus that adolescence represents a distinct developmental stage that can significantly shape one’s cancer experiences (Drew et al., 2019; Pathrose et al., 2025). However, Aotearoa is yet to see a concerted effort in integrating developmental theory and age-differentiated approaches into practice and research methodology, making comparisons with overseas literature difficult. The aforementioned research gaps reinforce the rationale for the present study’s focus on adolescent-specific cancer experiences and the integration of developmental theory and culturally grounded Māori frameworks to generate contextually meaningful insights currently absent from existing literature.

Diagnostic Stage

This section, organised by disease progression, examines how the diagnostic stage may play a critical yet underexamined role in shaping adolescents’ cancer experiences. Although global research—often derived from epidemiological International Agency for Research on Cancer (IARC) and Global Cancer Observatory (GCO) data—views cancer progression primarily as a negative experience of physical decline (Bradford et al., 2022; Bray et al., 2024), each diagnostic stage, as discussed below, may encompass broader positive and negative experiences that affect how adolescents navigate treatment, engage with support systems, and construct meaning to their cancer journey.

Stage I. This stage is typically assumed to be associated with favourable prognoses, less intensive treatment regimens, and less burdensome well-being outcomes (Drew et al., 2019; Patterson et al., 2012). However, this assumption is complicated by qualitative findings from AYACNA, where cancer at any stage can be life-changing and significantly disrupt well-being (Moss et al., 2019). Additionally, evidence from Aotearoa’s landmark cancer patient experience survey highlighted a paradox frequently reported by adolescents: feelings of relief from the high curability of cancer detected in this stage alongside intense emotional distress arising from the abrupt loss of normalcy and disruption of key developmental milestones such as pursuing education, forming wanted identities, and developing independence

(Ballantine et al., 2018). For instance, the WHO report *Adolescent Health: The Missing Population in Universal Health Coverage* (Lehtimaki et al., 2019) found that detrimental experiences of invalidation may relate to the comparatively low visibility of symptoms during this stage compared to later stages, underscoring the importance of contextualising adolescents' cancer experiences by diagnostic stage.

Recent quantitative research by Pathrose et al. (2025) indicates heightened social support during the initial diagnosis in Stage I, as peers and family networks mobilise around the adolescent. However, while stage I may involve stronger social engagement (Cayrol et al., 2024), proxy-focused methodologies might constrain the ability to interrogate how support is internally processed by adolescents, potentially masking feelings, including the pressure to be independent and maintain emotional composure, driven by their developmental desire to appear strong and self-regulated. The above findings raise questions about whether the perceived benefits of support at this stage might paradoxically contribute to later experiences of emotional disconnection or abandonment, as support is likely to wane.

Stage II. For adolescents, stage II often marks a perception shift: cancer becomes perceived as a more serious medical event (Drew et al., 2019). International research by WHO (2023) and Fladeboe et al. (2023) indicates that increasing diagnostic severity is closely linked to intensified disruptions in daily functioning, emotional regulation, and social belonging—domains developmentally salient to adolescents' well-being. AYACNA notes that stage II commonly involves more intensified treatment regimens and increased time in hospital compared with stage I, potentially contributing to reduced physical functioning and greater interference with normative developmental tasks, such as maintaining peer relationships and participating in social milestones (Moss et al., 2019).

Using WHO data, Lehtimaki et al. (2019) found that adolescents frequently reported feeling increasingly different from peers as cancer became more visible through treatment side effects, which often conflicted with their developmental goals of social integration and acceptance. Divergence from perceived appearance norms can leave adolescents feeling misaligned with social groups, affecting their psychological adjustment (Quinn et al., 2015). Stage II likely has a substantial impact on adolescents' well-being, with approximately 25% of Aotearoa adolescents reporting increased symptoms of depression—potentially linked to the cumulative effects of body image changes, treatment fatigue, and developmental disruption (Te Aho o Te Kahu, 2021).

The predominance of deficit-focused research has failed to account for possible positive outcomes, resulting in a skewed and incomplete understanding of the potential role diagnostic stages play in adolescent cancer experiences. Moss et al. (2019) noted that Aotearoa adolescents in stage II may also experience strengthened personal values, emotional resilience, and increased appreciation for family. As an earlier US study by Kim et al. (2016) emphasised, positive and adverse well-being outcomes are not mutually exclusive but may coexist, as both growth-oriented and distressing responses can be evoked simultaneously. However, limited existing research means knowledge of this phenomenon is largely unexplored.

Stage III. Research often disproportionately presents a biomedical imperative focused on managing immediate medical threats, including symptoms, disease progression, and treatment side effects (Koo et al., 2020). Consequently, other dimensions of adolescent cancer experiences shaped by stage III—such as psychosocial and developmental impacts—are often perceived as secondary, receiving limited academic attention globally (Kestler & LoBiondo-Wood, 2012; Whitaker, 2020).

The AYA HOPE study (Smith et al., 2019) extended prior research by suggesting that stage III may prompt significant existential reflection, as adolescents confront questions of mortality and purpose while their peers are developmentally oriented towards exploration and opportunity, which may be compounded in Stage IV. In Aotearoa, cancer organisations suggest that the immediacy and intensity of aggressive treatment protocols—often requiring prolonged hospitalisation and medical surveillance—can isolate adolescents from their peers and social environments, contributing to feelings of detachment, lack of control, and compromised opportunities to meet their developmental needs through building social connections and social roles (AYACNA, 2020; Moss et al., 2019). Methodologically, studies tend to conflate diagnostic stages, blurring potential stage-specific distinctions. Stage III outcomes may be influenced or overshadowed by Stage IV findings, where similar experiences occur but with potentially greater intensity.

Stage IV. Stage IV may indicate a terminal prognosis and typically involves complex, aggressive treatment regimens (Kim et al., 2016). Most global and local studies have instead focused on survivorship experiences (Belpame et al., 2019; Nandakumar et al., 2018; Tometich et al., 2024), resulting in an unclear understanding of how Stage IV might shape adolescent cancer experiences.

In Aotearoa, adolescents in stage IV frequently confront profound uncertainty, fear, and anticipatory grief, as documented in the limited international literature (Drew et al., 2019; Harris et al., 2022). The AYACNA survey report critiques the international biomedical focus, which narrowly prioritises the physical while overlooking potential existential and psychosocial distress (Moss et al., 2019). However, as Quinn et al. (2015) critique, AYA literature findings may not be generalisable to adolescents due to potentially significant developmental differences in cognitive and meaning-making capacities, leaving the broader non-physical impacts of stage IV cancer experiences poorly understood. Moreover, in the limited existing research, questions are raised about whether the cultural narrative of adolescent resilience in the face of adversity—often idealised in clinical settings—may be more pronounced at this stage, potentially leading to greater silencing of expressions of vulnerability and emotional pain than in earlier stages.

In sum, while there is clear recognition of how biomedical outcomes vary across cancer stages (Koo et al., 2020; Whitaker, 2020), existing literature on the psychosocial outcomes of each cancer stage remains limited and mixed. These research limitations make it difficult to meaningfully compare generalised findings across cancer stages in local and international studies, a gap that reinforces the rationale for the present study's focus on adolescent cancer experiences while accounting for diagnostic-stage-related nuances, enabling contextually grounded insights into the diverse factors that influence adolescents' cancer experiences.

The Impacts of Cancer on Adolescents' Well-Being

Cancer can present a wide range of co-occurring positive and negative well-being outcomes, with global research increasingly moving beyond biomedical interpretations and towards a more holistic and culturally informed perspective (Drew et al., 2019; Quinn et al., 2015). Given that most of the existing knowledge on cancer experiences is drawn from broader AYA literature, the ways cancer specifically impacts adolescents' well-being remain poorly understood. The following section is structured using the Te Whare Tapa Whā framework, and examines how cancer affects adolescents' social, psychological, spiritual, and physical well-being.

Social Well-Being

Cancer may have significant implications for an adolescent's social well-being. Landmark international population-based research from the United States and the United Kingdom has documented cancer's conflicts with AYA developmental norms, resulting in peer disconnection, redefined family roles, and reduced social skill development because they are frequently absent from peers and everyday social settings (Smith et al., 2019; Wickramasinghe et al., 2025). Extending this literature, Fladeboe et al. (2023) and Juth's (2016) adolescent-focused research indicates both overlap and divergence from AYA findings, demonstrating that while similar patterns of social disruption occurred, adolescents experienced social changes through a developmentally distinct lens, where impacts to peer connections were more impactful to their identity formation and the consolidation of social belonging. Evidence from a large-scale systematic review indicates that adolescents who experienced developmentally inappropriate social support had poorer social well-being outcomes, including feelings of isolation and sense of not achieving social milestones (Pahl et al., 2021). Similarly, a global NIH survey examining adolescents' social outcomes following cancer indicated that peer isolation within hospital wards and limited support from friends and family exerted a stronger negative influence on adolescents' social outcomes than the direct effects of cancer symptoms or treatment (Cayrol et al., 2024).

However, most existing research relies on deficit-based models that overemphasise adverse social well-being outcomes. For instance, Quinn et al. (2015) and Bradford et al. (2022), two influential systematic reviews of global AYA cancer experiences, focused narrowly on negative outcomes, overlooking how cancer may give rise to complex, contradictory, or even positive social outcomes. In contrast to this deficit-based research focus, Janssen et al.'s (2025) Strong-AYA project on AYA social well-being impacts from cancer in the United States adopted a more holistic approach, identifying potential positive outcomes, such as increased social connectedness, quality of peer interactions, and a greater sense of support by friends during this time, which may support feelings of developmental normalcy for adolescents. Janssen et al. (2025) concluded by challenging the reductive cultural assumption that cancer inevitably results in social harm, further demonstrating that, even amidst experiences of isolation and unmet developmental needs, adolescents may still perceive positive social outcomes.

Nonetheless, the limited international literature on adolescent-specific social well-being outcomes remains mixed, with conclusions largely dependent on the nature of the social interaction examined, reflecting differences in developmental social norms across relationships (Bradford et al., 2022; Quinn et al., 2015). Pahl (2021) identified that, for adolescents, support from friends—such as spending time together or helping with tasks—is perceived positively, whereas similar involvement from parents is perceived as an unwanted reliance, overprotective, or intrusive, straining familial dynamics as support is likely perceived as undermining and conflicting with their want for autonomy and developmental normalcy.

Drew et al.'s (2019) meta-analysis using population-based data from the US National Cancer Network reported positive social well-being when adolescents were treated normally by peers during treatment, while in contrast, LaRosa et al.'s (2017) research centred on family relationships revealed negative social well-being disruption as support conflicts with developmental norms, creating a sense for adolescents of moving backwards into negatively perceived childhood social roles. According to Janssen et al. (2025), these variations in research findings reflect a deeper methodological inconsistency in the field, where narrow, reductionist approaches—often focusing on a single type of social interaction—fail to capture the diversity and uniqueness of adolescent social worlds and therefore, while negative outcomes do occur, interpretations require caution to avoid an overly negative portrayal of social well-being outcomes.

In Aotearoa, there is a dearth of literature on this topic, raising potential concerns about the age-appropriateness and responsiveness of current cancer care models used to support adolescent social well-being. Pahl et al.'s (2021) recent systematic review of global research on social well-being outcomes in adolescents with cancer identified one Aotearoa study (Yallop et al., 2013), indicating minimal representation of Aotearoa adolescents' cancer-related social well-being needs. Yallop et al. (2013) conducted a quantitative case-control study examining the psychosocial well-being of adolescent cancer survivors using adapted questions from the Aotearoa Youth'07 well-being survey. The authors reported that Aotearoa adolescent cancer survivors (aged 12–16 years) demonstrated psychosocial well-being comparable to, and in some cases better than, their peers, challenging assumptions that survivorship (particularly the late effects) is uniformly associated with poorer well-being outcomes (Yallop et al., 2013). Most participants did not report elevated levels of anxiety, depression, or lower self-esteem relative to healthy peers, suggesting that the late effects of cancer may not negatively impact adolescents' perceived sense of well-being (Yallop et al., 2013). However, these findings raise questions regarding the influence of developmental positioning on reported well-being outcomes, as younger adolescents in survivorship may benefit from protective factors including limited cognitive maturation, which may limit self-awareness of social difficulties, alongside a greater normative reliance on family support (McLoone et al., 2021; Yallop, 2013). Such developmental protections may partially explain the largely positive adjustment reported among the younger adolescents in this study, contrasting with recent AYA cancer literature which identfies poor adjustment and significant psychosocial challenges among individuals in later adolescence and early adulthood (AYACNA, 2021; Moss et al., 2019).

Critically, the transferability of survivorship findings to other contexts is limited, as adolescents undergoing an active diagnosis may experience greater medical uncertainty and certain treatment-related contexts that may uniquely shape social well-being outcomes. More recent research suggests that adolescents’ cancer experiences can alter their peer relationships, with extended time in hospital and absence from school reducing the frequency and quality of peer connections, limiting social interactions with age-similar peers, and restricting opportunities for age-typical experiences that are critical for achieving milestones surrounding social skill competence (Moss et al., 2019).

In sum, although there is growing acknowledgement that adolescence represents a distinct developmental period in which social relationships, peer belonging, and social role changes are central (Drew et al., 2019; Pahl et al., 2021; Yallop, 2013), existing literature examining adolescents’ social well-being during cancer remains limited by a lack of developmentally grounded and relationship-differentiated analysis. As a result, the complexity and variability of adolescents’ social outcomes across diagnosis and treatment are insufficiently captured. These clear gaps in literature reinforce the rationale for the present study, which holistically examines adolescents’ social well-being during cancer by recognising how the illness may both strengthen and disrupt peer relationships, family dynamics, and broader social interactions.

Psychological Well-Being

Cancer treatment-related neurocognitive impairments—including “chemo brain”, deficits in memory, concentration, and attention, and challenges with cognitive flexibility—are well documented in large-scale international research by the NIH (Jim et al., 2018; Tometich et al., 2024). However, the interaction between these neurocognitive changes and adolescents’ broader psychological well-being outcomes remains poorly understood globally. This is reflected in the findings for of a WHO (2023) study where nearly 40% of US adolescents with cancer experienced unmet psychological needs related to fear, worry, and anger, indicating that current service models are likely failing to integrate adolescent developmental and emotional complexity into their current psychological care practices.

Emerging evidence using international GCO data further supports that cancer treatments for adolescents can impair executive functioning and emotional regulation by disrupting critical developing neurological processes, which, compared to adults (whose neurobiology and emotional regulation are fully formed), heightens their vulnerability to mood and anxiety disorders (Jim et al., 2018; John et al., 2016). In addition, Wong et al.'s (2017) comprehensive international meta-synthesis examining the unmet needs among AYA cancer survivors highlighted how cancer-related neurodevelopmental disruption can interfere with normative developmental processes, including emotional regulation and resilience formation, thereby potentially increasing adolescents' risk of developing mood disorders. Meanwhile, findings from Smith et al.'s (2019) international population-based AYA HOPE study and Drew et al.'s (2019) adolescent-focused cancer research indicate that psychological outcomes such as depression and anxiety are frequently overlooked or downplayed during cancer care. Cancer-related emotional distress was often interpreted by others as age-typical emotional volatility, contributing to patterns of dismissal or under-recognition of adolescents' psychological needs within healthcare settings (Smith et al., 2019). Consequently, despite experiencing significant psychological distress and having limited cognitive and emotional development, adolescents are often expected to make decisions and keep up with a fast-paced and overly clinical communication style that is poorly aligned to their developmental stage (Taylor et al., 2019). These age-inappropriate practices have been associated with heightened stress, cognitive overload, and dissatisfaction with care by adolescents (Vandermorris et al., 2020; WHO, 2023).

Similarly, in the 2018 AYACNA patient experience survey, approximately 67% of adolescents experienced cognitive or emotional regulation difficulties during their cancer treatment journey, which is higher than the rates for age-matched international peers documented in NIH research (Moss et al., 2019; Tometich et al., 2024). Poor psychological outcomes represented in these findings may reflect both adolescents' heightened developmental sensitivity to cancer-related stress and the relative scarcity of age-appropriate, developmentally informed support within Aotearoa's oncology system, which is yet to be addressed. Local studies echo global findings where adolescents lack metacognitive capacities to recognise or articulate cognitive-emotional well-being needs, which, alongside a lack of executive functioning and reduced planning capabilities, may contribute to experiences of internalised distress and under-recognised neuropsychological needs by clinicians (Ballantine et al., 2017; Sligo et al., 2019). When situating research within Aotearoa's sociocultural context, it could be suggested that adolescents' poor psychological well-being outcomes may be exacerbated by structural issues in the country's current psychosocial care system, which remains anchored in adult-centric biomedical models that neglect adolescents' neurodevelopmental complexity.

Additionally, research in Aotearoa consistently documents elevated rates of depression, anxiety, and guilt among adolescents with cancer—often associated with feeling like a burden to others—potentially leading to negative internalisations of cancer experiences (Marsh et al., 2024). AYACNA reported similar findings, with fewer than 40% of adolescents reporting that their emotional needs were adequately met during treatment (Moss et al., 2019). However, despite robust evidence of psychological distress, no nationally coordinated services currently provide tailored interventions that address adolescents' specific psychological concerns outside of an AYA context, mirroring the international scene (Drew et al., 2019; MOH, 2019). While most global adolescent cancer studies use deficit-based frameworks that view cancer as uniformly traumatic, emerging research argues that this is an overly simplistic interpretation, with recent studies showing a more complex emotional spectrum is experienced, including fear, relief, confusion, and mental resilience (Smith et al., 2019; Taylor et al., 2019). Adolescent psychological complexity is supported by Moss et al. (2019), who found that while many adolescents reported high levels of emotional distress (e.g., anxiety, embarrassment, fear), this distress can coexist alongside feelings of optimism, compassion, and hope, challenging one-dimensional views of adverse cancer-related psychological outcomes.

The neurobiological effects of cancer during adolescence are well recognised, with studies consistently demonstrating that cancer treatments—particularly chemotherapy and cranial radiation—can disrupt normative neural maturation (Koo et al., 2020). Evidence indicates that up to 40% of adolescents with cancer experience neurocognitive impairments from treatment across multiple domains, including attention, executive functioning, planning, cognitive flexibility, and memory, affecting daily psychological functioning (John et al., 2016; Marusak et al., 2018). These treatment-related disruptions are associated with behavioural and emotional difficulties that extend beyond isolated cognitive deficits, shaping adolescents' everyday psychological functioning and capacity to engage with social environments (McLoone et al., 2021).

However, the extent to which these neurobiological alterations translate into psychological dysfunction varies according to cancer type, treatment intensity, and age at diagnosis (Rosgen et al., 2022), reinforcing the heterogeneity of adolescents' psychological well-being outcomes. Several population-level studies link treatment-related neurobiological deficits to greater psychological vulnerability regarding risks of anxiety, depression, and emotional dysregulation (Chidobem et al., 2022; Patterson et al., 2012). At the same time, other literature highlights that adolescents' heightened neuroplasticity and psychological adaptation capabilities may buffer or mitigate the intensity of psychological outcomes compared to older adults (e.g., Fladeboe et al., 2023). Moreover, while neurobiological disruptions are often treated as objective outcomes, their psychological consequences are deeply shaped by developmental context. For example, diminished cognitive flexibility or slowed processing can exacerbate feelings of incompetence or emotional turbulence during a life stage defined by autonomy and identity formation (Jim et al., 2018; Marusak et al., 2018).

In sum, adolescence represents a unique developmental stage in which ongoing neurocognitive maturation and still-developing emotional regulation render psychological well-being particularly vulnerable to the challenges of cancer (Fladeboe et al., 2023). Research into psychological outcomes from cancer has previously been dominated by deficit-focused psychopathy frameworks, constraining a phenomenological understanding of how adolescents psychologically experience and make sense of cancer. These literature gaps reinforce the rationale for the present study, which alongside other well-being domains, seeks to explore the full spectrum of adolescents' psychological well-being outcomes from cancer, attending to developmental nuances in neurodevelopmental and emotional processes to generate in-depth, relevant, and adolescent-specific insights.

Spiritual Well-Being

Spiritual well-being remains one of the most underexplored aspects of cancer outcomes in foundational and contemporary adolescent cancer research. The frequent conflation of spiritual well-being with psychological outcomes in large-scale national studies obscures the distinct and potentially unstable nature of this domain, which—when compounded by cancer—may impact adolescents' developing identity, values, and perceptions of self-worth. However, there remains no clear consensus regarding how spiritual well-being for adolescents is affected by cancer, highlighting an important gap in the literature. Some older studies suggest patterns where cancer may amplify adolescents' normative existential questioning regarding who they are and their purpose in the world, resulting in poorer quality of life outcomes compared to healthy peers (McNeil, 2016; Wener & Woodgate, 2013). However, according to recent research, these foundational studies relied on traditional, religion-centric definitions of spirituality, resulting in outdated conceptualisations that fail to align with contemporary understandings of spiritual well-being grounded in self-perceptions, identity, and gratitude (Juškauskienė et al., 2023; Oyedele et al., 2024; Tirgari et al., 2022; Wei et al., 2025). This conceptual mismatch may limit the relevance and transferability of earlier research findings for a substantial proportion of adolescents today.

Even within religious-focused research, findings are mixed. Religious affiliations can provide comfort, hope, and a sense of control to some adolescents during challenging cancer experiences (McNeil, 2016), with other research similarly identifying how faith can positively affect cancer-related suffering interpretations (Park & Cho, 2017). However, faith-based benefits were not universal. Mahayati et al.'s (2018) US study found that, for some adolescents, cancer precipitated adverse spiritual well-being outcomes, including frustration or anger towards God, confusion surrounding beliefs, and tension between faith-based interpretations of illness and their medical reality.

Challenging religion-centric perspectives, both international and Aotearoa research suggests that non-religious dimensions of spirituality—such as self-worth, identity, and purpose—are equally critical and may be more universally relevant for adolescents, aligning closely with their core developmental tasks of autonomy, meaning-making, and self-definition that transcend specific religious or cultural affiliations (Barton et al., 2018; Tirgari et al., 2022; Tulip, 2021). Tirgari et al.'s (2022) systematic review of global research exploring spirituality in AYAs with cancer suggests that cancer's disruption to adolescents' sense of self-worth and self-esteem may function as a distinct mechanism of distress rather than a secondary outcome of psychological difficulty, indicating a potential bidirectional relationship between spiritual and psychological well-being. In the United Kingdom, Wickramasinghe et al.'s (2025) BRIGHTLIGHT study similarly found that cancer can disrupt adolescents' developing self-concept through unwanted physical appearance changes, delays in developmental milestones, and strained social roles—factors that critically affect spiritual well-being in a life stage when adolescents' identity and worldviews are unstable and rapidly evolving. Collectively, the above local and international research findings underscore a clear need to expand definitions of spiritual well-being beyond religion and towards a culturally inclusive, developmentally grounded definition that accounts for the diversity of adolescents' spiritual outcomes during their cancer journey in Aotearoa.

Adolescents may be more vulnerable to cancer-related identity disruptions than young adults, whose identities are more stable (Wickramasinghe et al., 2025). However, adolescents' developmental sensitivity is rarely theorised in spiritual well-being research, warranting further investigation. While some international studies report strengthened spiritual well-being among young adults with cancer (e.g., McNeil, 2016)—possibly linked to more advanced cognitive maturity, abstract thinking, and stabilised value systems—adolescents' still-developing abstract reasoning and value systems may lead to them having more intensive or unstable spiritual experiences, underscoring the importance of considering developmental stage within this well-being domain. In contrast to these narratives of spiritual distress, findings from the 2018 AYACNA patient experience survey (Moss et al., 2019) and Albert et al.'s (2024) Kaupapa Māori study indicate that Māori adolescents often self-reported strengthened self-esteem and self-efficacy throughout their cancer journey. These findings raise questions about whether cultural identity may serve as a protective resource during traumatic life events, but this remains incompletely understood.

Overall, the literature demonstrates that while spiritual well-being is increasingly acknowledged as an integral area impacted by cancer for adolescents (Mahayati et al., 2018), it remains conceptually fragmented, culturally constrained, and insufficiently theorised from a developmental standpoint. The persistent conflation of spirituality with either psychological well-being or religious beliefs may obscure the broader existential and identity-based developmentally driven processes through which adolescents make sense of cancer and themselves. Accordingly, this study seeks to address this gap by defining spiritual well-being in a way that is inclusive, contextually grounded, developmentally coherent, and culturally sensitive, enabling a wider spectrum of spiritual well-being outcomes as experienced and perceived by adolescents to be understood.

Physical Well-Being

Extensive research has explored the physical dimensions of cancer surrounding symptomatology, survival and mortality rates, and other clinically oriented outcomes (Kestler & LoBiondo-Wood, 2012; Pina-Sanchez et al., 2021). It is well documented globally that adults with cancer face an increased risk of chronic fatigue, impaired physical functioning, and reproductive complications from treatments (Koo et al., 2020; Whitaker, 2020). However, comparatively few studies have examined physical outcomes of cancer specifically among adolescents, obscuring potential age-specific patterns in symptom risk, recovery, and the ways these physical changes are experienced and understood. International research suggests that AYAs with cancer may face an elevated risk of growth and development complications, significant late effects, and poorer physical quality of life compared to healthy matched peers (Harris et al., 2022). In addition, studies indicate that AYAs undergoing more intensive treatment regimens or longer hospitalisation have a higher likelihood of adverse long-term outcomes, including chronic illness (affecting approximately two in three), greater limitations in physical functioning, and long-term loss of strength (Close et al., 2019; WHO, 2023).

Te Aho o Te Kahu (2024) report that the acute, short-term physical impacts of cancer—across diagnosis and treatment—commonly include pain, fatigue, nausea, reduced strength, and visible changes such as hair loss, all of which likely disrupt adolescents' daily functioning and routines. The landmark AYA HOPE study reported that greater limitations in physical functioning and mobility, alongside visible appearance changes during treatment, are associated with reduced self-reported quality of life, as physical appearance is a key aspect of adolescents' developing sense of belonging, normalcy, and identity (Smith et al., 2019). Although some research concludes that there are no significant differences in cancer's physical presentation between adolescents and young adults (Koo et al., 2020), the meaning attached to physical changes might be more pronounced for adolescents as these non-normative changes are occurring during an already sensitive period of rapid and developmentally significant normative physical transformations which are often distressing and uncomfortable (Zebrack et al., 2013).

The relevance of developmental context to adolescent cancer experiences is supported by recent research by Marsh et al. (2024) and a BRIGHTLIGHT study (Wickramasinghe et al., 2025), where adolescents frequently described visible physical changes—such as hair loss or swelling—as particularly challenging, as they occur during an already vulnerable stage of physical development, making physical well-being adjustment more difficult than for other age groups.

Using GCO data, Pina-Sanchez et al. (2021) identified consistent patterns in the physical presentation of cancer, such as weakness or muscle loss, across age groups, with these objective bodily outcomes less susceptible to interpretive variation than the broader psychosocial dimensions of well-being. However, this biomedical reductionist view of physical well-being can obscure important differences in how adolescents perceive and experience these physical effects. AYACNA found that approximately 40% of adolescents self-reported ongoing pain, with both the frequency and intensity increasing across treatment (Moss et al., 2019). Importantly, the report highlighted how age-related barriers affected adolescents' experiences of these physical well-being outcomes, particularly in whether their pain reports were believed and adequately supported within healthcare settings (Ballantine et al., 2018; Moss et al., 2019).

AYACNA (2020) subsequently reported that adolescents treated in paediatric settings were 2.5 times more likely to report satisfaction with pain relief and physical well-being support than those treated in adult spaces, which tend to prioritise biomedical efficacy over developmentally focused care. The same report noted that fewer than half of adolescents aged 16–20 reported receiving adequate pain management, suggesting a persistent shortfall in meeting adolescents' physical well-being needs. Overall, existing research suggests that although the physical effects of cancer are objectively understood, the intensity and impact of these outcomes for adolescents are likely impacted by contextual and developmental factors, but this rudimentary understanding in the literature requires further research.

A significantly underexplored aspect of adolescent physical well-being impacts from cancer surrounds fertility. International research by WHO (2023) highlights that fertility preservation and counselling should be prioritised within AYA oncology services. However, international evidence presented by Nelson and Levine (2023) and the AYACNA patient experience survey (Moss et al., 2019) indicate that adolescents frequently receive little to no fertility-related support, or are provided with resources that are developmentally inappropriate. This fertility support gap exists despite extensive self-report evidence identifying fertility as a frequently unmet aspect of adolescents' physical well-being during their cancer journey (Drew et al., 2019; McLoone et al., 2021).

From a developmental standpoint, fertility complications from cancer extend beyond clinical implications; reproductive issues can disrupt key adolescent developmental processes, including identity formation, sense of bodily control, future-oriented thinking and planning, and evolving self-concept (Maree, 2021). Unlike older adults—who typically approach cancer-related fertility threats from the context of established family structures or a more stable reproductive stance—adolescents experience these threats amid heightened normative uncertainty in their reproductive identity and imagined futures surrounding family (Kim et al., 2016; WHO, 2023).

In sum, while there is strong evidence that the physical manifestations of cancer appear largely consistent across age groups globally (Harris et al., 2022), existing research mostly emphasises biomedical symptom profiles rather than how these physical changes are lived, interpreted, and experienced by adolescents, making international research comparisons to Aotearoa contexts difficult. These gaps reinforce the present study's rationale, which recognises that adolescents' physical well-being is developmentally situated, encompassing biomedical outcomes, embodied experiences, functional change, and future reproductive concerns, to generate contextually grounded insights into how adolescents uniquely perceive and experience these physical well-being consequences of cancer.

Study Rationale

The international scope of cancer research has increased in recent years, yet the majority of studies informing current knowledge still originate from the United States and the United Kingdom (Pahl et al., 2021; Quinn et al., 2015). Awareness of the geographical concentration of literature is important as culture profoundly shapes how illness is experienced and understood (Albert et al., 2024; Huria et al., 2017). Most landmark research is situated within the US healthcare system and sociocultural frameworks, which differ markedly from the Aotearoa cultural context (Jones et al., 2023; Wilson et al., 2021). Consequently, international findings often conflict with local evidence, raising questions about the applicability of overseas research to Aotearoa adolescents' experiences and well-being outcomes. The scarcity of Aotearoa-based research—and the near-total exclusion of Māori adolescents, despite their disproportionate cancer burden (MOH, 2021)—further undermines the relevance and generalisability of the broader evidence base. Consequently, the use of overseas findings to inform local support practices likely contributes to the unmet needs and dissatisfaction with cancer support services reported by Aotearoa adolescents (Moss et al., 2019). The current study addresses the limitations mentioned by focusing on adolescents living in Aotearoa, enabling locally relevant insights that reflect Aotearoa's unique healthcare, social, and cultural contexts, which impact adolescents' cancer experiences and well-being.

A key limitation of existing literature is the frequent reliance on proxy reports from parents, siblings, or healthcare professionals to describe adolescents' cancer experiences (Kim et al., 2020).

Although this data collection method is ethically less complex and more practical—avoiding challenges such as treatment schedules or adolescents being too unwell to participate—findings consistently show that proxy reports diverge substantially from adolescents' direct accounts, particularly regarding the intensity and nature of their internalised distress and psychosocial needs (S. J. Erikson et al., 2017; Schwartz-Attias et al., 2022). International research has shown that parents often misinterpret or minimise adolescents' well-being outcomes, particularly internalised perceptions, with discrepancies increasing with age (Darcy et al., 2014). For example, in Aotearoa, Moss et al. (2019) found that while parents frequently equated "being there" with physical presence, adolescents described this well-being need in terms of emotional connection and meaningful relational support. Earlier international research similarly demonstrates that these two forms of data collection often produce conflicting findings, reflecting a fundamental disconnect between adult interpretations and adolescents' complex lived experiences, which are developmentally and contextually shaped (Darcy et al., 2014; Quinn et al., 2015).

Additionally, proxy reports often prioritise adult or clinical concerns, such as treatment adherence, while underestimating critical relational, emotional, and developmental aspects of adolescents' self-reported cancer realities (S. J. Erikson et al., 2017; Pathrose et al., 2025). Consequently, researchers have started to question the validity of proxy-based studies and their capacity to accurately reflect the full spectrum of adolescents' cancer experiences and well-being needs (Kim et al., 2020). The current study addresses this methodological limitation by privileging adolescents' own voices through using self-reported data to generate more developmentally accurate and representative insights that capture their whole world of lived cancer experiences and well-being.

Another rationale for this study is that much of the existing research on cancer experiences and unmet well-being needs focuses on adolescents in the survivorship stage, where their well-being needs may not accurately reflect those of adolescents who are undergoing active treatment or have been recently diagnosed (Pahl et al., 2021; Tometich et al., 2024; Wong et al., 2017). Although asking participants to reflect on survivorship rather than on experiences during active treatment reduces ethical and practical challenges associated with engaging adolescents during periods of heightened vulnerability and prognostic uncertainty, this approach limits insight into the immediate, evolving, and emotionally complex realities of adolescents' lived cancer experiences at diagnosis and throughout treatment (Drew et al., 2019; Smith et al., 2019). While survivorship-focused designs have generated valuable knowledge regarding late effects, long-term well-being, adjustment, and recovery, and have informed international efforts to strengthen post-cancer support services (Chidobem et al., 2022; Iannarino et al., 2017), they also introduce important interpretive constraints. Findings derived from survivorship populations cannot be confidently generalised to adolescents with an active diagnosis or undergoing treatment, as in-the-moment well-being needs are shaped by distinct conditions of uncertainty, treatment burden, and developmental disruption that differ fundamentally from the recovery-oriented context of survivorship (Barr et al., 2016; Vancoppenolle et al., 2025).

As a result of the global focus on the survivorship stage of adolescents' cancer journey, the literature findings may disproportionately represent the perspectives of those who have recovered well enough to participate, potentially skewing understanding towards narratives of resilience and post-traumatic growth while obscuring the distress, disruption, and developmental challenges experienced during active treatment (Wong et al., 2017). Consequently, this study addresses this limitation by recruiting adolescents with an active cancer diagnosis to capture their real-time lived experiences and self-reported well-being outcomes during diagnosis and treatment, rather than relying on survivorship-focused accounts that generalise poorly to this group.

Much of the international and national evidence reviewed in this chapter derives from studies that conflate adolescents within the broader AYA category, with few explicitly distinguishing between adolescents and young adults. This lack of differentiation persists despite emerging adolescent-specific research demonstrating divergent findings that highlight clear developmental non-homogeneity (Drew et al., 2019; Juth, 2016; Pathrose et al., 2025). Although AYA grouping in cancer research offers pragmatic benefits, such as larger sample sizes and simplified analyses, it does not account for critical developmental and psychosocial distinctions (Fladeboe et al., 2023). Adolescence is marked by heightened identity exploration, peer influence, and emerging autonomy, whereas young adulthood typically involves greater life stability and a more established identity (E. H. Erikson, 1970; Syed & McLean, 2017). Conflating these developmental stages may contribute to the developmental under-theorisation of adolescent cancer experiences, potentially risking the misrepresentation of adolescents' age-specific well-being needs.

Developmental stage significantly shapes how individuals experience illness, cope with treatment, and conceptualise well-being needs (Janssen et al., 2025; NASEM, 2020). The oversimplification in existing local research likely contributes to inconsistencies in psychosocial findings and constrains the development of age-responsive cancer care in Aotearoa (Pahl et al., 2021; Quinn et al., 2015; Sligo et al., 2019). Consequently, AYA-focused findings cannot be reliably extrapolated to adolescents, leading to confusion and uncertainty about their unique experiences and well-being needs—a gap reflected in persistent reports of low satisfaction among Aotearoa adolescents receiving cancer care, as documented by AYACNA (Ballantine et al., 2018; Moss et al., 2019). To address this common limitation in the literature, this study focuses exclusively on adolescents aged 16–21, exploring their cancer experiences and well-being outcomes separately from young adults to reflect their developmental specificity and avoid the oversimplifications inherent in broader AYA research.

In sum, given the limited recognition that adolescence represents a distinct developmental stage shaping how cancer is perceived and experienced, the existing evidence base remains minimal, fragmented, and largely generalised from broader AYA studies—both internationally and within Aotearoa. Heavy reliance on proxy reports, survivorship-focused designs, and AYA conflation obscures adolescents' developmental specificity, contributing to the absence of a clear consensus regarding the nature and intensity of adolescents' cancer experiences and well-being outcomes.

Within the Aotearoa context in particular, no dedicated research has explored the full scope of holistic impacts of cancer specifically among adolescents, nor has existing work incorporated culturally grounded well-being Māori frameworks into the discussion of findings related to their lived cancer experiences. Consequently, the rationale for this research arises from the ongoing absence of adolescent-focused cancer studies in Aotearoa, alongside the persistent reports of their unmet well-being needs in national cancer experience surveys (Moss et al., 2019). Ultimately, the multiple research gaps identified in this chapter underscore the timeliness of the present study, which focuses on adolescents' lived cancer experiences and holistic well-being outcomes, using a methodology that privileges adolescent self-report and employs frameworks attentive to developmental and cultural nuances. It is anticipated that such an approach will enable in-depth, contextually grounded insights into how adolescent-specific experiences, perceptions, and well-being outcomes can be understood in the Aotearoa context, generating original, critically needed knowledge. The following chapter discusses the research design and methodology used to address past research limitations and achieve the study's research aim.

Chapter Three: Methodology

This chapter outlines the qualitative research design used to address the study's aim. The first section examines the study's philosophical foundations and how these informed key methodological decisions. In the second section, ethical and cultural considerations are presented, including the study's alignment with the principles of the founding document of Aotearoa New Zealand (hereafter Aotearoa), Te Tiriti o Waitangi | the Treaty of Waitangi (1840). Information on participant details, recruitment strategies, and data collection procedures is outlined in the third section. The chapter's final section documents the data analysis process employed in this study.

Philosophical Underpinnings

The subsections below are organised hierarchically, progressing from the highest philosophical stance level (ontology) to the lowest level (theoretical perspective), with each level providing the conceptual scaffolding for the next (Rochecouste, 2001). The final subsection describes how these philosophical foundations collectively underpin the key methodological choices made to address the research aim.

Ontology: Realism

Realism considers reality as existing independent of human thoughts, perceptions, language, or interpretations (Crotty, 1998). From a realist perspective, social, psychological, and physical experiences are understood as real phenomena that exist and operate regardless of individuals' awareness or engagement with them (Armstrong, 2019). Although the external world is not constituted by human consciousness (and persists independently of it), experiences remain devoid of meaning unless they are acknowledged and interpreted through human awareness (Wener & Woodgate, 2013). Accordingly, realism believes in an underlying reality even when it is understood or experienced differently by individuals, with experiences shaped by real structures and conditions, including social systems and institutions (Crotty, 1998).

In this study, cancer is understood as a real phenomenon with physical, psychological, and social outcomes—such as fatigue, neurocognitive changes, and altered family roles—which exist and operate independently of adolescents' conscious awareness (Rochecouste, 2001). Within data interpretations a realist ontological perspective foregrounded the assumption of a single underlying cancer reality, within which treatment processes, healthcare systems, and ward environments (real mechanisms and structures), may shape diverse subjective interpretations. A realist ontological stance justified the use of reflexive thematic analysis (RTA; Braun & Clarke 2019) by recognising that the data collected reflected multiple, meaning-laden interpretations of acknowledged cancer-related phenomena, without negating the existence of a shared underlying cancer reality (Wener & Woodgate, 2013). For example, real treatment-related side effects and interactions within healthcare environments for some may be perceived as well-being outcomes characterised by bodily disconnection and feelings of not belonging. In practice, realism-informed data interpretation recognised that participants' lived cancer experiences were rooted in objective conditions and realities. A constructionist epistemology was used to understand how adolescents made sense of and responded to these experiences within their social and cultural contexts.

Epistemology: Constructionism

Constructionism positions knowledge as socially and culturally created through interactions, with individuals as both learners and meaning-makers (Crotty, 1998). Aligned to realism, constructionism views meaning as not fixed or inherent to reality, but instead actively created (Armstrong, 2019). People can shape—through social milieus and cultural interactions—the meaning-making of objects in the world realists say already exists (Dominic, 2023). Crotty (1998) argues that no one is culture-free; everyone is born into the world encased in a "mantle of meaning" (culture) that influences all experiences, which phenomenology seeks to remove. From a constructionist view, culture reflects meanings created by others that individuals inherently enter and engage with (Dominic, 2023).

Aligning with constructionist epistemology, this study explored the created knowledge within the existing world of being an adolescent with cancer in Aotearoa. Constructionism guided data interpretation by foregrounding the meanings adolescents created in relation to their self-reported cancer experiences and well-being outcomes. Participants' interpreted meanings of their cancer experiences were not fixed but co-constructed through interactions with the researcher, their unique perspectives, and the cultural meanings created by those who have previously navigated this world (Rochecouste, 2001). Constructionism, which views meaning as socially co-created through interactions and grounded in cultural and contextual realities (Dominic, 2023), supports the use of semistructured, open-ended interviews to capture the broader contexts shaping adolescents' meaning-making of cancer experiences. Lastly, constructionism informed the use of RTA, recognising that everyday cancer experiences and well-being perceptions are shaped by mantles of meaning encompassing cultural and systemic contexts, including ward environments and healthcare systems (Rochecouste, 2001).

Theoretical Perspective: Interpretivism (Phenomenology)

Interpretivism, specifically phenomenology, prioritises understanding knowledge through lived experience rather than the discovery of universal truths (Crotty, 1998). Phenomenology seeks to remove the mantle of meaning noted in constructionism, allowing experiences to be explored as new concepts, unfettered by layers of preconceived cultural assumptions or meanings (Dominic, 2023). Phenomenological approaches explore how individuals make sense of their experiences with openness and curiosity, positioning participants as experts of their own experiences and the researcher as the learner (Crotty, 1998). Additionally, phenomenology explores the embodiment of experiences in their nudity of meaning, understanding experiences beyond culturally embedded labels and symbols (Rochecouste, 2001). Alongside constructionism, which examines how meaning is constructed, phenomenology reveals how an experience of a real phenomenon is lived and subjectively made sense of from the participants' perspective (Pyo et al., 2023).

In this study, a phenomenological perspective informed the use of RTA, privileging adolescents' lived accounts of cancer while resisting dominant cultural biomedical narratives and mantles of meaning in data interpretations. Adopting a phenomenological perspective throughout the data interpretation process enabled the development of multiple holistic and alternative insights grounded in how adolescents themselves described and made sense of cancer and its well-being impacts, findings that could challenge prevailing cultural and developmental narratives. A phenomenological perspective also supports the use of semistructured, open-ended interviews, through which knowledge was co-constructed, and participants could freely describe their lived cancer experiences without being led by suggestive cultural assumptions, mantles of meaning, or clinical framings of cancer.

Furthermore, phenomenological research understands that the researcher cannot be neutral; in line with constructionism, how lived experiences are perceived and given meaning does not occur in a social or cultural vacuum (Braun & Clarke, 2019). In this way, it was important for me as the researcher to make explicit my prior experiences, assumptions, and positionality through a reflexivity statement (Crotty, 1998).

Overall, the chosen ontological, epistemological, and theoretical foundations of this study informed the selection of a qualitative methodology and RTA data analysis, which are well suited to address the research aim and objectives. Grounded in the above philosophical foundations, the study will uncover and explore the diverse meanings that Aotearoa adolescents ascribe to their lived cancer experiences and well-being outcomes, alongside how these existing worlds are shaped by interactions, sociocultural contexts, and my positionality as a researcher.

Reflexivity Statement

Both constructionism and RTA principles acknowledge that the philosophical assumptions and biases of the researcher and the chosen methodology of a study, influence the interpretation of participants' experiences (Braun & Clarke, 2019). The co-construction of knowledge was promoted throughout this study, I paid particular attention to potential biases when interpreting what was being said or not said (Braun & Clarke, 2019).

The motivation for this study arose during my time working in oncology hospital settings where I spent time supporting children and families. Supporting Aotearoa's young people introduced me to the diversity of young people's cancer realities. I vividly recall supporting families who had just been told their child had passed away, and trying to help them through their heartache and grief. Equally, I witnessed moments of hope, resilience, and connection in adolescents with cancer: joy in the efficacy of treatment, celebrating milestones, or growing closer to family.

I have worked in oncology support settings for four years. Having spent time alongside youth with cancer, I feel connected to phenomena surrounding this disease, particularly its impact on adolescents' well-being and how healthcare spaces and services can impact their experiences. During my professional engagement, I realised that despite the availability of substantial clinical knowledge and treatment-focused care, adolescents' wider support needs and holistic well-being experiences are often poorly addressed and discussed within oncology spaces. The prevailing discussions instead focus on the negative biomedical consequences of cancer, with limited attention given to their psychosocial, developmental, and contextualised well-being. These experiences motivated me to conduct research where adolescents directed the conversation and their perspectives were foregrounded. Their stories needed to be told by their voices, which I found to be rarely captured in existing literature.

Ultimately, form reflections on my own physical challenges and the time I have spent with young people with cancer in Aotearoa, I felt a connection to this topic and those stories should be shared, which became a passion for amplifying adolescents' voices and creating space for conversations around this topic to become more frequent, with the hope of contributing to positive change in Aotearoa's cancer care spaces.

According to Pyo et al. (2023), reflexive journaling is critical for research focusing on a collection of perspectives and knowledge. Reflexive journaling was therefore conducted (see Appendix B for an excerpt) to increase this study's analytic transparency. Reflexivity practices enabled me to continuously reflect on how my positionality could influence the project, acknowledge my assumptions, and challenge myself to approach adolescents' experiences from a place of openness, with them as experts of their own stories (Braun & Clarke, 2021). Reflexive processes guided several practical decisions: prioritising participants' agency in interviews; carefully attending to power dynamics; ensuring participants' ongoing emotional safety; and ensuring they had opportunities to review, clarify, or amend their narratives and how they were interpreted.

Research Method

Challenging traditional, quantitative research and arguing for a different way of knowing, contemporary qualitative researchers suggest that cancer experiences are more diverse and complex than previously recognised (Pathrose et al., 2025; Quinn et al., 2015). Quantitative measures often simplify complex illness phenomena, focusing on generalisable and statistical outputs rather than addressing the wider context and meaning behind experiences, thereby limiting the phenomenological depth of insights (Pyo et al., 2023). In contrast, this study's qualitative focus moves away from producing probabilistic conclusions to instead generate original insights into adolescents' subjective perspectives on cancer-related well-being, attitudes, concerns, and behaviours, while recognising the influence of broader cultural contexts—including hospital systems and healthcare environments—on their lived cancer experiences.

The flexible approach of semistructured interviews with open-ended questions aligns with the calls for participant-centred qualitative inquiry in healthcare research (Pyo et al., 2023) and research recommendations for novice researchers, as this research design provides enough structure to ensure the research aim is addressed in-depth while still encouraging participants to share their stories freely

(Roberts, 2020). The semistructured approach with guiding questions enabled active involvement by the participants and a deep exploration of the research topic through a conversational style of questioning, with participants having agency in the direction of the topics explored, which limited the risk of developing a hierarchical relationship (Pyo et al., 2023). Ultimately, the study's constructionist epistemology dictated the qualitative methodology and the subsequent semistructured interview style, where knowledge is co-constructed through interactions between the researcher and the participant (Wener & Woodgate, 2013).

For this study, RTA was selected because it supports an inductive analysis where themes and subthemes are developed from participants' accounts, focusing on depth rather than breadth (Braun & Clarke, 2019). Across qualitative psychology research, RTA is a widely used analysis approach (Pyo et al., 2023), and its contextual and meaning-oriented nature is well suited to this study's philosophical positioning, interview-based data collection approach, and subjective narrative data type. Central to RTA is the emphasis on reflexivity and researcher subjectivity (Braun & Clarke, 2019), which aligns with this study's constructionist epistemology and phenomenological perspective, where, according to Rochecouste (2001), meaning is not discovered but socially co-constructed, with the researcher as an active participant. Essentially, unlike other forms of analysis such as content analysis which prioritises coding consistency, RTA's flexible yet rigorous approach supported the interpretation of the shared patterns in adolescents' often complex cancer experiences and well-being outcomes while remaining sensitive to contextual factors (Braun & Clarke, 2021).

In sum, the above subsections justify the use of a qualitative, semistructured research design with RTA for data analysis in this study, demonstrating strong alignment between the method and its theoretical framework, epistemology, and ontology. Methodological coherence enhanced the study's credibility by ensuring that the findings are grounded in participants' voices and meaningfully interpreted in relation to the research aim. The following section outlines the ethical concerns addressed in this study, including measures to minimise potential psychological harm and protect participants' well-being, alongside a discussion of relevant cultural considerations underpinning this research and its alignment with the principles of Te Tiriti o Waitangi.

Ethical and Cultural Considerations

The project was completed in compliance with Massey University's Human Ethics Committee, Ohu Matatika 1, with ethics approval was granted on 4 June 2025 (ref. no. OM1 25/16; see Appendix C). The first subsection outlines the ethical issues addressed in this study, and the second subsection details this research's cultural relevance for Māori, with reference to Te Tiriti o Waitangi.

Mitigating Ethical Issues and Empowering Participants

Prior to conducting this project, the study was deemed high risk because participants were adolescents with an active cancer diagnosis, a population that could be considered medically and developmentally vulnerable. Given the sensitive nature of the research topic, a key ethical concern raised by the ethics committee was how discussing cancer experiences could evoke distress, trigger traumatic memories, or cause psychological harm to adolescents. This feedback and further discussions about this concern resulted in several connected ethical issues being addressed.

A primary practical ethical issue concerned recruitment—the researcher did not want to inadvertently approach adolescents who were vulnerable, had experienced cancer-related trauma, or were currently psychologically unfit to participate. To avoid causing potential discomfort to individuals during recruitment, the researcher did not directly recruit or approach adolescents. All potential participants who considered themselves psychologically fit and who voluntarily wanted to be involved made the initial contact with the researcher. This reduced the risk of recruiting adolescents for whom participation may have been inappropriate or harmful to their well-being.

To reduce the practical ethical concern of distress occurring during or after interviews, the Participant Information Sheet (see Appendix D) included an interview schedule that listed all questions that may be asked so participants could anticipate the topics in advance and assess whether they were in an emotionally suitable place to take part, thereby reducing the risk of unexpected distress. Participants were also reminded that they could decline any question before or during the interview without challenge (none did). Immense care was also taken in designing the inclusion criteria and interview questions to minimise the ethical risk of psychological harm; for instance, the use of open-ended questions avoided unintentionally prompting sensitive or triggering topics. Prior to the interviews, participants were also informed of their right to pause, skip, or stop the interview at any time if they felt uncomfortable to reduce the risk of unintentional distress occurring (no participant exercised this option).

During interviews, the researcher observed participants' non-verbal behaviours for signs of distress and was ready to pause the interview if there were indicators of psychological harm. Ultimately, none displayed distress or visible signs of discomfort. Regardless of how each participant appeared during the interview, every interview concluded with a discussion of how to access free counselling support services, ensuring adolescents had access to professional support should post-interview distress arise. It is unknown whether any participants used these services due to privacy and confidentiality rules. Participants also retained the right to request the removal or modification of their responses for up to three weeks after the interview, giving them agency over the information they shared. No participants asked for their transcript to be edited during this period.

Research Relevance for Māori

This research did not explicitly focus on Māori populations, but the study design deliberately sought to uphold Māori values by aligning with the principles of Te Tiriti o Waitangi—protection, participation, and partnership—which Came and Kidd (2020) identify as critical within cancer research and planning. Through discussions with and feedback from the research supervisor and an informal meeting with a group of Māori researchers, Te Tiriti o Waitangi principles were intentionally implemented across the study design, with every effort made to ensure that Māori adolescents had access to culturally appropriate opportunities to participate.

In the research process there were discussions with the supervisor and a Māori research group about ways to ensure that cultural practices and values were actively considered across all aspects of the research process. For example, in the participant information sheet adolescents were encouraged to share the information sheet and discuss interview topics with whānau (family) for their input and consent because decisions surrounding well-being and potentially tapu (sacred) topics are often discussed as a whānau. Whānau were also welcomed into the research process as a support person in the interview to ensure participation occurred in a culturally safe and supportive manner. The information sheet also detailed the appreciation of participants' time and sharing of knowledge through the giving of koha (gift), recognising the importance of tauutuutu (reciprocity) within the researcher's relationship with Māori (Boardsworth et al., 2024). Study documents also highlighted free access to Māori-specific support services, offering participants culturally appropriate external support spaces to safeguard their well-being during and after participation.

Te Tiriti o Waitangi obligations were upheld through actions that recognised Māori rights to benefit from research that affects them, including respectful engagement with Māori knowledge systems, cultural frameworks, and community groups throughout the research process (Wilson et al., 2021). Integrating Māori concepts of well-being into the discussion of findings strengthened the cultural relevance, Treaty responsiveness, and the practical implications of the research for Māori adolescents. The intention is to eventually share the research findings with local marae (centres for cultural, educational, and spiritual activities for Māori) and Māori organisations, maximising the potential benefits of the findings for Indigenous communities. While the study does not claim to represent Māori voices, it responds to the call to centre Indigenous well-being frameworks within cancer research in Aotearoa (Albert et al., 2024) and lays important groundwork for future Kaupapa Māori-led research.

In sum, the research contributes to amplifying Māori well-being values in cancer care research, which Smyth (2023) argues is critical for the movement towards decolonisation of healthcare research in Aotearoa. The inclusion of Māori well-being frameworks throughout the project fostered a more inclusive and holistic research paradigm that protects and recognises Indigenous knowledge systems as integral to improving Aotearoa cancer-related well-being outcomes.

Data Collection

This section outlines the data collection procedures undertaken in this study, including participant characteristics and recruitment processes. The next two subsections describe the semi-structured interview procedures used for data collection, alongside the transcription transcript review procedures used to ensure accuracy and familiarity with the data prior to analysis.

Participant Details

Seven participants aged between 16 and 21 years (17 years, *n* = 1; 19 years, *n* = 2; 20 years, *n* = 2; 21 years, *n* = 2) were recruited over 3 months (June to August 2025). At the time of participation, four had a stage 2 diagnosis, three had a stage 3 diagnosis, and none had a stage 1 or stage 4 diagnosis. Diagnoses included Hodgkin's lymphoma (*n* = 4), osteosarcoma (*n* = 1), and germ cell tumours (*n* = 2). All participants identified as New Zealand European (Pākehā).

Recruitment

A purposive sampling approach was employed to intentionally recruit participants in this hard-to-reach population who met the eligibility criteria and could meaningfully help address the study's aim. The inclusion criteria required participants to be aged 16–21 at recruitment, have an active cancer diagnosis at any diagnostic stage, reside in Aotearoa, and be proficient in English. Individuals who did not meet the criteria were excluded from the study.

Recruitment approaches included posting flyers (see Appendix E) in publicly accessible, adolescent-focused Aotearoa cancer support groups on Facebook and Instagram. Flyers were also put on public community hub notice and support boards near healthcare settings in Auckland, where no permission for placement was required. Recruitment flyers included key study information, eligibility criteria, and the researcher's contact details. Interested adolescents made initial contact via the provided contact details. Ultimately, five participants were recruited through social media and two through noticeboard adverts.

During participants' initial contact, the researcher answered any questions they had about the study, confirmed eligibility, and emailed relevant documents— interview schedule, participant information sheet, and consent form (see Appendices A, D, and F). To schedule an interview, participants had to return a signed copy of the consent form to the researcher.

Lastly, data saturation was used to determine the final number of participants. Saturation was assumed after seven interviews when it was agreed with the research supervisor that any additional interviews would not provide any new themes (Braun & Clarke, 2021).

Semistructured Interviews

Interviews were held either in person at Massey University's Albany campus in a private room or via Zoom. Each one-off individual interview lasted approximately 30–45 minutes. Four interviews were conducted in person, and three were conducted via Zoom. Data collection ran from June to August 2025.

Before starting each interview, the researcher outlined the interview process, including participants' right to take breaks, skip questions, or stop the interview at any time (no participants requested these options during the interview). The contact details for the support services mentioned on the information sheet were reiterated.

Next, participants were asked whether they had brought a support person; one participant did. Prior to that interview commencing, the support person was asked to take a non-active role, and to not respond to questions on behalf of the participant. The support person was permitted to advocate for the participant's well-being by requesting breaks, pausing or stopping the interview, or suggesting that a question be skipped if the participant showed distress.

Next, the researcher confirmed the participant's readiness and began the interview and audio-only recording. Participants were asked whether they had brought any media with them; one participant brought in beads that visually documented their treatment journey so far. For this participant, the opening question was "I see you brought in your beads—would you be comfortable talking to me about them?" For those who did not bring in media, the first interview question was "What do you think is important for others to understand about your experiences of cancer and how it has impacted your well-being?"

During the interview, only the open-ended questions listed in the interview schedule (see Appendix A) were used. Semistructured interviews were guided by what the participant chose to share, with questions used flexibly rather than as a strict script to encourage a conversational style. The number of questions used varied depending on how much participants wished to share. Open-ended questions provided space for participants to prioritise what mattered most to them and to discuss unexpected or unanticipated experiences or well-being outcomes. Interviews and the corresponding audio recordings ended when participants stated they had no further information to share.

At the end of each interview, the researcher checked in with the participant to ensure they were not experiencing any immediate post-interview distress and reminded them of where to access free support services. No participant experienced visible distress during or immediately after the interview. Lastly, as a gesture of appreciation, each participant was given a $20 Prezzy card as *koha*.

Transcript Review and Editing

Post-interview, I personally transcribed each audio recording verbatim in a Microsoft Word document, listening to recordings multiple times to ensure transcript accuracy. Any personal or identifying information participants mentioned was redacted from the transcript to ensure privacy and confidentiality. The researcher then emailed the participants (within three days of the interview) an editable version of their transcript, along with an Authority for Release of Transcript form (see Appendix G). To include their data in the analysis, participants were required to sign and return the form via email within three weeks, either after editing the transcript or leaving it unchanged; no participant chose to edit their transcript. Once the signed Authority for Release of Transcript form was returned, transcripts could no longer be withdrawn from the study.

Data Analysis

This study adopted Braun and Clarke's (2006) inductive RTA approach, with the analysis conducted on printed transcripts for easier annotation and iterative theme and subtheme construction. An Excel spreadsheet version acted as a digital backup. The six RTA stages, as detailed in subsections below, were used flexibly and iteratively—moving back and forth between stages as understanding of the data deepened—to provide a systematic yet adaptable process for identifying and interpreting shared patterns of meaning in adolescents' self-reported accounts. Across all six stages, a reflexive journal was used to record thoughts on the data and on how my perspectives, positioning, and assumptions impacted interpretations (see Appendix B for an excerpt).

Data Familiarisation

Following transcription, transcripts were read iteratively to increase familiarity and data immersion (Byrne, 2022). During re-readings, initial reactions, reflexive responses, and observations to each transcript were documented in a logbook, alongside initial notes connecting each participant's experiences to the wider dataset (see Appendix H for an excerpt of the digital copy).

Generating Initial Codes

Each transcript underwent several rounds of rigorous manual coding to ensure close engagement with the data and careful identification of meaningful data segments (words and phrases) relevant to the aim (Byrne, 2022). Handwritten notes in the margins and colour-coded highlighting of transcript lines captured recurring ideas, key phrases, and emerging touchpoints that informed later theme development (see Appendix I for an excerpt). Interpretive labels (codes)—concise labels that captured significant or interesting features of the data in relation to the research aim (Braun & Clarke, 2006)—were inductively formed from participants' data. Multiple re-readings of transcripts enabled flexible coding and iterative refinement of provisional codes, open to revisions, merging, or splitting of codes, with reflexive notes made in the journal (see Appendix B for an excerpt).

Searching for Themes

The next stage involved collating initial codes across the entire dataset into provisional themes that captured shared patterns of meaning across participants' cancer experiences and well-being outcomes relevant to the research aim. Searching for themes involved iterative movement between initial codes, candidate themes, and original transcripts, with participant codes examined in relation to one another to identify conceptual similarities, differences, and overlaps (Byrne, 2022). As initial themes began to form, grouped codes were refined by merging, collapsing, and separating of ideas.

Within provisional themes, potential subthemes were developed to capture nuances within initial themes. Themes and subthemes were actively constructed rather than discovered, with the researcher's positionality influencing interpretations.

Review of Themes

Previously constructed candidate themes were iteratively reviewed and refined to ensure each theme meaningfully captured a segment of the overall story and remained relevant to the research aim. Each theme was revisited to assess internal coherence, ensuring that all associated data codes aligned within the overarching theme. The review process involved repeated cycles of reading codes; defining theme boundaries; and, where necessary, merging, splitting, or discarding themes that lacked sufficient data support or relevance to the research aim. Editing continued until each theme and subtheme was distinct, internally coherent, and demonstrated clear relevance to the study.

Reflexive peer reviews were conducted by the research supervisor. Peer reviewing involved reflexive questioning and discussion of how themes and subthemes were conceptualised, including their scope, boundaries, and internal coherence (Braun & Clarke, 2006). Peer reviewer feedback included potential overlaps and boundary issues among subthemes, with the researcher deciding whether to merge or separate them. Reviews were not intended to verify theme accuracy or to achieve consensus, but to function as a reflexive tool alongside the reflexive journal to strengthen the rigour, transparency, and depth of data engagement (Byrne, 2022).

Defining and Naming Themes

In this stage, developed themes and subthemes were named and defined with concise, meaningful labels. Theme and subtheme names were carefully chosen and reviewed to ensure they conveyed a distinct aspect of the narratives and, where possible, drew on participants’ own language (Braun & Clarke, 2021). Distinctive definition boundaries for each theme and subtheme were also clarified to avoid overlap and redundancy. Multiple rounds of reviews and refinement were undertaken to ensure that labels reflected the entire dataset and meaningfully addressed the research aim.

Writing the Report

Final themes and subthemes are presented in Chapter Four, alongside illustrative participant quotes, to demonstrate how the themes and subthemes are grounded in participants' lived experiences. Each theme and subtheme is discussed in terms of what it captures, its relevance to the research aim, and its relation to existing literature and developmental theories.

Summary

This chapter has outlined the study's methodological foundations, which informed the use of semistructured interviews and RTA to explore adolescents' lived experiences of cancer and associated well-being outcomes in Aotearoa. Recruitment, data collection, and analysis decisions were intentionally aligned with the study's aim and objectives, while a critical examination of ethical and cultural considerations contextualised the research and demonstrated sensitivity to the research topic. Collectively, these methodological decisions positioned the research to generate rich, contextually meaningful findings.

Chapter Four: Results

This chapter presents the findings from seven qualitative, participant-led interviews with adolescents aged 16–21 years living with a cancer diagnosis in Aotearoa New Zealand (hereafter Aotearoa). The study aimed to explore adolescents' lived experiences of cancer and the associated impacts on their well-being within the Aotearoa context. Themes were generated inductively using reflexive thematic analysis (RTA), enabling a coherent story to be told that reflected participants' voices and experiences rather than situating them within pre-existing conceptual frameworks. Five overarching themes and associated subthemes were developed, and these are presented in Table 1. Participant quotes are integrated into the chapter to enhance the credibility and validity of the analysis (Braun & Clarke, 2006), with participants coded by age and cancer stage (e.g., 21yr, stage 2). The following subsections present each theme and its associated subthemes in detail, supported by illustrative participant quotes.

Table 1

Summary of Themes and Subthemes

Theme	Theme Heading	Subthemes
One	Connectedness and social participation	1. Strengthening of family relationships 2. Altered non-familial relationships 3. Disruptions to everyday life 4. Missed milestones
Two	Cognitive and emotional responses in the face of cancer	1. The first moments of diagnosis: Emotional reactions

		2. Living between hope and distress: The mental roller-coaster of cancer 3. Future uncertainty and worry
Three	Meaning, identity, and self-reflection	1. Confronting personal vulnerability: The “not me” reality 2. Existential questioning in the face of cancer 3. Identity and self-perception changes
Four	Living in a changed body: Disruption and adjustment	1. My body no longer looks like me 2. Reduced strength and functioning 3. Adjustment to and acceptance of living in a changed body
Five	Navigating belonging in healthcare contexts as an adolescent	1. Invisibility of age-appropriate support 2. Experiencing spaces of non-belonging

Theme One: Connectedness and Social Participation

This theme captures how cancer shaped adolescents’ social worlds, affecting their relationships, support networks, and participation in everyday life. Primarily, this theme includes movement away from previously familiar routines and social roles and towards navigating a changed social landscape with altered everyday lifestyles, missed or delayed milestones, and changing relationships with others marked by both strengthened and lost connections. Participants described shifts in family dynamics as reliance on parental and sibling support increased, alongside experiences of distance, disruption, and loss within friendships and intimate connections. A shared experience noted across narratives was a growing sense of being left behind as peers continued to progress through normative social milestones, with experiences of social comparison and feeling removed from previously occupied everyday activities and lifestyles. The following subsections explore adolescents' interpretive meaning-making processes in relation to how cancer affected their diverse social landscape.

Strengthening of Family Relationships

A shared pattern among most adolescents was experiencing noticeable change in family networks during diagnosis and treatment, with many recalling how relationships were strengthened. Some reflected on relationships deepening through the increased presence of family who continued to visit, with one participant noting, "Some family come over more now and just spend time with me" (20yr, stage 2). Some shared that relationships with their parents and siblings grew closer during their cancer journey, strengthening their family bond and dynamic, with several participant narratives echoing the following sentiment: "My relationship with my family has deepened during this journey" (19yr, stage 2).

A few participants shared gravitating to familiar connections with some relationships becoming "more positive and supportive" (20yr, stage 2) through consistent, ongoing acts of emotional and practical support in what felt like basic tasks, such as regular visits, driving them to hospital appointments, preparing meals, managing medications, and being there as a listening ear.

> I found that because of cancer I gravitated more towards my family for support and building up that relationship from them visiting more where now it [relationship with their family] is stronger than before. (20yr, stage 2)

> Some family still come over quite often when I am in hospital and just simply spend time with me and talk which is nice to have that strong family support during this time. (21yr, stage 2)

> My parents and siblings drive me to hospital appointments, cook dinner, help with my meds—just always there when I need them during this hard time doing the basic tasks for me. (20yr, stage 3)

A few adolescents reflected on how the smaller, everyday acts of care made them feel more connected to their family, explaining that support did not need to be large or elaborate to be deeply valued: "It is the little things my family always does to help that actually mean the most to me and make me feel most loved, not the big stuff" (19yr, stage 3).

A smaller group of adolescents described becoming closer with family members they had been less connected to before their diagnosis, with one noting that they were "going through this [cancer] together" (21yr, stage 2). Increased closeness was described as developing naturally as adolescents spent more time at home and shared more day-to-day moments with family during treatment.

> It just happened naturally [becoming closer to family] as I spent more time with them. I have definitely gotten closer with my wider family since being home. (20yr, stage 2)

> Because of cancer I've been home a lot more, so we spend heaps of time together now doing things, so I would say I am closer to my family now than before my cancer diagnosis. (19yr, stage 2)

One participant reflected on a sense of continuity and lack of change in how family members were and the type of support they provided, noting that their closeness before diagnosis continued in the same way during cancer through regular messaging and visits:

“My parents and siblings have been messaging, obviously, and keeping in touch and spending as much time with me as they did before my cancer diagnosis, so I haven’t been affected socially” (17yr, stage 2).

Overall, the majority of participants spoke of becoming closer with their family during cancer, noting increased time together and ongoing practical and emotional support. Several participants spoke about family members visiting more often, helping with basic tasks, and being consistently present. One adolescent uniquely described no change in family closeness, reflecting continuity in support already established before cancer. Discussed next are the changes cancer brought to participants’ wider relationships with friends and intimate partners, with their reflections on shifts in closeness, interactions, and how these relationships functioned since diagnosis.

Altered Non-Familial Relationships

A common experience described was the noticeable changes in friendships during many of the participants’ cancer journey, with some reflecting on how some relationships strengthened while others “fell away” (17yr, stage 2) or became “more distant” (19yr, stage 2). Many described some friendships abruptly ending during difficult moments in treatment or because they perceived that some friends “did not know how to show up” (20yr, stage 2):

> Some friends just kind of ghosted me when things got hard with my cancer. (20yr, stage 3)
>
> Some of my friendships became more distant, and we don’t talk much anymore as I think they are unsure how to be there for me during treatment. (21yr, stage 2)
>
> I think friends don’t know how to support me now that I have cancer. (19yr, stage 2)

Several participants described how they perceived social support to be the strongest at the time of their cancer diagnosis but that it gradually declined over time. Many adolescents reflected on this shift, noting that friends who were initially present became less involved over time, creating feelings of isolation. Most participants did not attribute this tapering of support to a lack of care, instead perceiving it to stem from their friends feeling unsure about how to engage with, support, or behave around someone with cancer.

> At first people were really supportive, but over time that social support kind of tapered off. (19yr, stage 2)

> Over time, that social support kind of tapered off. (21yr, stage 2)

> Support tapered off … not because people don't care or want to be here—I think they just feel unsure or uneasy about how to act or be around someone with cancer, so friends often avoided seeing me, which felt isolating. (21yr, stage 3)

While experiences varied, most adolescents described a pattern in which their perceptions of friends' uncertainty about how to support them was a factor behind the changed interactions. Several participants noted conversations often shifted in unhelpful ways, with some friends narrowly focused on cancer while others avoided the topic altogether. Many adolescents described cancer as creating a sense of distance in their friendships, leaving them feeling disconnected and withdrawn from their previous social circles.

> Some avoid talking about cancer at all; others only talk about it, which makes me feel distant from my friends, as in neither way I don't want cancer to be the only thing that we talk about. (21yr, stage 2)

> Lots of my friends don't know how to be around me now, and our interactions are different. I think it had led to distance and unhelpful interactions with my friends where I don't feel as much part of my friend groups anymore. (21yr, stage 3)

Some participants described feeling a sense of discomfort and difficulty when trying to connect and communicate with friends who did not have cancer, noting that their interactions felt different from before. Several adolescents shared perceptions that, despite friends' efforts to be supportive, they felt limited in how much they could understand or relate to their experiences, which made connecting to them difficult or strained. The majority of participants expressed this social disconnect over time, which resulted in a quieter, less socially active life:

> There's still life happening, it's just … a lot quieter than before socially with friends. (19yr, stage 2).

> It was really weird to talk to my friends without cancer. They tried their hardest, but it was still hard with them not being able to relate as they don't have cancer. (19yr, stage 2)

> My friends have been supportive, but it's hard for them to connect. (21yr, stage 2)

Despite these social challenges, a minority of adolescents described friendships that strengthened during their cancer journey. Some participants reflected on the supportive nature of some friends who remained consistently present, noting the value of regular check-ins and steady support throughout treatment. At the same time, a few adolescents recalled learning “who my real friends are” (20yr, stage 2).

> Everyone’s like my friends and school mates have been checking in. (21yr, stage 2)

> I’ve been pretty good; my friends have been keeping in touch. (19yr, stage 2)

> I do have a few close friends who’ve stuck around. One of my best mates still comes over and just hangs out. (21yr, stage 2)

> Knowing who my people are and experiencing that support from work and friends as everyone has been very supportive. (21yr, stage 2)

One adolescent uniquely described how their romantic relationship was significantly affected during their treatment, with the relationship ended despite initial support: “I did get broken up with because of the cancer, even though at the start of the journey he was the one who also shaved my head” (20yr, stage 2). This participant reported that the break-up stemmed not from personal fault but from their partner’s inability to cope with the demands of cancer: “Getting broken up with and knowing that it’s not because of me—it was him obviously not being able to deal with it” (21yr, stage 2). Although some had experienced intimate relationship loss, they reflected that cancer also prompted a shift in relationship priorities, with one participant describing how it led to deepened friendships: “So obviously [I] went through the break-up, but I think that strengthened my relationships with my friends” (20yr, stage 2).

In sum, while some adolescents shared experiences of loss or weakening of non-familial relationships, a smaller group, in contrast, spoke about the emergence of meaningful bonds with those who remained involved and present. The next subtheme discusses participants’ experiences with how cancer reshaped participants’ everyday lifestyles and routines as they found themselves less able to sustain their previous independence and daily activities.

Disruptions to Everyday Life

Most participants described significant disruptions to their everyday lives during cancer treatment. For several adolescents, being diagnosed with cancer led to returning home and re-entering familiar but constraining social environments, disrupting their previous daily routines. A few participants spoke about how this shift in their everyday life was a noticeable contrast to the independence they had before diagnosis, with one sharing, “It’s like my life got split in two, the before me, which was healthy, independent, and free, and now I feel like my life has changed so much compared to before and my normal routines don’t exist anymore” (21yr, stage 2). Returning home also often meant stepping away from previously independent living arrangements, such as flatting, and re-entering a household where parents were described as having a central, and at times frustrating, role in their day-to-day life. For several participants, reliance on family for basic needs such as transport, meals, and getting to appointments was seen to strengthen relationships, while others expressed contrasting views, noting that family involvement was frustrating and that their previous lifestyle and independence had been lost, which they valued.

> I am now at home and spend most of my time with just my parents who do the everyday things for me. I’m not doing anything by myself anymore like cooking or driving unlike before [diagnosis], but I think having them look after me has actually improved our relationship, as I can see they care. (19yr, stage 2)

> Going back home felt like I was losing the normal life I had that I valued. I can't do normal things and parts of my day that I enjoyed now as I need my parents to do everything, which is annoying sometimes. (20yr, stage 3)

> Since being diagnosed, I've stopped my normal daily lifestyle. I moved back home with my parents, and I stopped doing what I want to do. (20yr, stage 3)

A shared pattern among participants was cancer's disruption of everyday commitments such as study, work, and social activities previously managed. Adolescents shared that the structure and pace of everyday life were altered by treatment effects, noting that activities that once filled their daily lives were reduced or stopped altogether because of new cancer-related commitments.

> Before cancer I had my flat, my own routine, but I had to drop uni courses because of radiation treatment exhaustion. (19yr, stage 2)

> I used to fill my everyday with classes, netball training, part-time work, but now that is stopped because of my cancer commitments. (21yr, stage 2)

Several adolescents described experiences where disruptions to everyday life led to them feeling more "babied and overprotected" (21yr, stage 2) at home. Most adolescents described parents taking responsibility for organising daily schedules, assisting with everyday tasks, and regularly checking in with them, which was said to be "restrictive" (19yr, stage 2), "frustrating" (20yr, stage 2), and "controlling" (21yr, stage 3) at times. A common pattern participants described was how their family's increased involvement changed how they performed normal daily activities, with some feeling they were treated younger than their age or as less able to act independently.

> Now I live back at home where I am in my childhood bedroom, and my parents help me with basic activities like I'm a child. (19yr, stage 2)

> I feel like I am falling back into this unwanted dependency that I haven't had in years since childhood. (19yr, stage 3)

> They mean well, but sometimes I feel watched all the time, like I can't just do normal things without someone checking in on me like I am a baby. (18yr, stage 2)

In sum, several adolescents described how cancer reshaped their participation in various aspects of everyday life. While experiences varied, a shared pattern was that adolescents no longer participated in activities as they once had and began managing on their own, with daily life described as becoming more structured since living at home again. These disruptions to everyday life flow into the next subtheme, in which adolescents reflected on broader social activities they were no longer able to participate in. Several described comparing themselves to others socially and missing age-related social milestones, with one noting feelings of "moving backwards" (20yr, stage 2) while peers continued to progress through key milestones.

Missed Milestones

Many adolescents described how cancer had interrupted the big social milestones that they associated with growing up and moving away from childhood. These milestones included birthdays, moving into first flats, educational achievements, and attending significant social events. Most participants described the physical realities of cancer treatment, including fatigue and immune system vulnerabilities, as delaying or preventing their ability to engage in social milestones.

> I kept missing the big events and moments that you're meant to go to like graduations and first flat things, as from treatment I was too weak. (21yr, stage 2)

> Because of my lowered immune system…I can't be around large groups or go to parties anymore, which at my age is important to do to make friends and not feel like a kid. (19yr, stage 2)

A common experience among participants was feeling "stuck in time" (19yr, stage 2) while peers moved forward with age-typical milestones:

I feel stuck on pause socially while everyone else is in fast-forward, doing normal things like partying or hanging out. (19yr, stage 3)

Everyone is moving forward compared to me. (21yr, stage 2)

One described having to watch friends transition into new life stages while they were unable to as their life was "stuck on pause":

"Socially, I feel like I've missed out on so much and [am] stuck on pause, especially at this age when online I see friends are out socialising, travelling, or starting careers" (20yr, stage 3).

A smaller group of participants expressed contrasting responses, describing missing milestones not as a temporary pause but as actively going backwards:

> Missing these things…it's not just life going on pause, but I feel like I am actually moving backwards. (20y, stage 3)

> It feels like I’ve gone backwards. I was finally getting my life sorted and doing stuff with my friends, and now it’s like I’m back to square one while everyone keeps going without me. (20yr, stage 3)

> I have struggled a lot with feeling I am moving backwards compared to my friends. (21yr, stage 2)

Many participants spoke about these missed opportunities in terms of social comparisons and feeling isolated. Several reflected on a growing sense of distance and relationship strain as they saw peers progress through milestones without them.

> I often feel I am missing out on a lot compared to my friends who I see moving through life events and, I don’t know [*pause*]. It makes me feel a bit isolated and distant from them as can’t relate as much with them now. (20yr, stage 2)

> There is also FOMO [fear of missing out] as I am watching everyone carry on with classes, parties, and road trips, so we are less close now. (20yr, stage 3)

In sum, a shared experience across most adolescents was missing developmental milestones from cancer, as they reflected on the distance between their own experiences and the transitions their peers were moving through. Feelings of missing out were raised by several participants, who described these missed opportunities as affecting their broader sense of progression, belonging, and movement towards adulthood, with one commenting, “Everyone else my age is out there doing stuff like going to festivals, travelling, and dating, you know more adult stuff, while I am trying to keep my white cell count high enough for chemo” (19yr, stage 2). Similarly, several adolescents shared that life unfolded differently from what they had expected, which leads into Theme Two, which relates to participants’ unexpected emotional and cognitive responses in the face of cancer, which were marked by initial shock and overwhelm, unstable emotional states, and persistent concerns about the future.

Theme Two: Cognitive and Emotional Responses in the Face of Cancer

This theme captures the emotional and cognitive meaning-making participants described in response to their cancer experiences. It describes the psychological outcomes perceived by adolescents when attempting to process the gravity of a diagnosis, and takes into account the limited emotional regulation and resilience-focused coping capacities associated with thier stage in life. The suddenness of a cancer diagnosis was described as placing participants in a state of worry and emotional disorientation. During treatment, many described fluctuating and difficult-to-regulate emotional states, with several recalling a roller-coaster of emotional calmness and distress, often experienced alongside constant undercurrents of low-level fear.

The First Moments of Diagnosis: Emotional Reactions

The majority of participants described the emotional impact of receiving a cancer diagnosis as intense, overwhelming, and mentally exhausting. Many recalled the moment of diagnosis as being filled with disbelief and distress as they struggled to process what was happening, describing it as “stressful and scary” (19yr, stage 2) and “definitely a shock” (20yr, stage 2). Coming to terms with the diagnosis and demands of treatment was challenging, with frequent experiences of mental fatigue and overwhelm, with one sharing, “I mentally struggled to come to terms with the diagnosis and treatment plan” (21yr, stage 2), and another summing up the ongoing emotional weight thus: “I often feel overwhelmed” (21yr, stage 3).

For several adolescents, the gravity of being diagnosed took time to register, with some describing unexpectedly mute initial reactions which did not match how they assumed they would feel. A few participants recalled experiencing an initial lack of emotion when diagnosed:

> I didn't feel sad or cry straightaway [after getting the diagnosis], which surprised me as you would think someone would be crying and emotionally all over the place hearing this news. (19yr, stage 2)

> I think I was just feeling emotionally numb and blank [when getting the diagnosis]. (21yr, stage 3)

While fear and shock were common responses to receiving a cancer diagnosis, several adolescents also described feeling reassured when told that their cancer was treatable. For many, being told this information eased the initial intensity of their distress and provided relief.

> Bit freaky at the start, but when I quickly found out it was curable, like that took a lot of initial stress and weight on me away. (19yr, stage 3)

> I'm not worried at the moment, because I know it's going to be temporary, so I've been pretty good mentally. (21yr, stage 2)

In sum, the majority of adolescents described receiving a cancer diagnosis as emotionally intense and cognitively challenging to process, and as characterised by feelings of shock, fear, disbelief, and moments when emotional responses felt muted or delayed. Several participants did experience reassurance when learning their cancer was treatable, making them feel calmer in the initial diagnostic meeting. These early reactions formed the starting point for a wider pattern of emotional experiences that unfolded across treatment, which leads into the next subtheme, which relates to the ongoing mental "ups and downs" (19yr, stage 2) of participants cancer journey.

Living Between Hope and Distress: The Mental Roller-Coaster of Cancer

Across adolescents, many spoke to how their emotional experience of cancer often included unpredictable movement between feelings of hope and distress, with one participant reporting that "mentally it has been an ongoing roller-coaster" (17yr, stage 2). After the initial shock of diagnosis, participants experienced ongoing psychological turbulence during treatment as daily life became centred around cancer. One adolescent stated, "There are days I feel positive. Then there are days where I feel completely negative throughout my treatment and how my life now is" (19yr, stage 2). However, while some participants seemed mentally resilient, most highlighted the unseen emotional burden of cancer.

> People don't realise that you don't just deal with the physical side, it's the mental toll that eats away at you. (21yr, stage 3)

> I'm pretty vulnerable and tired mentally, a little bit, just in constantly feeling this up and down emotionally. (19yr, stage 2)

Positive emotional experiences often related to the use of coping mechanisms to distract from or lessen the intensity of difficult feelings. For most participants, small acts of stability—such as continuing with work or keeping up with study—were described as helpful in maintaining a sense of normalcy and control throughout treatment.

> I tried to stay very positive about it, which I think came from the fact that I was still going to work so still had some control that made me feel more emotionally okay. (20yr, stage 2)

> I was still doing uni work at home, which meant I was doing something else and the treatment was off my mind. (19yr, stage 3)

Several adolescents reported feeling anxiety and distress before hospital appointments. Many also shared feelings of emotional fatigue and vulnerability from the ongoing emotional roller-coaster:

> I'm able to, through the week, forget about my cancer, but then when I'm there in hospital, I'm constantly reminded of my cancer which causes feelings of sadness and overwhelmment [*sic*]. (21yr, stage 3)

> It is pretty up and down my emotions, but there is definitely anxiety—especially before scans. (21yr, stage 2)

While experiences varied, many adolescents spoke about feeling a constant undercurrent of fear throughout their treatment journey. Several spoke to this quieter, ongoing discomfort existing beneath the more intense emotional highs and lows.

> There's also this constant low-level fear. Even on good days, it's there in the background. (17yr, stage 2)

> I think I feel a lot more uneasiness just every day now with going through cancer at the moment and doesn't matter if I feel good or not it seems to always be there. (20yr, stage 3)

In sum, most adolescents described their cancer journey as an ongoing emotional roller-coaster rather than a linear emotional adjustment, marked by moments of calmness and stability alongside times of distress, and recurring fear about treatment. While some participants noted developing a sense of resilience, many also described an undercurrent of persistent fear. The next subtheme explores how these ongoing emotional fluctuations were accompanied by worries about their future, with the majority feeling uncertain and worried about treatment outcomes, recovery, and what life after cancer might hold.

Future Uncertainty and Worry

Participants described how cancer created uncertainty and worry about their education, career, and later life goals. Many reflected on the sudden shift from envisioning a "normal" future to abruptly confronting this unpredictable journey that included intensive internal questioning.

> Since being diagnosed there is a lot of anxiety about the future, like "What kind of life I will have after this treatment?" (19yr, stage 3)

> A lot of questions ran through my mind [after the diagnosis] like "What does this mean for my future?" (20yr, stage 3)

Most adolescents described worry and panic about their future ability to return to a normal adolescent life, with one stating, "I wonder if I will ever be a normal teenager again" (17yr, stage 2) and another reporting, "I felt so panicked, spiralling about my future plans" (20yr, stage 2). For some participants, even thinking about future appointments triggered a response of acute anxiety and worry, with one noting, "I have had panic attacks thinking about future scan days" (20yr, stage 3).

Some adolescents expressed contrasting views where, instead of thinking ahead to long-term plans or their future life after treatment—thoughts described as overwhelming or panic-inducing—a small group spoke about narrowing their attention to immediate tasks, upcoming appointments, or weekend plans. A short-term focus was described as helpful to manage their emotions and reduce the intensity of uncontrollable future-related worries.

> I think about the future differently now, rather focus on the day-to-day than the long-term as that makes me worry too much. (17yr, stage 2)

> Instead of thinking about the whole year, I focus on the short-term, the next blood count, the next weekend at home, things I can control. (20yr, stage 3)

In sum, most adolescents described a strong sense of uncertainty about their futures following their cancer diagnosis, marked by internalised reflections and questions about education, career, and wider life plans. A few spoke to managing these worries by focusing on their short-term goals, describing this as a way to reduce distress and regain a sense of control during what was a very unpredictable time for them. The next theme focuses on participants' reflections on meaning and identity as their experience of cancer reshaped their sense of who they were and life's meaning.

Theme Three: Meaning, Identity, and Self-Reflection

This theme captures the internal meaning-making adolescents engage in as they attempt to understand new and unfamiliar questions about life, who they are now, and how cancer has affected their sense of self. Primarily, this theme reflects adolescents' perceived shift from an assumed sense of invincibility towards an emerging awareness of vulnerability, mortality, and the negotiation of altered self-perceptions. Participants described experiences of existential questioning as confronting and unfamiliar, as many grappled with meaning, purpose, and identity in ways they had not previously considered, while for one adolescent, religion provided spiritual reassurance.

Confronting Personal Vulnerability: The "Not Me" Reality

For many adolescents, receiving their diagnosis was described as a moment of confrontation, marking the point when they no longer perceived themselves as invincible. A few were shocked by having cancer at their age and most spoke about the disbelief that accompanied this new cancer reality, saying they "never thought it would be me" (20yr, stage 2):

> I thought, "Oh, that'll never be me," and then it just happens suddenly. (21yr, stage 3)

> Cancer was always something I saw in movies or on the news, not something I imagined happening to me—so when they told me, it didn't feel real at all. It's like I used to think because of my age I was invincible. (20yr, stage 3)

Most adolescents saw their cancer diagnosis as disrupting their sense of normality and as exposing an unexpected vulnerability during what was supposed to be a healthy stage of life. Many described how, even after noticing concerning symptoms, cancer still felt almost impossible, which led to some not seeking medical attention immediately. The recognition that their bodies could fail them at such a young age prompted discomfort and disbelief among the majority of participants, particularly as they viewed cancer as an "old people" disease.

> Before this, I just assumed I was healthy and nothing like getting cancer would ever happen to me—getting diagnosed made me realise how quickly that can change. (20yr, stage 2)

> So originally, I was away overseas doing a student exchange, and I found a lump in my neck, and I actually didn't come back because of the lump as didn't think would be cancer. (17yr, stage 2)

> Cancer felt like something old people get, not someone my age. (19yr, stage 2)

> I never thought my body could just break like this at my age. It made me realise I’m not as invincible as I thought. (19yr, stage 3)

In sum, most participants described their cancer diagnosis as a moment that abruptly disrupted their sense of normality and exposed an unexpected awareness of vulnerability. Several spoke to what once felt impossible, becoming immediate and personal. The next subtheme explores adolescents’ engagement in broader existential questioning, including reflections on life’s meaning and mortality.

Existential Questioning in the Face of Cancer

Adolescents without a religious positioning commonly described cancer as prompting a deep and unfamiliar reflection about life, mortality, and meaning. Many recalled thinking about the big questions around death and the purpose of life which they had never previously considered, and these thoughts were often unavoidable.

> I’m not part of any faith, but I’ve definitely thought more about life, death, meaning. When you’re faced with something like cancer, you start to ask those big questions that I haven’t really thought about before. (21yr, stage 3)

> I never used to think about death, but now it crosses my mind a lot even when I don’t want to think about it. (17yr, stage 2)

Alongside questions of meaning, several adolescents described gaining a heightened awareness of life’s fragility. A few spoke about how cancer changed their view of what matters, describing a shift towards clarifying their life’s purpose and meaning. Even those without religious affiliations described changes in their outlook on life and surrounding values.

> I’m not religious, but cancer made me look at life differently even my life purpose. (20yr, stage 3)

> Cancer made me question things like my purpose, values, and to strip it back to what is real. (17yr, stage 2)

Only one adolescent expressed a religious faith, describing an experience contrasting with the uncertainty and non-religious existential questioning that most of the other participants experienced. For this participant, religion offered a steady sense of reassurance, grounding, and acceptance throughout their cancer experience. This adolescent reflected on how their faith functioned as internal support where trust in God alleviated fear, allowing them to worry less about their cancer.

> I mean, pretty good, because I got God, so I haven’t worried about it too much. (21yr, stage 2)

> Well, I haven’t really doubted God during it. I’m just trusting him, so I feel more calm about my cancer journey so far. (21yr, stage 2)

In sum, adolescents commonly described being diagnosed with cancer as prompting new reflections about life, death, and meaning, with many recalling thinking about unfamiliar topics they had never considered before. For those without a religious belief, this often involved questioning their purpose and recognising the fragility of life, while the one participant with faith described spirituality as a steady source of reassurance throughout treatment. The next subtheme explores how participants experienced changes in their identity and self-perception during treatment.

Identity and Self-Perception Changes

Across participants, cancer was described as affecting how they saw themselves, expressed particularly through changes to confidence, self-esteem, and self-image. Many spoke about feeling disconnected from their pre-cancer identity, with treatment and visible appearance changes affecting their self-perception. One adolescent reported “I didn’t expect how much cancer would change my sense of self-identity” (20yr, stage 3), and several described the unwanted loss of a central aspect of who they were before cancer, with one noting, “It is hard [lack of mobility] because sport was a huge part of my identity” (21yr, stage 3).

Visible changes in appearance and physical functioning often led to lowered self-confidence and increased self-comparison. Several participants described feeling different and unsure of themselves; others spoke to how these shifts disrupted their sense of self-worth.

> I’ve struggled with a lot of comparison that has lowered my self-perceptions, mainly in self-confidence because I look different, and it feels harder to belong. (20yr, stage 2)

> I am mostly struggling with my new appearance impacting my sense of self-confidence. (21yr, stage 3)

However, for a few adolescents, cancer also prompted the emergence of new, more positive self-perceptions. These participants narrative described the discovery of unexpected positive aspects of self-confidence and identity. Many were surprised to discover these positive aspects of their inner selves during such a challenging time.

> I’ve discovered new sides of myself—self-confidence I didn’t know I had before cancer. (17yr, stage 2)

> I didn’t think from cancer and how hard it is I would find more self-confidence in myself; I feel like I found new parts of my identity I didn’t know where there. (19yr, stage 3)

In sum, the majority of participants reported treatment disrupting their body confidence and self-perceptions, but some also developed new and unexpected positive self-perceptions regarding self-confidence during this difficult journey. Many experienced unfamiliar existential questioning and explored their personal vulnerability to illness. The next theme discusses how cancer affected adolescents’ physical well-being and the meaning-making they attached to these changes.

Theme Four: Living in a Changed Body: Disruption and Adjustment

This theme is about the bodily disruption adolescents experienced from having cancer, with treatments perceived as significantly affecting their appearance, strength, and everyday functioning. It explores how their physical symptoms, treatment side effects, and altered capabilities were understood and experienced. Beginning with adolescents’ feelings of body disconnection in response to new and distressing appearance changes, this section explores how the loss of strength, mobility, and energy—living in a changed body—was experienced as a frustrating disruption to everyday life. This section concludes by examining how some adolescents described a gradual process of adjustment, learning to navigate new bodily limits, as they moved from resistance to bodily acceptance.

My Body No Longer Looks Like Me

For most participants, a shared experience was visible, outward physical changes that occurred during diagnosis and treatment. Frequently mentioned treatment side effects and symptoms included hair and eyebrow loss, muscle loss, and altered skin appearance. Many found these bodily changes confronting, disrupting their sense of bodily connection to the point of not recognising themselves.

> I lost my hair, I look skinny, and I feel like everything about how I look on the outside is not me anymore. I don't see myself anymore. (21yr, stage 3)

> That's probably the biggest thing I've had to deal with—obviously you lose your hair and your eyebrows. (17yr, stage 2)

> I don't want to say it, but I looked pale. I just didn't look like I had any colour in me at all. (20yr, stage 3)

A small group reflected on the particularly discomforting and intense experience of appearing sick, where visible signs of cancer made the diagnosis feel tangible and real. A few adolescents described the experience as intense and emotionally confronting, as their physical changes marked the transition from being healthy to being unwell.

> It has been hard to look in the mirror as losing my hair and eyebrows makes me look physically sick—means I look sick. It all started to feel real when that happened. (21yr, stage 2)

> Probably the biggest thing to deal with is my appearance changes, which has been uncomfortable. (20yr, stage 2)

> They were like, "Oh, you're going to lose it [hair], and then just pulling it out makes it real and overwhelming. (19yr, stage 3)

Most participants described bodily changes, such as noticeable weight loss, as disrupting their sense of bodily connection, with some rpeorting that alterations to their taste meant they wanted to eat less. Weight loss made their clothing ill-fitting, accentuating bodily disconnection. For many, such changes evoked embarrassment or discomfort as others were able see their cancer.

> Food tastes weird, so I don't eat as much and [that] meant I lost weight [*pause*]. My body no longer feels familiar. (17yr, stage 2)

> I've lost so much weight from treatment, so nothing fits properly. It feels uncomfortable this change to my body as everyone can see it. (21yr, stage 2)

> It's just that you look sick from the weight loss, which was embarrassing as people can see you have cancer now. (20yr, stage 2)

In sum, physical changes were commonly described as disrupting participants' sense of bodily connection, with one reporting that "nothing about my body is familiar" (19yr, stage 2), and another stating, "I have often felt disconnected to my body since my cancer diagnosis" (21yr, stage 2). The next subtheme explores participants' loss of strength and physical functioning from cancer, and how this shaped the ways they understood their body during cancer.

Reduced Strength and Functioning

Adolescents frequently described the desire to return to their normal physical routines despite the new bodily limits imposed by treatment. One participant recalled feeling stuck in their reduced capabilities, despite wanting to do tasks: "Even though I want to do things my body can't because of my chemo treatment" (21yr, stage 3). Several participants described spending long periods resting, with one sharing, "I have been basically stuck in bed for hours during the day" (21yr, stage 2) and another stating, "normally I sit around all day" (17yr, stage 2). Alongside this, a few spoke of reduced stamina, making even small tasks and their daily functioning physically demanding and at times unachievable.

> Even small tasks—like cooking, cleaning, or going to the supermarket—are physically exhausting some days. (20yr, stage 3)

> Now just getting up and showered is tiring and makes me exhausted. (20yr, stage 2)

> I can't really get up to much these days. Doing anything, no matter how simple, wipes me out as it is too much on my body sometimes so can't do it. (17yr, stage 2)

Many expressed frustration at not being able to do everyday activities that had once been effortless, describing how fatigue, weakness, and pain now restricted their movement and energy. Some adolescents spoke of losing muscle strength and being unable to maintain their pre-cancer activities. Cancer was also perceived as bringing about a mind-body separation.

> It's frustrating because mentally I want to live life normally, but my body just won't let me. (21yr, stage 3)

> I've lost a lot of muscle strength because I am so tired all the time so can't exercise like before. (21yr, stage 2)

> I used to go for runs most mornings. I haven't been exercising as much because I haven't had much energy. (19yr, stage 2)

Instead of a complete loss of functionality, several participants described attempting to maintain some mobility, with one stating, “Most days I attempt to go for a short walk” (20yr, stage 2), and another reporting, “I try to do small things like walking to the kitchen for food” (19yr, stage 3). A few adolescents, however, found that treatment side effects or surgical interventions restricted most of their movement, with one noting, “I’ve got a metal rod in my femur now, so no more physical activity in running or jumping” (21yr, stage 2).

In sum, most adolescents experienced a noticeable decline in physical strength and functioning, sharing how everyday tasks had become exhausting, with previous levels of activity no longer manageable. Fatigue, weakness, and reduced mobility shaped daily life, leaving many feeling limited and frustrated by what their bodies could no longer do. The next subtheme explores how participants began to adjust to these changes, moving towards acceptance and finding new ways to live in a changed body.

Adjustment to and Acceptance of Living in a Changed Body

Adolescents described experiencing both good and bad days while trying to adjust to their new bodies. Many described a gradual process of positive meaning-making towards their changed body, learning to accept and adjust to days when they felt fatigued, weak, and physically limited.

> It’s an ongoing adjustment—some days I feel strong and able, and other days I feel fragile from my tiredness and pain. (20yr, stage 3)

> There are days when I feel physically okay, but it has been a slow adjustment. (19yr, stage 3)

> It’s been slow trying to adjust to how my body is now since starting treatment. It’s been hard to adjust to such a different way of living as I am always tired now compared to before, but I am way more okay with going at this new pace now. (21yr, stage 2)

Several participants described learning to read their body’s new signals and the need to respond to them with great care. They recognised that pushing too hard could lead to setbacks, highlighting the physical unpredictability and non-linear effects of their cancer journey. A few discussed the risk of overdoing it when feeling normal and recognising the need to pace themselves to avoid unwanted physical consequences.

> Since starting chemo, I’ve had to listen to my new body signals. If I ignore signs, then I end up paying for it later. Some days I feel almost normal, and the day after it has been that I couldn’t even get out of bed. (17yr, stage 2)

> I have found my physical journey unpredictable. Sometimes I have accidentally overdone it, and [that] made me really have to start tuning into my body with more care. (20yr, stage 2)

These quotes above illustrate how participants made sense of their need to balance activity and rest while adjusting to their new body. For many, the physical journey required shifting from frustration to acceptance, reflecting patterns of bodily awareness and self-compassion, with one adolescent sharing:

> At the start I was often frustrated at these changes to my body, however now that I have gone through a bit I am way more kind to myself and accept that this healing from chemo in my body is slow, so I try to be more patient now. (19yr, stage 2)

Several adolescents described a growing sense of acceptance as they gradually re-engaged with their bodies during treatment. Despite ongoing fatigue and physical limitations, many described starting to appreciate and adjust to what their bodies could still manage, working with their new body rather than focusing solely on what had been lost. This shift to acceptance was often achieved through small efforts to move, be active, or reconnect with activities, reflecting a new respect for their body.

> Well, it makes me want to be more healthy, more fit, and get outside a lot more. (21yr, stage 3)

> And physically… well, I appreciate my body in a new way. (21yr, stage 2)

> Even though I still get tired all the time, I've started to push myself a little. It makes me feel like I am working with my body [*pause*], accepting these new limits. (17yr, stage 2)

In sum, the majority of participants described adjusting to and accepting their bodies during cancer treatment as a slow and uneven process. Many spoke about learning to pace themselves in daily life and becoming more accepting of their body's limits and boundaries. Small routines and movements became markers of progress, with many describing a growing appreciation for what their bodies could still manage despite ongoing fatigue and discomfort. The next theme explores how adolescents faced challenges to their sense of belonging within healthcare environments not designed for people their age.

Theme Five: Navigating Belonging in Healthcare Contexts as an Adolescent

This theme focuses on how adolescents made sense of their interactions within healthcare services and environments, and how these experiences shaped their cancer journey. The following subsections explore adolescents' narratives related to their access to support, healthcare spaces, and engagement with services, highlighting how developmentally ill-suited services and limited age-appropriate spaces influenced their experiences of cancer, and capturing their feelings of discomfort and disconnection within and beyond clinical settings.

Invisibility of Age-Appropriate Support

Many adolescents described healthcare services as fast-paced, confusing, and poorly designed for their age group, with one feeling “overwhelmed and not part of the process, but just told what to do, with nothing explained to me to help me understand what was happening” (20yr, stage 2). Participants felt that healthcare practices were confusing because communication was overly clinical and technical for their age, and recalled difficulty making decisions and understanding what was happening.

> The whole process has been very clinical…hard for me to understand. I felt like I didn’t always know what was happening because everything was so fast-paced, where I often felt confused. (19yr, stage 3)

> A lot of the information they give is very medical and clinical, which felt overwhelming and hard to understand. (17yr, stage 2)

The majority of adolescents spoke about feeling unseen and excluded within the healthcare system, with many noting that while support existed, neither children’s nor adult resources were well suited to their well-being needs. Services were perceived as being more appropriate for older people, and participants described limited recognition of their needs, both those directly connected to their cancer diagnosis and those related to their wider life stage. Consequently, many adolescents reported support services missing opportunities to provide meaningful support for issues they viewed as significantly affecting them outside the hospital context. A few also described how current care practices left them feeling “invisible” (17yr, stage 2) and unsupported.

> Honestly, the healthcare support hasn’t always met all my needs as a young person, with both my cancer needs like treatment support and more life-related support needs, like help with

> understanding my new family relationships not often met. Another thing is that the support available in the hospital isn't always tailored to someone my age. (19yr, stage 2)

> I wanted to talk about things like how cancer affected my relationships, my plans for study and career, or worries about fertility, but it felt like those conversations were sometimes brushed aside or not offered enough space as were not happening in the hospital. (20yr, stage 3)

> Most resources seemed to focus on older patients. (17yr, stage 2)

Another shared experience was a lack of age-appropriate fertility support, despite most participants describing it a big part of their cancer journey.

> I feel like there definitely could have been a lot more support at the fertility clinic within the process from healthcare workers because it was a big thing to go through mentally. (19yr, stage 2)

> The fertility support was not enough for someone my age where this is a big deal. (21yr, stage 2)

Some adolescents also recalled the emotional weight of fertility-related decision-making, with one describing it as occurring without adequate support or empathy from staff: "Once it [egg freezing] was done I was like, now what, because there was no closure or anything after this pretty emotional event" (20yr, stage 3).

In sum, there was a consistent perception across participants that healthcare services were not designed for people their age. Adolescents felt support was oriented towards much younger children or older adults, with their own concerns—about relationships, study, career plans, or fertility—receiving insufficient attention. One participant captures the overarching sentiment of this theme*:* "Young people with cancer aren't just mini adults or big kids, and that makes our experiences different, but I found the support was invisible for my people in my age group" (21yr, stage 2). The next subtheme discusses participants' shared perceptions of not belonging in Aotearoa healthcare spaces.

Experiencing Spaces of Non-Belonging

The majority of adolescents described how they lacked a sense of belonging when navigating Aotearoa's oncology healthcare environments, spanning hospitals, treatment wards, and fertility clinics. Many described the absence of peers in these healthcare spaces, alongside feelings of isolation and invisibility.

> It's lonely being the only young person in those ward rooms. You don't really feel like you belong there. (19yr, stage 3)

> It's sort of been isolating, I have not been able to talk to anyone and relate to anyone my age. (21yr, stage 3)

Adolescents commonly described hospital and clinical environments as spaces where they struggled to feel like they belonged. Several shared how children's wards felt "too young" (21yr, stage 2), while adult wards felt disconnected and unfamiliar, contributing to descriptions of a "weird in-between experience" (20yr, stage 2). For most participants, being surrounded by much younger patients was perceived as reinforcing a sense of difference and discomfort, highlighting how current cancer spaces are not designed for adolescents.

> Being in the hospital, the ward is mostly little kids with nothing for my age group. (20yr, stage 2)

> Even in the cancer waiting room environment it felt not for me because everyone was much younger. (20yr, stage 3)

> There's this weird in-between where I feel like I don't quite belong in either ward—not a child, but not fully an adult either, at least not in the eyes of the healthcare system. (19yr, stage 2)

Several participants experienced feelings of not belonging within adult wards, away from peers their age, with many finding these spaces isolating and uncomfortable. Several participants described having a heightened awareness of feeling out of place across multiple healthcare spaces, intensifying their meaning-making of cancer-related environments not being designed with them in mind.

> It's been very isolating [in the adult wards], like no space has been thought of us [adolescents] in mind. (19yr, stage 2)

> I haven't come across anyone else my age because I'm not within Starship [Children's Hospital]. (19yr, stage 3)

> I got my eggs frozen and that felt really weird going though that process as everyone around me was like [in their] 30s or 40s trying to start a family, but I was trying to save mine for later. (17yr, stage 2)

In sum, adolescents commonly described hospital and treatment environments as uncomfortable, and as places where they did not belong. Many reported being the only young person in waiting rooms or wards, surrounded by either much older adults or young children, which contributed to their ongoing feelings of isolation and disconnection. Across accounts, adolescents described multiple healthcare spaces as lacking peers their age and offering few opportunities for age-relevant social contact.

Summary

This chapter has presented the findings of this study, which collectively demonstrate that participants' experiences of cancer were multidimensional and extended well beyond just the physical outcomes of illness. Narratives spoke to how cancer reshaped their social worlds, inner spiritual lives, and sense of psychological stability. Across the five main themes, participants described strengthened yet strained relationships, disrupted participation in everyday life, and a sense of missing key developmental milestones. Emotionally and cognitively, cancer journeys were characterised by initial shock, the sense of riding a roller-coaster fluctuating between hope and distress, and descriptions of persistent uncertainty about the future. Through their embodied experiences of visible and internal physical changes caused by cancer, adolescents also spoke about engaging in deep meaning-making and self-reflection, confronting their vulnerability, questioning life's purpose, and renegotiating their identities. Spiritual shifts were described as closely tied to unwanted identity changes, feeling disconnected to their bodies, and learning, over time, to live within their new body.

In addition, all participants expressed how the health system and healthcare environments they encountered were rarely designed with them in mind, leading to experiences of invisibility, isolation, and feeling out of place in both paediatric and adult oncology care structures. In the next and final chapter, I interpret these findings in relation to existing literature, developmental theories, and cultural frameworks tied to the Aotearoa cultural context.

Chapter Five: Discussion

This study exploring adolescents' lived cancer experiences and related well-being outcomes within the Aotearoa New Zealand (hereafter Aotearoa) context is the first of its kind. It extends and challenges existing cancer research by explaining wider well-being complexities, incorporating cultural models into the discussion of findings, and offering novel insights into the impacts of limited age-appropriate and culturally responsive cancer care environments and services. The first section of this chapter discusses the themes and subthemes presented in Chapter 4 in relation to the Te Whare Tapa Whā framework (Durie, 1984) and the Meihana model (Pitama et al., 2007; Pitama et al., 2014), and compares this study's findings with those of the existing literature and the insights of Social Developmental Theory (SDT; Erikson, 1950/1964). Organising the discussion using culturally based models provides a clear structure for the multidimensional findings while contextualising adolescents' experiences within Aotearoa's context. In the second section, the study's strengths and limitations are critiqued. Implications for policy and practice along with directions for future research are outlined in the third section. The chapter's final section concludes with reflections on the study as a whole.

Findings in Relation to Existing Literature and Theoretical Models

This section examines the experiences of seven Aotearoa adolescents aged 16–21 years living with cancer and evaluates whether their well-being outcomes align with or challenge existing literature. Findings are situated within stage five of SDT to deepen understanding of how adolescents' cancer experiences intersect with normative developmental processes. The discussion of the themes and subthemes is structured using the Te Whare Tapa Whā framework and the Meihana model. The subsections address the social well-being outcomes of cancer, followed by the psychological, spiritual, and physical well-being domains, before turning to the concepts of ratonga hauora (health services) and taiao (health spaces) to explore how healthcare-related services and spaces shaped adolescents' cancer experiences.

Social Well-Being

For all participants, cancer impacted the ways in which their relationships with family and friends were navigated, with some connections altered, lost, and/or strengthened. Consistent with a UK BRIGHTLIGHT study (Wickramasinghe et al., 2025) and developmental life course literature (Docherty et al., 2015), the findings reveal how the sudden absence from school, sport clubs, and daily social settings removes key relational environments that adolescents rely on for developing social belonging and affirmation, intensifying experiences of isolation and "being left behind" (19yr, stage 2), as peers continued along normative developmental trajectories. The fifth stage of SDT provides a useful framework for understanding why adolescents' abrupt absence from social contexts due to cancer holds particular developmental significance, with treatment constraints reducing adolescents' opportunities to practise social skills, negotiate belonging, and explore social roles—the very social mechanisms through which fidelity is ordinarily strengthened.

Existing cancer literature emphasises that adolescents' social difficulties occur because they are physically absent from peer environments (Juth, 2016; Kim et al., 2016). However, this study's findings show that social disruption was not only about absence; it was also about the relationship strain and awkwardness experienced while they spent a significant portion of time in hospital, losing shared routines, falling out of step with peers, and missing everyday social activities that typically support fluid and natural peer connections. These findings mirror Smith et al.'s (2019) and Wickramasinghe et al.'s (2025) recent international research documenting adolescent and young adult (AYA) experiences of otherness, isolation, and uncertainty about their ability to navigate age-typical social transitions while facing cancer.

In their self-reports, many adolescents described difficulties in maintaining close non-familial relationships during cancer, which they interpreted as reflecting peers' uncertainty about how to respond to new social role expectations. Relationship difficulties may have been shaped by adolescents' heightened experiences of developmental conflict related to identity and role confusion (E. H. Erikson, 1970). However, while adolescents' absence from social settings may have initially contributed to friends distancing themselves, many described experiences of avoidance or "ghosting" (20yr, stage 3) by peers during more challenging moments. This finding suggests relational strain may vary across contexts, demonstrating situation variability, challenging existing research that treats social loss as universally fixed (Pathrose et al., 2025). Participants' narratives suggest that distancing was driven by peers' uncertainty and discomfort in not knowing how to act or engage with cancer, rather than intentional abandonment. However, as the study only captured adolescents' perspectives, the findings cannot account for peers' intentions or explanations for changes in friendships. Despite this drawback, the findings on friendship disruptions during cancer challenge the prevailing view in the literature that friendships and intimate relationships provide universal stability, closeness, and continuity during times of adversity or trauma (Bradford et al., 2022).

Aligning with Juth's (2016) findings, the more conversations centred solely on cancer, the poorer-quality participants perceived those relationships to be, as such interactions amplified their developmental sensitivities to difference and exclusion. Existing literature often does not separate peer support into categories and therefore concludes that all peer support is perceived positively (Cayrol et al., 2024), whereas this study found that overtly cancer-focused peer support and interactions were often perceived negatively. Adolescents were not treated normally in relation to social belonging; the broader aspects of their identity were ignored. Similar to the findings of Iannarino et al. (2017), many of this study's participants were aware that interactions with friends, even those trying to be supportive, were cancer-focused and no longer resembled their pre-illness relationships. The study provides novel insight into how adolescents make sense of relational change. Relationship disruption is experienced not only through the absence of contact but also through a perceived loss of relational connection, with non-familial disruptions more pronounced at more difficult moments, suggesting this pattern fluctuates rather than remains constant across the cancer journey.

Aligned with Janssen et al.'s (2025) study, adolescents' family relationships were often strengthened during their cancer journey. Increased time at home and acts of consistent support, including family members' presence through visiting their loved one regularly, helping with medications, or sitting beside them during treatment, facilitated opportunities for deeper connection. In contrast to the findings of Quinn et al. (2015), which portray family involvement as primarily autonomy-limiting, this study demonstrates that family relationships can function as a protective force for adolescents, attributed to the consistency, reliability, and safety family can provide during moments of heightened vulnerability. For some, parents and siblings acted as a stabilising force countering the instability experienced in other relationships.

In alignment with developmental studies by Degges-White (2017) and Maree (2021), strengthened family relationships during cancer may suggest an adaptive reprioritisation rather than stage regression. When faced with existential threat, adolescents may temporarily renegotiate the autonomy-seeking typical of SDT's fifth stage, shifting instead towards secure attachment, stability, and protection tied to lower developmental stage contexts. Unlike literature that positions adolescents as passive recipients of family care (Drew et al., 2019), participants' accounts show adolescents actively navigating, accepting, resisting, or renegotiating family involvement—depending on the context of perceived vulnerability versus capability. Participants' descriptions demonstrate how adolescents search for familiarity through supportive family involvement during cancer, gravitating to family as peer environments become unpredictable, which aligns with research highlighting the protective role of family in buffering wider social disruption (Janssen et al., 2025).

A novel insight was how a few participants described contrasting moments of strengthened relationships alongside feelings of being "babied" (20yr, stage 2) in basic tasks and decision-making. Similar to LaRosa et al.'s (2017) research, participants described family support as at times conflicting with developmental norms, but the findings also offer novel developmental nuances about how adolescents subjectively interpret and negotiate developmental tension, often through concerns about "moving backwards" (21yr, stage 2). Increased protectiveness and hands-on involvement from parents during treatment was at times intrusive and conflicted with their emerging autonomy; the more care felt unnecessary, the greater the feelings of developmental regression into child like roles, contributing to tension in relationships.

Dependency on family did not universally bring closeness; rather, support was dynamic and conditional upon adolescents' capabilities, fluctuating between comforting and intrusive, which challenges the literature's one-directional framing of family support as positively received during cancer (Quinn et al., 2015). At a time of growing cognitive maturity and intense social comparison, participants had a greater awareness that moments of heightened reliance on parents emphasised their cancer-related limitations and differences to peers: "moving backwards by living at home" (20yr, stage 3) meant falling behind the norms of the adolescent developmental stage (ages 13–21). Participants demonstrated characteristics of SDT's fifth stage, during which reliance on parents can be perceived as a non-normative social position for adolescents, creating further social identity-role confusion. Participants were unable to exhibit their desired autonomy, which explains why many felt overprotected and frustrated at this practical outcome of illness. These findings provide novel insight into the dynamic and conditional nature of family relationships during illness, adding to the literature base by illustrating that family connections were experienced by adolescents as protective during vulnerability, but this often coexisted with a sense of constraint when they were feeling capable.

In summary, the literature primarily treats social well-being as a singular construct without differentiating among relationships. This study, however, illustrates that adolescents' social well-being outcomes differ across relational contexts, reflecting relationship-specific developmental expectations and experiences in the face of cancer. Participants' accounts demonstrate that adolescents' social worlds are particularly vulnerable during cancer, as the disease removes the very social mechanisms that they rely on, with many friendships becoming strained, diminishing over time, or disappearing altogether as shifting social dynamics collide with adolescents' desire for developmentally normative peer connections.

While social changes were commonly attributed to peers' uncertainty and discomfort with cancer rather than intentional withdrawal, peers often contributed to significant feelings of isolation and social loss among adolescents. Importantly, participants' narratives also highlight that relational disruption was not universal; for many, the adversities associated with cancer strengthened family relationships, with parents and siblings becoming key sources of stability, care, and emotional security. Next, I discuss the inner cognitive and emotional meanings participants ascribed to their cancer journey, seeking to understand how they processed cancer events initially and across their journey.

Psychological Well-Being

Many adolescents in this study experienced negative psychological outcomes during their cancer journey, which shaped their still-developing emotional regulation, affect modulation, and cognitive processing capacities (Drew et al., 2019). As Rosgen et al. (2022) found, participants experienced ongoing rapid and intense emotional shifts across their cancer journeys, oscillating between fear, uncertainty, sadness, hope, and resilience, as they attempted to process the diagnosis, manage treatment demands, and reconcile illness with relevant developmental expectations. Participants' narratives emphasise the struggle to process the emotional weight of a cancer diagnosis, contributing to significant psychological destabilisation. Emotional outcomes were experienced within a developmental stage in which adolescents are starting to understand the complexity and intensity of what is occurring while lacking the cognitive, emotional, and developing regulatory capacities to manage these intensified affective states (E. H. Erikson, 1970), contributing to disruptive and turbulent psychological outcomes (Marusak et al., 2018).

As observed by McLoone et al. (2021) and Tometich et al. (2024), a cancer diagnosis often presents with heightened feelings of fear, shock, and distress. However, in diving deeper into adolescents' lived experiences, this study's findings also capture adolescents' interpretations of *why* early diagnostic and treatment phases are perceived as so psychologically overwhelming—an aspect overlooked in previous quantitative research, which has focused on the severity or frequency of psychological outcomes (Koo et al., 2020; Rosgen et al., 2022). For instance, while a cancer diagnosis is widely recognised as traumatic (Kim et al., 2016), many adolescents described muted initial responses, such as "I felt numb, it was like it just all went blank," (21yr, stage 2) and "I [emotionally] shut off in that moment" (17yr, stage 2), with these experiences of emotional numbness potentially reflecting dissociation and complex trauma markers. Rather than reflecting avoidant coping or emotional suppression, these responses signalled emotional overload, where the intensity, stress, and suddenness of the diagnosis exceeded adolescents' developmentally limited capacity to cognitively and emotionally process the event. Aligning with Docherty et al.'s (2015) developmental research on AYAs with cancer, still-developing cognitive and emotional systems of adolescents in this study impacted their capacity to process, regulate, and make sense of the trauma surrounding cancer's challenging moments, thereby contributing to their dissociation and psychological vulnerability.

Although treatment-related neurobiological deficits are commonly linked to heightened risks of anxiety, depression, and emotional dysregulation (Chidobem et al., 2022; Wickramasinghe et al., 2025), adolescents' neuroplasticity and adaptive psychological meaning-making may support resilient trajectories, buffering or mitigating the intensity of cancer-related psychological outcomes (Rosgen et al., 2022), which may partially explain why a small number of participants in this study reported minimal disruption to their psychological well-being, despite cancer often being considered a potentially traumatic life event. These findings show similarities to patterns described in medical and complex trauma literature, where a cancer diagnoses involve prolonged exposure to cumulative stressors, repeated medical procedures, persistent uncertainty, and heightened physical vulnerability (Belpame et al., 2019). Trauma-related cancer experiences are associated with a wide range of potential psychological outcomes, including hyperarousal, persistent worry, and dissociative responses, which may disrupt developmental processes and young people's evolving sense of self (Cameron et al., 2021). However, further investigation is required to strengthen these interpretations, especially given the cross-sectional design of the present study where the chronic trajectory of adolescents' psychological outcomes cannot be determined, limiting conclusions regarding whether these experiences reflect enduring markers consistent with medical or complex trauma.

Adolescents' psychological well-being was affected not only at diagnosis but also along the treatment journey, with ongoing emotional fluctuations intensifying outcomes of psychological strain. Mirroring Drew et al.'s (2019) findings, participants' narratives highlight a continual emotional "roller-coaster" (17yr, stage 2) with periods of emotional stability and downturns during treatment that could be reflected in trauma-related psychological presentations. Research by McLoone et al. (2021) suggests adolescents' experiences of psychological fluctuations during cancer treatment occur as they attempt to process and integrate cancer-related trauma into their emerging sense of self, with experiences of positive emotional states, such as optimism and hope, often interrupted by resurfacing fear, uncertainty, and heightened emotional reactivity. Challenging Jim et al.'s (2018) quantitative conclusions of a linear psychological decline across their cancer trajectory, participants' psychological well-being was instead experienced as fluctuating and iterative, potentially characterised by trauma cycles of emotional containment and reactivation as they continually renegotiated the meaning of their cancer experiences. However, as trauma was not an explicit analytic focus of the present study, its findings cannot confidently distinguish trauma-related responses from broader psychological distress.

Many adolescents reported high levels of emotional distress (e.g., anxiety, embarrassment, fear), coexisting alongside momentary fluctuations of feelings of optimism, compassion, and hope, which challenges one-dimensional patterns of distress noted in neurocognitive deficit-oriented research (Rosgen et al., 2022). Relatedly, adolescents described psychological and cognitive outcomes—including emotional instability and internal distress—as frequently overlooked within their cancer care. It may be that clinicians dismiss these well-being outcomes as age-typical emotional volatility associated with the fifth stage of SDT, rather than recognising them as cancer-related psychological needs. Similar patterns were identified in Pathrose et al.'s (2025) international study, where cancer-related psychological and cognitive dysregulation was frequently misinterpreted as normative adolescent psychological volatility. Such misattribution and dismissal of psychological well-being experiences may contribute to the persistent patterns of adolescents' dissatisfaction with Aotearoa's cancer care (AYACNA, 2020; Moss et al., 2019).

Additionally, several adolescents discussed how their emotional fluctuations were not episodic but rather embedded within their everyday lives. The pressure to manage ongoing internal instability—in the absence of fully developed cognitive processing capacities or the language to articulate distress—aligns with findings that adolescents frequently carry an invisible emotional load with them during treatment (Drew et al., 2019). Ferrari et al. (2020) found that adolescents' feelings of being an emotional burden to others contributed to their internalisation of negative experiences, leaving others unaware of the intensity and nature of their psychological distress. In addition, participants' accounts describe moments of emotional resilience; however, for many, outward expressions of resilience and stability were met with internal psychological distress that "ate away" (21yr, stage 3) at them, contesting the perceived binary distinctions between resilience and vulnerability noted in Quinn et al.'s (2015) study. Despite research suggesting that emotional expression during illness-related challenges supports adolescents' psychological adjustment (Sligo et al., 2019), participants' growing awareness of family dynamics and emerging expectations of emotional maturity partially led them to minimise outward expressions of distress, and instead often internalise their cancer experiences to protect family members, with emotional regulation operating as containment rather than recovery (McLoone et al., 2021).

Outside of the emotional ups and downs, several adolescents described experiencing event-specific and anticipatory anxiety surrounding cancer-related events, including scans or hospital visits, which is well understood in local and international research (Janssen et al., 2025; Moss et al., 2019). In contrast to narratives of emotional instability during AYA cancer journeys (Taylor et al., 2019), several participants described a more nuanced experience of persistent background fear "even on good days" (17yr, stage 2), suggesting a more sustained psychological undercurrent during their cancer journey, which, if sustained, might reflect markers of complex trauma. As observed by Wong et al. (2017), persistent hyperarousal experiences can also reflect how cancer may threaten adolescents' emotional safety, leading to "constant worry" (19yr, stage 2) that "never really went away" (21yr, stage 3).

Participants' narratives, in line with existing research, highlighted that experiences of persistent fear were mentally straining and that negatively impacted their everyday psychological reality (Kim et al., 2020).

Together, these findings indicate that adolescents' psychological well-being is significantly affected by the initial diagnosis and then throughout their cancer journey, with many reporting ongoing patterns of psychological instability. Cancer intrudes upon a developmental period in which emotional regulation, cognitive processing, and resilience are still maturing (Rosgen et al., 2022), likely contributing to adolescents' experiences of heightened emotional vulnerability, fluctuating hope and distress, and persistent low-level fear. While these emotional responses align with existing literature on cancer-related distress (Marusak et al., 2018; Tometich et al., 2024), this study extends current understanding by exploring how cancer experiences are internally managed, normalised, and carried beneath presentations of outward resilience. The following section examines how adolescents grappled with changes to their identities, self-perceptions, and broader understanding of who they were becoming as a result of being diagnosed with cancer.

Spiritual Well-Being

A central theme across adolescents' narratives was how cancer amplified age atypical engagement with existential questioning, purpose, and life's meaning. This study's findings align with McNeil's (2016) research on spirituality in AYAs, which identified cancer as contributing to developmental acceleration, whereby cancer abruptly intensified an unfamiliar and unavoidable existential focus on life, death, and broader purpose—emerging not from normative developmental curiosity but from the traumatic confrontation of this new reality. For example, one participant in this study reflected, "You start to ask those big questions…I hadn't really thought about before and it's kind of unavoidable" (21yr, stage 3). These spiritual well-being outcomes contrast with the fifth stage of SDT, which is marked by identity versus role confusion. Instead, the findings suggest atypical developmental compression, whereby adolescents' cancer experiences prompted existential concerns more commonly associated with the eighth and final stage of SDT, integrity versus despair, which is characterised by intensive grappling with the meaning and finitude of life (E. H. Erikson, 1950/1964). Acknowledged by Cameron et al. (2021) illness may delay, overlap with, or accelerate developmental processes during adolescence.

Spiritual well-being in the context of cancer research has traditionally been understood through Judeo-Christian religious frameworks, with research attributing religious belief to reduced existential distress, increased comfort and sense of control (Weaver & Wratchford, 2017). Religious meaning-making of cancer experiences, however, was only mentioned by one participant in this study, for whom faith provided mental peace and emotional stability throughout their treatment journey: “I’ve got God, so I haven’t worried too much” (20yr, stage 2). In line with Juškauskienė et al. (2023), who found that faith served as an internal anchor for understanding suffering and reducing cancer’s existential weight, this participant found religion to be a source of hope and reassurance, illustrating positive spiritual well-being amid the adversities of cancer. However, while cancer literature has commonly framed religion as central to spiritual well-being (Mahayati et al., 2018), such conclusions are increasingly limited in relevance for a growing proportion of adolescents who identify as non-religious (Tirgari et al., 2022). Consistent with the trend in recent literature, most participants in the present study perceived spiritual well-being outcomes through a modernised, secular lens, supporting Tulip’s (2021) argument that spirituality can also be perceived through meaning-making processes related to life, mortality, and the self, independent of religious belief.

The findings also extend and complicate existing research presented in McNeil’s (2016) literature review by providing original insight into adolescents’ modernised, secular perspective on spirituality, which remains under-theorised within cancer research. The limited use of religious meaning-making within participants’ accounts does not necessarily indicate an absence of spirituality (with most experiencing existential questioning) but rather suggests that adolescents may be engaging with alternative, deeply reflective non-secular forms of spirituality during adversity (Barton et al., 2018; Wei et al., 2025). Participants’ reflections, including accepting uncertainty, re-evaluating life perspectives, and trying to make meaning out of their suffering resonate with Eastern-informed spiritual concepts such as mindfulness and acceptance, which emphasises engagement with the present moment rather than reliance on structured belief (Oyedele et al., 2024). Barton et al. (2018) argue that adolescents' making sense of cancer and mortality may reflect experiential and internally constructed spirituality, offering a different and less structured system for understanding spiritual well-being beyond Judeo-Christian religious models.

Several participants in this study also mirrored Drew et al.'s (2019) finding of unanticipated positive changes in self-perceptions, including increased self-confidence and self-esteem, which emerged amid the challenges of cancer. For example, while receiving a cancer diagnosis unsettled and disconnected adolescents from older views of themselves, it also, for some, saw the emergence of new positive self-perceptions: "I've discovered new sides of myself—self-confidence I didn't know I had before cancer" (17yr, stage 2). Existing literature often positions cancer-related changes in appearance, functioning, and social participation as factors that diminish adolescents' confidence and self-esteem by disrupting peer validation and engagement in developmentally normative social roles (Kim et al., 2016). However, that pattern was only described in the narratives of younger participants (aged 17–19 years) in this study. As suggested by Marusak et al.'s (2018) developmental research, these findings can reflect younger adolescents' earlier positioning in the fifth stage of SDT, in which self-worth is more closely contingent on peer comparison and bodily appearance. However, in contrast, older adolescents expressed fewer and less destabilising self-perception outcomes in response to cancer-related changes, which, as suggested by Maree (2021), may be explained by their more advanced cognitive maturity, increased capacity for abstract thinking, and more consolidated identity and fidelity development.

Similarly, as argued by McLoone et al. (2021), the findings of this study also illustrate how positive self-perception reconstruction through emerging self-confidence, inner strength, and renewed self-worth can challenge the fundamental assumption that cancer erodes confidence rather than contributes to its growth. Ultimately, many participants described discovering an "unexpected inner strength" (20yr, stage 2) during their cancer journey, reflecting nuanced processes of identity reconstruction rather than identity collapse. This finding challenges deficit-focused cancer literature (Koo et al., 2020; Rosgen et al., 2022), which has traditionally prioritised vulnerability and loss while overlooking the potential for unexpected, growth-oriented adaptive outcomes to emerge alongside adversity.

Aligned with Kim et al.'s (2016) qualitative study of AYA cancer experiences, cancer for many participants led to significant identity changes, including the unwanted presence of a "cancer patient" identity. Adolescents perceived the cancer patient label as overshadowing who they actually were, with valued non-cancer identities (e.g., sports-related) minimised. Juškauskienė et al. (2023) note how the salience and visibility of cancer is often why it becomes the most common reference point through which others perceive adolescents' with cancer. Through the lens of SDT, the extent that adolescents were defined by their cancer constrained opportunities for identity exploration and role experimentation that are normatively central to adolescent development. However, complicating the literature's tendency to conceptualise illness identity internalisation as a passive, uniform, and unavoidable outcome of cancer (Sligo et al., 2019), the present findings demonstrate that, despite the salience and external reinforcement of the cancer patient label, some adolescents actively resisted, renegotiated, or delimited cancer as defining who they were, revealing a level of agency and complexity in adolescent identity development that has hitherto been under-recognised in research.

This study's findings indicate that adolescents' cancer experiences often involve significant spiritual disruption and reconstruction. Shared spiritual well-being outcomes included intensified existential questioning and active negotiation of identity in the context of cancer. In this study, adolescents' spiritual well-being outcomes were predominantly secular and oriented towards meaning-making related to life, mortality, and shifts in self-perceptions. This modern conceptualisation of spirituality challenges dominant cancer literature, which frames spirituality largely through faith-based paradigms (Tirgari et al., 2022; Tulip, 2021), and highlights the limited relevance of such perspectives for many contemporary adolescents. Across the cancer journey, many adolescents described working towards an emerging sense of fidelity, integrating cancer into—rather than allowing it to define—their developing self-identities. Cancer was ultimately experienced neither as the totality of self nor as a detachable life event, but as a formative influence woven into their evolving understanding of who they were and who they might become. The following section turns to the physical impacts of cancer, extending beyond biomedical accounts to consider adolescents' meaning-making when inhabiting a changed body.

Physical Well-Being

Adolescents in this study shared the destabilising physical impact of cancer, particularly in relation to how visible and functional alterations affected their sense of body connection. Treatment-related symptomology and clinically oriented outcomes of cancer described by participants, such as hair loss, eyebrow loss, skin changes, and weight changes, are well understood across local and international research (Marsh et al., 2024; Quinn et al., 2015), yet this traditional biomedical viewpoint obscures the meaning-making adolescents attributed to living in a "new" body.

Adolescence, through the lens of SDT, is characterised by the developmental task of forming a coherent identity, with the physical body and its capabilities typically serving as a central mechanism through which identity is explored, expressed, and validated by others (Docherty et al., 2015; E. H. Erikson, 1950/1964). Consistent with this developmental framing, adolescents in the present study described treatment-related appearance changes as making them feel unrecognisable to themselves, resulting in a "not me" (20yr, stage 3) phenomenon and reflecting a disruption in the alignment between internal identity and external presentation. These adolescents' embodied sense of body disconnection complicates existing literature, which has largely prioritised objective physical outcomes and symptom measurement (e.g., Koo et al., 2020; Rosgen et al., 2022). Physical changes caused by cancer are frequently viewed as threats to normal development, creating barriers to exploring and building a sense of normalcy and knowing who one is (Smith et al., 2019).

Consistent with AYA literature, adolescents in this study described physical presentations of cancer, such as fatigue, weight loss, and skin alterations (Kim et al., 2016; LaRosa et al., 2017). However, in contrast to existing AYA research, which tends to view these physical changes in terms of their impacts on employment and intimate relationships (Quinn et al., 2015; Smith et al., 2019), adolescents in this study emphasised meaning-making tied to how visible appearance changes disrupted identity continuity and peer belonging, highlighting developmentally distinct meanings that may be diluted within AYA literature.

In line with Wickramasinghe et al.'s (2025) UK findings, non-normative physical changes associated with cancer were experienced as particularly distressing by Aotearoa adolescents, who were already navigating rapid and vulnerable bodily transformations. While there is extensive international literature on the objective biomedical outcomes from cancer, including hair loss, skin changes, and weight fluctuations (Koo et al., 2020; Pina-Sanchez et al., 2021; Rosgen et al., 2022), this study extends knowledge by providing novel insight into the phenomenological experience of these well-known clinical outcomes. For example, adolescents spoke to their loss of body connection through feeling that they were "living in a changed body where when I look in the mirror it [my body] doesn't look like me" (20yr, stage 3). Physical changes were often what adolescents felt made cancer "real" (22yr, stage 2), because, as noted by McLoone et al. (2021), these visible changes marked the transition from cancer feeling like an internal illness to being an outward marker of unwellness, threatening their appearance of normality.

Interestingly, many adolescents described nuanced positive physical outcomes arising from their cancer experiences, including processes of bodily adjustment, acceptance, and the emergence of body compassion—outcomes that are poorly theorised in existing Aotearoa literature. Alongside reflections on physical loss, some participants described a gradual emergence of renewed respect for what their bodies could still do during treatment. Through the lens of SDT, this positive physical well-being outcome represents a re-establishing of body and identity continuity—an acknowledgement that, despite cancer, adolescents could still achieve identity continuity through it being reshaped rather than undone, with their changed body becoming part of a revised, yet still stable, sense of self. This adaptive meaning-making—through which adolescents renegotiated their relationship with their body amid illness—is rarely captured in cancer research. Instead, existing literature predominantly adopts a medicalised lens that prioritises functional decline and symptom presentation over subjective, embodied experiences (e.g., Harris et al., 2022; Koo et al., 2020).

In summary, while this study's findings align with extensive literature documenting the physical symptoms of cancer (Koo et al., 2020; Whitaker, 2020), adolescents' narratives also demonstrate the subjective, embodied, and developmental significance of physical changes beyond a medicalised viewpoint. While participants experienced reduced connection to their body—"My body is no longer me" (20yr, stage 3)—for some, this evolved into gradual acceptance, intertwined with their growing sense of self and identity. The relative absence of adolescent-specific theorisation on body connection and physical self-perception in the cancer literature underscores the importance of this research for understanding phenomenologically how changes in appearance, loss of physical capability, and living in a changed body are experienced. The next section examines how adolescents' cancer experiences included the navigation of healthcare services and spaces that often struggled to meet their developmental and well-being needs.

Ratonga Hauora and Taiao: Healthcare Services and Spaces

A common pattern discussed by adolescents in this study that shaped their experiences of cancer care was the pervasive experience of healthcare services and environments "not [being] designed for people my age" (19yr, stage 2), resulting in feelings of invisibility, confusion, and social disconnection. Aligned with the findings of the AYA Cancer Network Aotearoa (AYACNA; Moss et al., 2019), many adolescents self-reported negative healthcare experiences, partially due to their inconsistent placement across developmentally ill-suited oncology units. Despite the Ministry of Health ([MOH], 2019, p. 30) advocating for cancer care being centred around whānau (family) and "an emphasis on collective rather than individual thinking", adolescents in this study often experienced individualist care and separation, resulting in cancer feeling like a private burden.

Aligned with Came and Kidd's (2020) analysis of Aotearoa's current cancer action plan (MOH, 2019), the disjunction between policy intentions and the study's participants adverse and isolating experiences in healthcare spaces challenges the aspirations of the MOH to frame healthcare and illness as an inherent shared responsibility. Research critiquing Western healthcare systems often attributes adolescents' dissatisfaction with care to systemic issues such as fragmented care pathways, limited age-appropriate services, and the dominance of biomedical models (Ferrari et al., 2020; Quinn et al., 2015). This goes some way to explaining the factors behind adolescents' feelings of alienation and non-belonging across Aotearoa's clinical healthcare environments in this study. However, this study reveals new insights into what is missing in adolescents' cancer care. Even when services were easily accessible, adolescents felt marginalised, feeling they were being spoken *to* rather than *with*. For instance, for most adolescents, information and the communication by healthcare workers was overly clinical and technical, with developmentally salient concerns tied to adolescent life outside of cancer (education, peer belonging, identity, and fertility) commonly sidelined in favour of treatment-centric conversations.

This study's findings challenge the previous literature's dominant emphasis on service insufficiency as the primary explanation for adolescents' cancer care dissatisfaction (MOH, 2014; Pathrose et al., 2025), instead revealing subtler yet consequential forms of developmental invisibility operating within healthcare settings and services. Consistent with the 2019 AYACNA survey report (Moss et al., 2019), this study suggests that service satisfaction is shaped not only by whether support is available, but also by how that support is experienced and aligned with adolescents' developmentally situated well-being needs.

Instead of focusing on barriers, such as socioeconomic status, to cancer experiences noted across AYA literature (Cayrol et al., 2024; Pettit et al., 2023), participants described how their experiences of non-belonging and invisibility in ill-suited healthcare spaces were internalised. Participants' accounts echoed Aotearoa research showing how the lack of adolescent-specific services contributes to their poorer cancer experiences (Moss et al., 2019; Sligo et al., 2019). Participants' narratives provided novel insight into the developmentally specific consequences of how contemporary healthcare spaces in Aotearoa were experienced. For example, in many healthcare settings, adolescents described feeling stuck "in-between" (20yr, stage 2). In contrast to AYA research—where the broader age range can mask experiences of age-related feelings of misplacement due to the greater likelihood of occupying the same healthcare spaces as peers (Pathrose et al., 2025)—adolescents in this study identified healthcare environments as isolating and developmentally misaligned. Consistent with Drew et al.'s (2019) study findings, adolescents reported that placement alongside children during treatment felt infantilising, while care alongside older adults heightened their feelings of discomfort. These experiences reinforce adolescents' perceptions of their developmental invisibility within Aotearoa's healthcare system, where no spaces or supports are felt to be age-appropriate (Moss et al., 2019).

Through the lens of SDT, the fifth stage (16–21 years) is a period in which young people seek to establish a coherent identity and locate their place within social systems, yet current Aotearoa healthcare environments instead heighten experiences of identity disorientation and amplify negative well-being outcomes of emotional and social strain (Ferrari et al., 2020). In this study, experiences of non-belonging occurred across healthcare settings, including oncology waiting rooms, treatment wards, and fertility clinics, contesting the local literature's often limited focus on ward environments (Marsh et al., 2024; Pettit et al., 2023), which clearly underestimates the pervasiveness of adolescents' experiences of non-belonging across healthcare settings. Participants' narratives highlighted the emotional discomfort of occupying multiple age-inappropriate healthcare spaces: "Even in the waiting room or when I went to the fertility clinic it was like I wasn't a child, but not an adult" (20yr, stage 3). Despite the significance of these negative experiences, there has been scarce attention paid to them within Aotearoa cancer research, and the MOH's healthcare services and spaces inadequately support adolescents throughout their cancer journey.

Adolescents' accounts often described healthcare services and spaces as developmentally misaligned, contesting dominant portrayals of Aotearoa's healthcare system as collective, supportive, and age-responsive (MOH, 2014, 2019). Recent research and policy critiques (Came & Kidd, 2020; Moss et al., 2019) acknowledge current gaps in age-appropriate care; however, this study extends that understanding by describing how ill-suited ward environments, clinical communication, and limited psychosocial support were experienced not merely as structural shortcomings but as factors that resulted in experiences of invisibility and non-belonging. Together, this study's findings contest and extend the existing national cancer literature on adolescent cancer experiences, while underscoring the need to create developmentally attuned, adolescent-centred cancer care in Aotearoa.

Study Strengths, Limitations, and Future Directions

This section critiques the study's design, scope, and interpretive considerations, examining how these decisions influenced the research findings. The first subsection outlines key methodological strengths to demonstrate the study's quality, significance, and rigour. The second subsection acknowledges methodological constraints that affected the research scope and data interpretation, and suggests possible avenues for future research.

Strengths

This is the first study in Aotearoa to integrate culturally grounded Māori well-being frameworks—Te Whare Tapa Whā and the Meihana model—into discussions of adolescent-specific lived cancer experiences and associated well-being outcomes. The use of these frameworks enabled the discussion to capture a diverse range of relational, spiritual, psychological, and physical outcomes associated with adolescents' cancer experiences, generating original and unexpected insights beyond a Western-centric view of the illness. Contextualising adolescents' cancer experiences within Māori well-being concepts and Aotearoa's sociocultural context enhanced the depth of the discussion and strengthened the relevance of the findings for developing responsive cancer practices and service delivery in Aotearoa. Additionally, integrating the aforementioned frameworks into the study addressed a long-standing limitation within cancer literature—the fragmented and inconsistent definitions of well-being that limit cross-study research comparisons (Albert et al., 2024)—by providing a coherent, culturally grounded definitions through which cancer-related well-being findings could be discussed.

In addition, the study's exclusive focus on adolescents, rather than the broader AYA population often used in global cancer research, is a key methodological strength, contributing original insights in this under-researched area. Avoiding conflating adolescents with young adults enabled a more precise exploration of adolescents' unique cancer-related well-being experiences, capturing how their distinct developmental context and meaning-making affects their cancer experiences and well-being outcome perceptions. Existing evidence from AYA studies (Kim et al., 2016; Wickramasinghe et al., 2025) and the limited adolescent-specific literature (Drew et al., 2019; Juth, 2016) suggests that while there are some cross-overs, such as experiences of distress and overwhelm during treatment, there are also meaningful differences in cancer experiences and psychosocial outcomes for these cohorts. For instance, in this study, adolescents focused more on disruptions to identity formation and peer belonging, whereas in Janssen et al.'s (2025) study, young adults' cancer-related well-being outcomes focused more on employment and intimate relationship changes. By focusing exclusively on adolescents, this study generated adolescent-specific insights that may be obscured, diluted, missed, or misrepresented within broader AYA research, thereby strengthening the relevance and validity of the findings for informing the development of adolescent-specific cancer care services in Aotearoa.

A key methodological strength of the study was the qualitative, participant-led interview design, which contrasts with the predominance of structured quantitative approaches in international AYA cancer research (Drew et al., 2019; Pahl et al., 2021). This study's qualitative approach addressed a core limitation of dominant quantitative cancer research (Koo et al., 2020; Rosgen et al., 2022), which prioritises biomedical knowledge surrounding outcome severity or frequency over building a comprehensive understanding of contextual and interpretive processes underlying adolescents' cancer experiences. By allowing adolescents to guide the discussion and express their cancer experiences in their own language, the study captured not only what was experienced but also how well-being outcomes were developmentally and contextually situated. The study design also enabled the identification of cancer experiences that are under-recognised in the literature, as well as unexpected well-being outcomes that may have been missed without such a flexible, participant-led approach, including how healthcare spaces and interactions shaped adolescents' cancer experiences beyond service availability in Aotearoa.

Reflexive thematic analysis (RTA) was well-suited to this research as it aligned with the study's aim of understanding shared patterns of meaning across adolescents' cancer experiences and well-being outcomes, rather than drawing population-level conclusions. The use of RTA is appropriate for under-researched and complex topics, and prioritises patterned meaning across narratives, interpretive depth, and reflexivity (Braun & Clarke, 2021), making it appropriate for generating foundational knowledge about adolescent-specific cancer experiences, an area that is poorly researched internationally and within Aotearoa. Additionally, given the diversity of cancer types represented in the study, the use of RTA strengthened the analysis by enabling the interpretation to focus on shared developmental and well-being impacts rather than discrete diagnostic categories. As Kim et al. (2016) observe, outcomes such as changes to identity, autonomy, and peer relationships often transcend specific cancer diagnoses. Janssen et al. (2025), in a similar study to the present one, argued that the impact of cancer on AYAs is more significant than the effects of a specific cancer type, with common experiences occurring across all cancer types. Ultimately, RTA was selected because it aligned with the aim of capturing the broader picture of how cancer shapes adolescents' well-being rather than focusing on diagnostic distinctions.

A final methodological strength was the use of adolescent self-reports rather than using partial or full proxy narratives. Similar previous research consistently demonstrates discrepancies between adolescents' and adults' perspectives, with parents, caregivers, and clinicians often underestimating or misinterpreting the nature and intensity of adolescents' illness and well-being experiences due to differing developmental positions, contextual norms, and interpretive lenses (Darcy et al., 2014; S. J. Erikson et al., 2017). In this study, the use of self-reports was justified, as many participants described internalised well-being outcomes—such as psychological distress and body disconnection—that are often invisible and poorly understood by others (Kim et al., 2016). As demonstrated in Kim et al.'s (2020) later research, such subjective and highly internalised experiences are frequently missed, under-recognised, or inaccurately represented when inferred by others; therefore, reliance on proxy reports would have constrained the depth and interpretive validity of the study’s conclusions. Directly interviewing adolescents—despite their well-recognised limited developmental capacity (Syed & McLean, 2017)—was critical, as it enabled access to otherwise often concealed dimensions of their cancer experiences and well-being outcomes. Use of self-reports strengthened the study’s validity by comprehensively capturing adolescents’ entire cancer world and the meanings they attributed to their experiences, extending beyond what is visible to others (Kim et al., 2020).

Limitations and Future Research

This study was designed to be culturally inclusive, through recruitment strategies that encouraged Māori and Pasifika adolescent participation and a review of the proposed study with my supervisor, who has been involved in extensive Māori-focused research, to ensure the research aligned with relevant tikanga (customs), upheld cultural safety, and benefited Māori. Ultimately, however, all seven participants recruited identified as Pākehā. Barriers to Māori participation may have included greater geographical distance from hospitals and cancer support sites—an inequity disproportionately experienced by Māori adolescents (Moss et al., 2019)—where recruitment adverts via public noticeboards were focused. Limited digital access may have further reduced participation among Māori adolescents living outside Auckland, where in-person interviews were not available.

Given that Māori and Pasifika adolescent populations experience a disproportionately higher cancer burden rate and poorer healthcare interactions in Aotearoa compared to Pākehā (Te Aho o Te Kahu–Cancer Control Agency, 2021), their absence from the study constrains the diversity and cultural representativeness of research findings. The findings exclusively reflect Pākehā meaning-making and do not capture the culturally diverse sociocultural realities, structural inequities, and perspectives that may shape Indigenous adolescents’ cancer journey and well-being outcomes in Aotearoa. Although the collective and relational dimensions of well-being conceptualised in Te Whare Tapa Whā and the Meihana model were commonly discussed, culturally specific meanings and well-being experiences were poorly captured, with minimal insight into how Māori cultural values, whānau dynamics, and Indigenous worldviews may shape adolescents' interpretations of their cancer journeys. There is an urgent need for Kaupapa Māori research that prioritises the recruitment of Māori participants to ensure their voices and experiences are comprehensively understood and represented, enabling original insight into Indigenous accounts of lived cancer experiences and well-being outcomes, including the potential influence of institutionalised racism and cultural identity on lived cancer experiences (Dew et al., 2015). Exclusively exploring Māori cancer experiences could help inform the development of Māori-focused, adolescent-specific cancer support services to effectively address their low support service engagement and treatment adherence rates within Aotearoa (Moss et al., 2019).

Another limitation relates to the use of a self-selection sampling approach, whereby participation was limited to adolescents who felt psychologically stable enough to discuss their cancer experiences. While self-selection approaches are ethically necessary when exploring sensitive and potentially distressing topics to ensure voluntary participation, minimise psychological risk, and avoid coercion, this approach unintentionally introduces recruitment bias and constrains the external validity of conclusions (Tometich et al., 2024). Consistent with concerns raised in Aotearoa qualitative illness research (Sligo et al., 2019; Smith et al., 2019; Yallop, 2013), self-selection may have favoured adolescents experiencing comparatively more manageable treatment side effects, fewer psychosocial challenges, or more positive well-being outcomes. Consequently, adolescents with later-stage diagnoses or those experiencing heightened distress, complex psychosocial needs, or severe treatment impacts may be under-represented, resulting in narratives predominantly reflecting participants who were relatively well resourced and supported. To address this, future research should employ ethically appropriate recruitment and methodological approaches that support the inclusion of adolescents across diverse stages of diagnosis, treatment intensity, and cancer trajectories. Such research may enable the inclusion of perspectives that are less likely to be represented within self-selecting samples, thereby broadening the depth, diversity, and relevance of the findings. In turn, such future research may assist caregivers and clinical workers in feeling better equipped and confident in supporting adolescents with cancer who are experiencing more complex or intense well-being challenges.

Reliance on a single, one-off interview was another key limitation. Although only conducting one interview per adolescent is ethically appropriate to minimise participation burden for vulnerable individuals who were also juggling cancer treatment and its side effects (Juth, 2016), this data collection approach prevented opportunities to discuss later experiences or meanings that may have evolved later in their cancer journey. Adolescents' understandings of their cancer experiences—particularly those related to identity, belonging, and future orientation—may change as treatment progresses and contexts change, suggesting that some concepts introduced during interviews may have benefited from further discussion and exploration in a second interview. For example, several adolescents described feeling "in-between" (17yr, stage 2) and "out of place" (19yr, stage 3) within healthcare environments, language that appeared to carry layered meanings relating to age, identity, and belonging. Without follow-up interviews, opportunities to clarify how these meanings shifted across treatment stages, or how adolescents themselves came to understand these feelings over time, were limited. Subsequently, conducting interviews across multiple time points would allow adolescents time to reflect and elaborate on initial descriptions, and refine meanings not fully understood by the participant at the time of the one-off interview (Drew et al., 2019). The current study captured adolescents' experiences with depth and sensitivity; however, future research incorporating repeat interviews would enable a more nuanced understanding of how adolescents' cancer experiences and well-being meanings develop and change across their cancer journey, while also mitigating issues created by relying on adolescents' early meaning-making about cancer experiences that are still unfolding during the one-off interview.

It is also important to acknowledge that participants' responses to interview questions were relatively short on average in this study. According to Drew et al. (2019), adolescents' developmental positioning, level of neurobiological maturation, and capacity for abstract and reflective language may influence the depth to which they understand and can articulate their cancer experiences. Although non-verbal options such as visual elicitation were encouraged in this study, the findings may privilege discussions of cancer experiences that were easy to articulate and reflect on, while more embodied, nuanced, or internalised experiences—such as fear, bodily distress, or future uncertainty—may have been less detailed by participants in interviews. In addition, cancer-related physical side effects, emotional strain, and cognitive difficulties during participants' cancer journey may have affected their memory recall, ability to engage in longer interviews, and reflective capacities, potentially contributing to many adolescents' shorter interview responses and constraining the depth to which some cancer experiences and well-being outcomes were explored. Although participants voiced comfort in sharing their cancer experiences, future research using multiple shorter interviews may support deeper reflections by adolescents, as this would spread the cognitive and physical burden placed on individuals with time between sessions would enable emotional processing and meaning-making. This adapted interview approach may yield richer insights into adolescents' cancer experiences and well-being outcomes, which, in this study, were potentially constrained by fatigue, cognitive demands, or reduced concentration capacity within a single, longer interview.

Research Implications

Using these findings to create resources for the family members, friends, and partners of adolescents with cancer may help prepare support networks for the potential experiences and well-being outcomes their loved one may encounter. Such resources could potentially serve as problem solving tools and assist support networks in understanding cancer experiences from an adolescent's developmental lens. This would increase others' awareness of adolescents' less visible or internalised impacts of cancer (e.g., changes in self-perception and body connection) and deepen insight into the dual crisis adolescents face as they navigate cancer alongside ongoing normative developmental change. Rather than prescribing what to say or what not to say, such resources could synthesise the positive and negative cancer experiences identified across adolescents' accounts and highlight interactional approaches adolescents described as helpful or unhelpful, thereby facilitating communication and interactions that are responsive to adolescents' well-being needs. By reducing uncertainty about how to engage and increasing confidence in everyday interactions, these resources may help families and peers remain present over time, minimise avoidance, and support more stable, meaningful relationships. This could reduce the risk of relationships becoming awkward or fading due to others' uncertainty about how to engage (McLoone et al., 2021). Consistent with adolescents' reports of unwanted identity changes and living in an unfamiliar body, such resources would shift psychoeducation away from resilience-focused narratives (Drew et al., 2019) and towards supporting adolescents to live alongside cancer as an integrated part of their lives, without allowing it to dominate their sense of self.

In addition, given participants reports of their poor experiences in Aotearoa healthcare settings, targeted training and workshops for clinical staff may be beneficial for developing adolescent-specific communication and service practices within current paediatric and adult oncology settings, with the goal to best support adolescents' holistic well-being. As McLoone et al. (2021) argued, healthcare approaches that engage and support adolescents only from a biomedical perspective are unlikely to be successful, as adolescents' well-being needs span multiple interconnected domains. Adolescents in the study consistently described healthcare environments as developmentally ill-suited; characterised by overly clinical and difficult-to-understand language; and lacking age-appropriate support for non-physical concerns such as relationship changes, identity disruptions, and education challenges. Training that acknowledges these lived experiences in healthcare contexts could support clinicians' recognition of adolescents' unique well-being needs and the developmental impact of cancer on this age group, leading to the appropriate adaptation of healthcare spaces and practices. In effect, workshops could create spaces for conversations with adolescents that extend beyond physical treatment, helping clinicians build understanding and confidence in how to specifically support adolescents and address their differences in care needs, including holistic impacts commonly overlooked, such as missed milestones and identity disruptions.

Additionally, the findings highlight the importance of forming adolescent-specific cancer care practice pathways, as adolescents' well-being outcomes were not only impacted by cancer and related treatment, but also by how care was structured, accessed, and perceived. Adolescents described psychological instability, social disconnection, and feeling out of place in both paediatric and adult units, with those spaces reported as not adaptive to their developmental context. Based on the research findings, the MOH and local health boards should work collaboratively with adolescents, whānau, clinicians, and support organisations to inform the development of adolescent-specific cancer care pathways within Aotearoa healthcare settings, dispelling assumptions of adolescents' cancer care being met within current cancer systems. Developing adolescent-specific cancer care pathways may help ensure adolescents' holistic well-being needs are recognised as an integral component of care rather than a secondary concern, supporting adolescents to feel seen, understood, and appropriately supported, potentially increasing their treatment adherence and engagement with support services (Ferrari et al., 2020). This study calls on national health bodies to recognise the importance of attending to adolescents' distinct needs in healthcare contexts and to provide system-level designers with ways to better support adolescents' cancer-related well-being needs.

A unifying theme that emerged from all adolescents' narratives was that although cancer had significantly impacted to their well-being, they did not position the illness as wholly determining who they were, nor as preventing them from forming positive relationships and self-perceptions. As such, the findings may help alleviate concerns identified by Kim et al. (2020) among caregivers and professionals regarding adolescents' well-being during what is often a highly traumatic event. Caregivers may find reassurance in the fact that adolescents' accounts were not uniformly negative; they also reflected on the positive moments of their cancer journey. Cancer was not considered to entirely define adolescents; however, it was also not described as a temporary or inconsequential disruption, instead cancer was described as something they learnt to live alongside while navigating normative developmental transitions. Consequently, in initial diagnostic appointments and early treatment consultations clinicians in Aotearoa can draw on the findings of the present study to guide reassuring and supportive conversations with parents, who Kim et al. (2016) study reported are often anxious about the potential effects of cancer on their adolescent. In essence, caregivers and professionals are encouraged, while interacting and providing support to adolescents, to recognise potential vulnerabilities while avoiding overly vigilant or anxious responses that may inadvertently undermine their autonomy and sense of competence.

Conclusion

In the qualitative study conducted for this thesis, seven adolescents completed a one-off individual semi-structured interview, with the aim of exploring their lived cancer experiences and the associated holistic impacts on their well-being within the Aotearoa context. This thesis concludes that adolescents' lived cancer experiences in Aotearoa represent distinct, multidimensional impacts on their well-being, with a dual crisis occurring as the challenges of cancer intersect with the volatile developmental transition of adolescence. Existing cancer literature has often focused on AYAs' biomedical outcomes, such as treatment burden, physical decline, and psychopathology (Pina-Sanchez et al., 2021; Rosgen et al., 2022). While participants' narratives in this study included physical well-being outcomes, such as reduced functioning and appearance changes, the findings also highlighted other ways in which cancer uniquely impacted them. Social and spiritual outcomes such as identity loss and friendship challenges, while minimally represented in past research, were central to how cancer was lived and made sense of, alongside other well-being outcomes, including experiencing an emotional roller-coaster and lifestyle disruptions. Cancer was experienced as a developmentally disruptive event that intersected with adolescence as a period of increasing autonomy, identity formation, and social expansion, resulting in interconnected changes across relationships, daily life participation, and emotional and cognitive functioning (Janssen et al., 2025). Challenging the predominantly deficit-focused literature (Koo et al., 2020; Whitaker, 2020), the adolescents' accounts in this study also demonstrate nuanced insight into how well-being outcomes of fear, uncertainty, and loss, coexisted with positive outcomes, including personal growth, strengthened family relationships, heightened appreciation of the present, and emerging resilience. Across narratives, adolescents described navigating healthcare environments poorly aligned with their developmental positioning, fostering feelings of invisibility and non-belonging, as spaces and services were not attuned to their cancer realities or well-being needs. While some aspects of adolescents' cancer experiences overlap with AYA research findings (McLoone et al., 2021; Taylor et al., 2019), this study demonstrates that adolescents' cancer experiences are largely developmentally embedded and that contextual factors interact uniquely to shape well-being in both challenging and transformative ways.

In closing, adolescents' cancer experiences and related well-being needs require more intentional and developmentally informed support in Aotearoa. Effective care, therefore, must extend beyond addressing medical concerns alone; it requires recognition by family, peers, and clinicians that cancer is not merely an illness to be treated but a profound disruption that affects adolescents' holistic well-being and developmental trajectories. Change requires Aotearoa's cancer support and healthcare spaces to view adolescents not just as patients, but as young people in the midst of becoming, and the creation of developmentally attuned, adolescent-centred models of care that support both cancer-related and non-cancer-related well-being needs.

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Appendix A

Semistructured Interview Schedule

Semistructured Interview Schedule

Formal Study Title: Lived Experiences of Cancer and the Impacts on Well-Being Among Adolescents in Aotearoa New Zealand

Lead Researcher: Abbigail Birkett

Study Site: Massey University Albany

Contact phone number: [redacted]

Ethics reference: OM1 25/16

Introduction

1. **Welcome**

Hello, my name is Abbigail Birkett. I would like to warmly welcome you and thank you for taking the time to be here today and for agreeing to take part in this interview.

2. **Interview Overview**

The interview will take approximately 30–45 minutes. During this time, you will be asked some questions about your cancer experiences. You may take breaks at any point, skip any questions you do not wish to answer, or stop the interview at any time, depending on what feels most comfortable for you. If you choose to bring a support person, they may speak on your behalf if you need a break, wish to skip a question, or decide to end the interview.

3. **Support Services Reminder**

If you feel upset or require additional support at any point after the interview, the information sheet sent via email includes contact details for free support services you can access.

4. **Personal Media Check**

   Did you bring any personal items with you today, such as photos, music, or other items? If so, please note that you will take these items with you after the interview.

5. **Audio Recording Consent**

   Before we begin, I would like to check that you are comfortable with me audio-recording this interview. The recording is to ensure that I can correctly transcribe what you share.

6. **Check Readiness to Begin**

   Do you feel ready to start, and do you have any questions before we begin?

7. **Start Interview Recording**

   With your consent we will start the recording that will only capture the audio and not any video.

Interview Section

If you brought any photos, drawings, or other media with you, I will begin by asking: “I see you brought in [photo, drawing, or other media]. Would you feel comfortable talking to me about it?”

If you did not bring any media, the interview will begin with the following question: “What do you think is important for others to understand about your experience of cancer and how has it affected your well-being?”

During the interview, I may draw on the questions below to support the conversation. However, the interview will be mostly led by what you choose to share. Guiding questions are intended to serve as prompts rather than a fixed script, and I may use fewer or more questions depending on what you would like to talk about and the level of support you prefer for expressing your experiences.

Interview Questions

- How have your everyday activities changed since being diagnosed with cancer?
- Can you share, in as much detail as you feel comfortable, what your experience was like in being diagnosed with cancer?
- Can you tell me about your current everyday experiences of living with cancer?
- What does a typical day look like for you during cancer treatment?
- Can you share, in as much detail as you feel comfortable, how cancer has affected your social well-being?
- Can you share, in as much detail as you feel comfortable, how cancer has affected your spiritual well-being?
- Can you share, in as much detail as you feel comfortable, how cancer has affected your mental well-being?
- Can you share, in as much detail as you feel comfortable, how cancer has affected your physical well-being?
- Throughout your cancer journey, have you experienced any positive impacts on your well-being in any of the four dimensions (physical, social, spiritual, and mental)? If so, would you be willing to share what those positive impacts were?
- If you're comfortable sharing, did you face any challenges during your cancer journey? If so, what were they, and how did they affect your well-being?
- Can you describe any unexpected ways cancer has impacted your well-being that you didn’t anticipate?
- How has your understanding of your well-being needs changed throughout your cancer journey?
- Is there anything else you’d like to share about your cancer experience or the impact of cancer on your well-being?

Closing

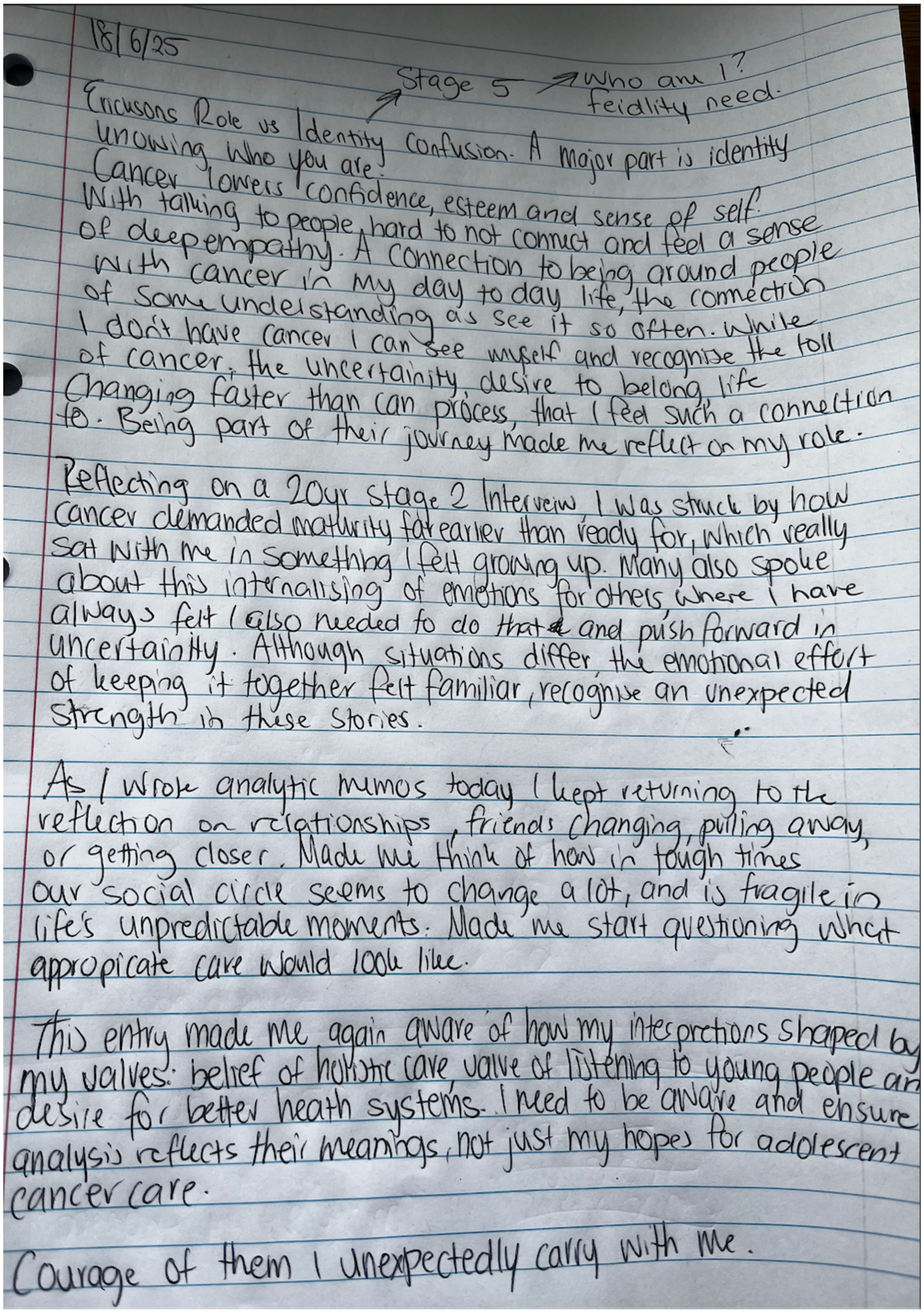
At the 30-minute mark, I will ask whether you would like to finish the interview or if there is anything else you would like to share. You may also choose to end the interview at any time before the 30 minutes are up, and you do not need to provide a reason. The audio recording will be stopped once the interview has finished.

After the interview, I will check in with you to see how you are feeling and remind you that the information sheet includes contact details for free support services you can access if needed. I will also explain what will happen next.

Within three days, you will receive a copy of your interview transcript and an Authority for Release of Transcript form by email. You will have three weeks to review the transcript and make any changes you wish, such as adding detail, clarifying responses, or removing anything that feels too personal. To include your interview data in the study, you will need to sign and return the Authority for Release of Transcript form, even if you choose not to make any changes.

Appendix B

Reflexive Journal (Excerpt)



18/6/25

Stage 5 → Who am I? feidlity need.

Ericksons Role vs Identity confusion. A major part is identity unowing who you are. Cancer lowers confidence, esteem and sense of self. With talking to people, hard to not connect and feel a sense of deepempathy. A Connection to being around people with cancer in my day to day life, the connection of some understanding as see it so often. While I don't have cancer I can see myself and recognise the toll of cancer, the uncertainity, desire to belong, life Changing faster than can process, that I feel such a connection to. Being part of their journey made me reflect on my role.

Reflecting on a 20yr stage 2 Interveiw I was struck by how cancer demanded maturity far earlier than ready for, which really sat with me in something I felt growing up. Many also spoke about this internalising of emotions for others, where I have always felt I also needed to do that and push forward in uncertainitty. Although situations differ, the emotional effort of keeping it together felt familiar, recognise an unexpected strength in these stories.

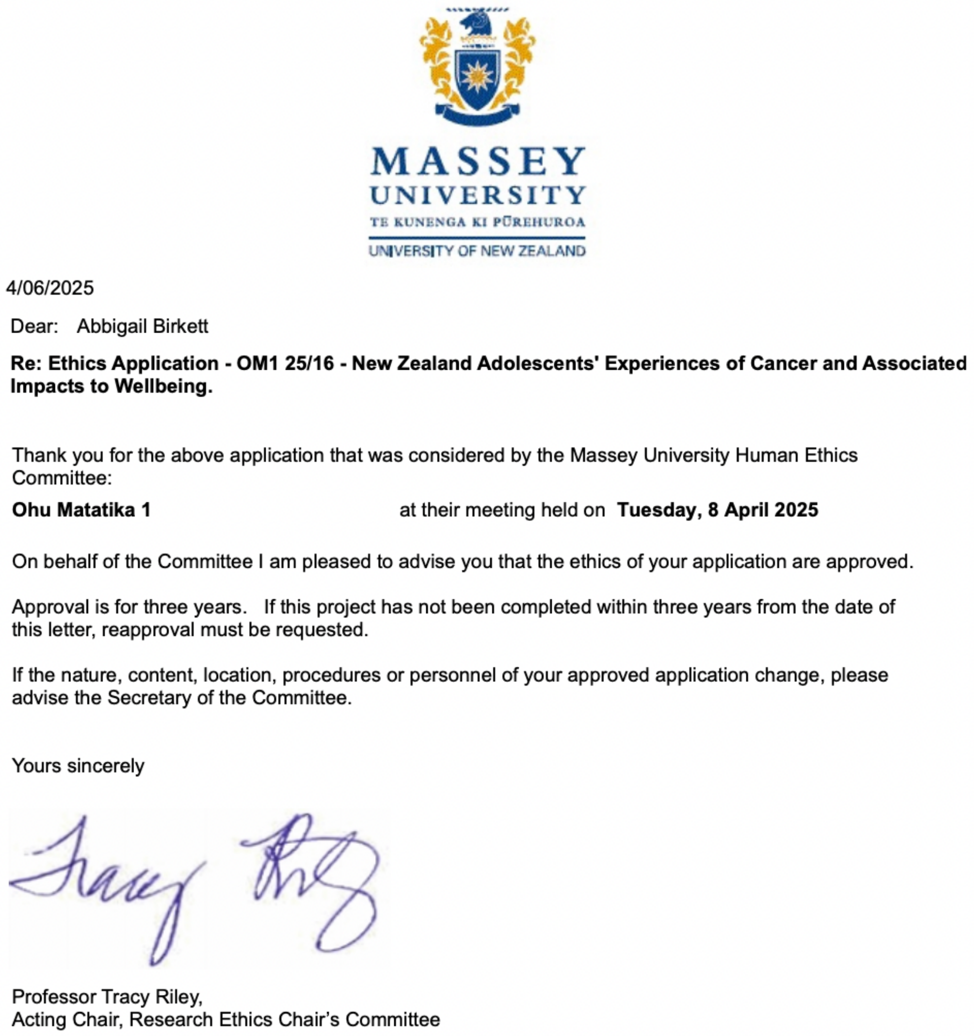
As I wrote analytic memos today I kept returning to the reflection on relationships, friends changing, pulling away, or getting closer. Made me think of how in tough times our social circle seems to change a lot, and is fragile in life's unpredictable moments. Made me start questioning what appropicate care would look like.

This entry made me again aware of how my intesprections shaped by my valves: belief of holistic care, valve of listening to young people an desire for better heath systems. I need to be aware and ensure analysis reflects their meanings, not just my hopes for adolescent cancer care.

Courage of them I unexpectedly carry with me.

Appendix C

Ethics Approval



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

4/06/2025

Dear: Abbigail Birkett

Re: Ethics Application - OM1 25/16 - New Zealand Adolescents' Experiences of Cancer and Associated Impacts to Wellbeing.

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 1 at their meeting held on **Tuesday, 8 April 2025**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

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

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

Yours sincerely

Professor Tracy Riley,
Acting Chair, Research Ethics Chair's Committee

Appendix D

Participant Information Sheet

Lived Experiences of Cancer and the Impacts on Well-Being Among Adolescents in Aotearoa New Zealand

Information Sheet

Primary Researcher: Abbigail Birkett

Supervisor: Matthew Shepherd: Associate Professor, School of Psychology, Massey University, Albany.

This qualitative research thesis is a partial requirement for the Masters of Health Science in Psychology qualification at Massey University.

Invitation and Project Description

The information sheet provided is designed to help you decide whether you would like to participate. You do not need to make a decision immediately, and you are encouraged to discuss the study with others—such as whānau, friends, or healthcare providers—before deciding.

If you choose to participate, please sign the consent form and return it via email to the primary researcher (contact details are provided on the final page). You will be given a copy of both the information sheet and the consent form for your records.

What is this study about?

The study aims to understand what it is really like to experience cancer and how it impacts you as an adolescent in Aotearoa. The study's purpose is to understand how people your age navigate cancer and how it can influence how you feel emotionally, how you relate to others, how you see yourself, and how you make sense of your life, not just your physical health.

Much of the existing research does not fully reflect adolescents' lived experiences of cancer. Well-being outcomes are often assumed rather than directly described by adolescents, and these assumptions can shape the types of support offered. Adolescents are frequently grouped with children or adults in healthcare and research; however, adolescence is a distinct stage of life with unique needs, experiences, and ways of understanding illness. As a result, services and support are not always designed in ways that work well for people your age, and gaps in support can occur.

The study is focused on listening directly to adolescents because your voice matters. There is also limited research in Aotearoa that explores adolescent cancer experiences through a cultural lens. Identity, whānau, community, and broader understandings of well-being are important parts of people's lives, and these may be experienced differently depending on who you are and where you come from. This research seeks to recognise and explore those differences, including Māori perspectives and culturally grounded ways of understanding well-being.

What will happen if I take part?

If you choose to take part in this study, you will be invited to participate in a one-on-one interview with me, the primary researcher. The interview will last approximately 30–45 minutes. You may choose to take part either in person at Massey University's Albany campus (Auckland) or online, whichever feels easiest and most comfortable for you.

The interview will be guided by what you choose to share. I will ask open-ended questions to help support the conversation; however, there are no right or wrong answers. You may share as much or as little as you wish about your cancer journey and how it has affected your well-being, both positively and/or negatively.

You may skip any question you do not wish to answer, take breaks whenever needed, or stop the interview at any time without consequence. After the interview, you will receive a written transcript of what you shared. You will have the opportunity to review the transcript, make changes, or remove any content before deciding whether you are comfortable with your interview data being included in the study.

Participant Identification and Recruitment

You might see information about this study shared online through cancer support groups, blogs, or social media platforms such as Instagram and Facebook. Printed flyers will also be displayed at youth centres, community health hubs, and public noticeboards to ensure the study is accessible to individuals with limited access to online platforms.

If you are interested in taking part, you can contact me (the researcher) using the contact details provided on the flyer or at the end of this document. After you make contact, I will communicate with you via email or phone to provide further information about the study and check whether participation would be appropriate.

If you meet the selection criteria and choose to participate, I will email you an information sheet and a consent form. Once these documents are signed and returned, a time will be arranged for your interview, either online or in person, depending on your preference. You are also welcome to share information about the study with others who may be interested and who meet the selection criteria outlined below.

Selection Criteria

You may take part in this study if you meet all of the criteria listed below. If you have any questions, please contact the primary researcher (Abbigail Birkett) using the contact details provided on the final page of this information sheet.

- Be aged between 16–21 years at the time of enrolment in the study.
- Currently live in New Zealand.
- Have a current cancer diagnosis, at any stage of diagnosis.
- Be fluent in English.

Participants

The study will be hoping to include ten adolescents. A sample of this size is small enough to prevent individual voices from being lost, while also being large enough to capture the diversity of ways cancer can affect adolescents. Since this is a personal topic, it is completely understandable if you do not feel comfortable discussing your cancer experiences, with participation being entirely voluntary.

Cost of Participation

The only possible cost associated with participation is travel if you choose to attend an in-person interview at Massey University's Albany campus. Participation via an online interview is also available if this option is more convenient. Regardless of the interview format chosen, you will receive a $15 Prezzy e-voucher by email as koha, in appreciation of your time and contribution to the study.

Potential Risk of Being Part of the Study

Previous research acknowledges that discussing cancer experiences may be distressing. If you choose to share your experiences, this may involve talk about personal or sensitive topics, such as changes in how you view your body, challenges in friendships, or aspects of mental well-being. Discussions may cause temporary distress; however, this study has been designed to prioritise your well-being and minimise potential discomfort. You may bring a support person for comfort, take breaks, skip any questions you do not wish to answer, or stop the interview at any time. Information about additional support services will be provided both before the interview and at the end of this information sheet. Any distress experienced is expected to be short lived.

Project Procedures

If you decide to take part in this study, you will be invited to participate in a one-off interview lasting approximately 30–45 minutes. The interview will be scheduled for a day and time that works best for you and can take place either in person at Massey University's Albany campus or online, whichever feels more comfortable for you.

You are welcome to bring a support person to the interview. The person may be a friend, whānau member, or someone else you trust. The support person will not speak for you about your experiences; however, they may request a pause, break, or that a question be skipped if they notice you need support.

The interview will be audio-recorded (voice-only). An interview guide containing open-ended questions will be used to support the conversation (this will be emailed to you as well). You may skip any question or choose not to answer at any point before or during the interview. The focus of the interview will be on your experiences of cancer in Aotearoa and how this has affected your well-being, such as emotions, friendships, mental health, identity, or any other areas that feel important to you.

When the interview reaches approximately 30 minutes, I will let you know. At that point, you may choose to finish the interview or continue if you would like to share more. The recording will stop once the interview has ended.

You may pause or stop the interview at any point. If you request a pause or stop, the recording will stop immediately. You may then choose to take a break, resume the interview, or end it entirely. If you decide to resume the interview, the recording will begin again. You are encouraged to only talk about what you feel comfortable sharing, and you can take as many breaks as you need.

If you decide to stop the interview, you will be asked how you would like any information already shared to be handled. You may choose one of the following options:

- Give permission for the recorded portion of the interview to be used in the study
- Request to re-do any part of the interview
- Request that all interview data be deleted and not used in the research

Within three days of the interview, you will be emailed a copy of the interview transcript (a written record of what was said) and an Authority for Release of Transcript form. The form provides permission for your interview data to be included in the study. You may review the transcript and make any changes you wish, as you have full control over how your story is shared. If you are happy with the transcript, you may simply sign the form and return it by email.

You will have three weeks from the date the transcript is emailed to you to:

- Correct any inaccuracies
- Add to clarify your responses
- Remove any information you no longer wish to include
- Withdraw your data from the study entirely

After these three weeks, the transcript will be finalised and cannot be edited further. Once you return a signed Authority for Release of Transcript form you can no longer withdraw your transcript. If you do not return the form your transcript will not be included in the research.

Support for Participants

You are encouraged to only take part if you feel comfortable sharing your cancer experiences and how they have affected your well-being.

To support you throughout the interview process, the following procedures are in place:

- You will have access to a range of free support services (including helplines and counselling) if you feel you need additional support after the interview.
- You may contact me, the primary researcher, at any time if you have questions or concerns about the study or would like assistance accessing available support services.

- You will receive a copy of the interview questions in advance, allowing you time to reflect on them and decide whether there are any questions you would prefer to skip.
- During the interview, you can pause, take a break, skip any question, or stop the interview entirely at any time.

Your comfort, safety, and well-being are prioritised throughout the research process. If anything is unclear or you feel uncertain at any point, please feel free to contact me for further information or support.

Data Management

Handling your data with respect and safety is important in this study, with approaches in place to manage and decode your personal information, as well as to securely store your data.

Identifiable Information

Identifiable information refers to any details that could reveal your identity, such as your name, date of birth, or address. When your interview is transcribed, any identifiable information you mention will be removed.

The following groups may have access to your identifiable information:

- The nominated research staff involved in this research project.
- In rare situations, researchers may be required to share your information with others—for example, if there is a serious threat to public health or safety, or to the life or health of you or another person.

De-identified (Coded) Information

To protect your privacy, a code will be used instead of your name in all reports and publications. The code will include only your age and cancer status. No information that could reasonably identify you will be used.

Security and Storage of Your Information

Once the interview is completed and the transcript has been finalised, all research materials—including interview transcripts, consent forms, and other forms—will be securely stored on Massey University's approved OneDrive system. Each form will be kept in a separate, password-protected folder, with access restricted to the primary researcher and the research supervisor.

Your identity will always remain confidential. The information you provide will be used for this Master's thesis to better understand how cancer affects adolescents' well-being in Aotearoa. The research data you provided may also be published, used in future presentations or academic articles, and/or shared with community groups; however, no information that could identify you will ever be included.

After the study is completed, your data will be securely stored for 5 years on Massey University's secure OneDrive. After this time the research supervisor will permanently delete all the research data. All data storage and handling will follow Massey University's Research Data Management Policy and local data security standards.

Rights to Withdraw Your Information

Until the Authority for Release of Transcript form is returned you may withdraw your consent for the collection and/or use of your information. To withdraw, simply send an email to the primary researcher stating that you wish to withdraw your data from the study. You do not need to provide any explanation. As a participant, you have the right to receive a brief summary of the main findings of this research, written in plain language. This summary will be emailed to you by December 31st, 2025.

Participant's Rights

- If you decide to participate, you have the right to:
- Decline to answer any question during the interview;

- Withdraw your data from the study up until you return the Authority for Release of Transcript form;
- Ask any questions about the study at any time throughout your participation;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Receive a summary of the project findings when the study is concluded;
- Ask for the recorder to be turned off at any time during the interview.

Project Contacts

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

Abbigail Birkett: Primary researcher
Phone: +64 [redacted]
Email: [redacted]@massey.ac.nz

A/Prof Matthew Shepherd: Associate Professor, School of Psychology, Massey University, Albany
Phone: +64 092136094
Email: M.Shepherd1@massey.ac.nz

Please Note

I cannot provide mental health support as I am not a trained mental health professional. However, I can answer any questions about the research and help you navigate the support options below.

Support Services For Participants

If anything was brought up for you during or after the interview that is distressing or uncomfortable, or if you want to talk to someone for mental health support, please contact these confidential services:

WHATS UP

Phone: 0800 942 8787

Lifeline

Phone: 0800 543 354

Youthline:

Phone: 0800 376 633

Mind and Body

Access to free two one-on-one sessions with a trained support worker with experience in mental distress.

Email: admin@mindandbody.co.nz

Website: https://www.mindandbody.co.nz/our-services/peer-support-and-advocacy/

I AM HOPE

- If you would like to talk to someone after the interview, you can access two free counselling sessions. Support from this organisation is available to anyone under 25, and you can choose to have your sessions in person, online, or by phone.
- To access this support, visit the website, choose a qualified counsellor who feels like a good fit for you, and send them a message to request a session. Support is usually available within two days of your request.

Email: team@gumbootfriday.org.nz

Website: https://help.gumbootfriday.org.nz/

Māori Mental Health Support:

For adolescents who would like to access Maori-focused support, the services listed below are free, confidential, and provide counselling sessions.

National Hauora Coalition Trust

Ph: 0800 100 642

Email: administration@nhc.maori.nz

Te Puna Hauora o Te Raki Paewhenua:

Ph: +64 9 489 3049

Email: info@tepuna.org.nz

Compulsory Statements

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 25/16. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz.

Low Risk Notifications

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researchers named above are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you wish to raise with someone other than the researchers, please contact the Director, Research Ethics, email humanethics@massey.ac.nz.

Appendix E

Participant Recruitment Flyer

RESEARCH PARTICIPANTS WANTED

Researchers want to understand the experiences of New Zealand adolescents with cancer and how these experiences impact their wellbeing.

The findings will help improve healthcare systems and support services for adolescents with cancer.

Inclusion Criteria:

- Aged 16–21 years at the time of recruitment.
- Have a current cancer diagnosis (at any diagnostic stage).
- Currently residing in New Zealand.
- Willing to complete a 30-minute interview (online or in person).

If you meet the criteria and want to particpate or learn more about the study:
Ph: [redacted]
Email: [redacted]@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 25/16. If you have any concerns about the conduct of this researh, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz

Appendix F

Consent Form

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Lived Experiences of Cancer and the Impacts on Well-Being Among Adolescents in Aotearoa New Zealand

Participant Consent Form

I have read and understood the information sheet I received, and I have a clear understanding of the study's details. Any questions I had have been answered to my satisfaction, and I understand I can ask further questions at any time. I have had sufficient time to consider my participation, and I understand that taking part is voluntary. I may withdraw from the study at any time until the Authority for Release of Transcript form is returned, without any consequences.

Please tick to indicate you consent to the following:

☐ I agree to participate in this study under the conditions set out in the information sheet.

☐ I consent to my information being shared with other people if significant risk to personal or others safety is disclosed.

☐ I consent to the research staff collecting and processing my information, including information about my health.

☐ If I decide to withdraw from the study, I understand that any information collected about me up until the return of the Authority for Release of Transcript form may still be used in the study.

☐ I understand that my participation in this study is confidential where no material, which could identify me personally, will be used in any reports generated.

☐ I understand that the results of this study will be available to relevant cultural community groups and may be published and/or presented to relevant healthcare organisations.

☐ I know who to contact if I have any questions about the study or need support.

☐ I understand that if I choose to pause the recording during the interview, the researcher will stop data collection immediately, and I can decide whether to end the interview or take a break before resuming. I also understand that if I choose to stop the interview, I can decide whether my partial data is used, revised, or withdrawn entirely.

☐ I acknowledge that, as part of my rights, I will receive a summary of the study results.

Declaration by Participant

I [print full name] ________________________________ hereby consent to take part in this study.

Signature: _______________________ Date: ________________

Appendix G

Authority For the Release of Transcript

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Lived Experiences of Cancer and the Impacts on Well-being Among Adolescents in Aotearoa New Zealand

Authority for the Release of Transcript Form

I confirm that I have had the opportunity to read and amend the transcript of the interview conducted with me.

I agree that the edited transcript and extracts from this may be used in this thesis and future publications arising from the research. I understand that once I return this document to the researcher via the provided email ([redacted]@massey.ac.nz), I will no longer be able to withdraw my data from the research project.

Signature: .... Date: ....

Full Name - printed ....

Appendix H

RTA Logbook (Excerpt)

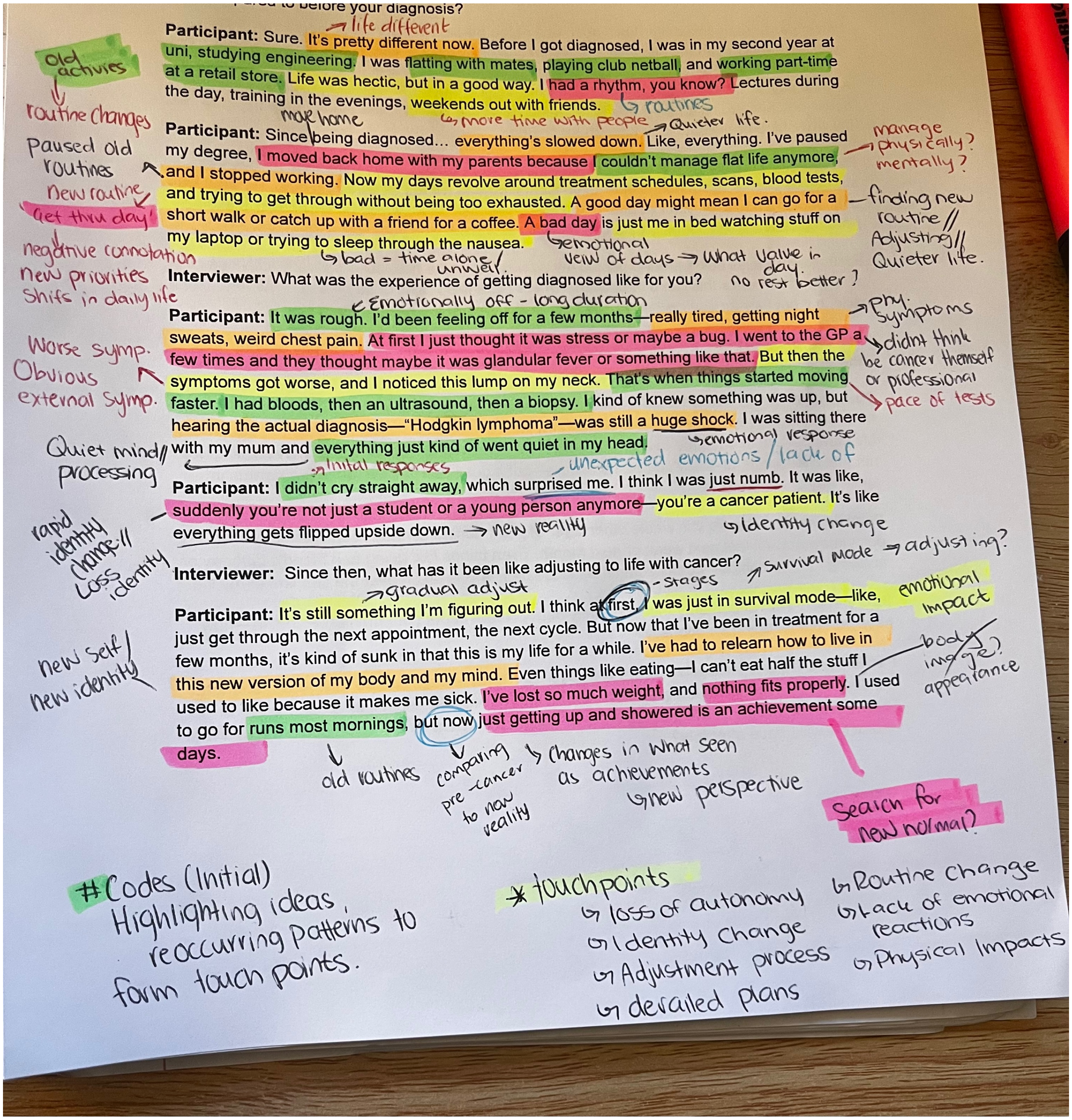
Transcript Excerpt	Initial Reactions	Reflexive Responses	Observations and Patterns	Relation to Dataset
“At first, I was just in survival mode… I’ve had to relearn how to live in this new version of my body and my mind.”	Immediate sense of disruption and disorientation; strong emotional weight in how the participant describes bodily and cognitive change	I notice I am drawn to the language of “survival mode,” which aligns with dominant illness narratives. I need to remain reflexive about not imposing this framing as central without attending to how the participant’s account shifts over time	Adjustment is framed as ongoing and embodied, not limited to treatment milestones; bodily change extends into identity and daily functioning	Similar accounts of “learning to live differently” appear across transcripts, particularly among participants further into treatment
“I used to go for runs most mornings, but now just getting up and showered is an achievement some days.”	Stark contrast between pre- and post-diagnosis functioning stands out	I feel an instinctive comparison response; reflexive reminder to privilege the participant’s own meaning-making rather than my evaluative reaction	Loss is articulated through everyday activities rather than medical detail; achievement is redefined	Common dataset pattern where well-being shifts are expressed through changes in ordinary routines

"I've had to find new routines… there's still life happening. It's just… a lot quieter than before."	Sense of quiet adaptation rather than overt positivity	I am aware of potential labels such as "coping" or "resilience"; however, it is important to hold this descriptively at this stage	New routines and slowed pace emerge without denial of loss; coexistence of limitation and continuity	Aligns with comments of reduced pace and felt that their life was being dominated by treatment
"Everyone else my age is out there doing stuff… and I'm at home trying to keep my white blood cell count high enough for chemo."	Striking juxtaposition between normative adolescent life and illness demands	This reinforces the importance of developmental framing; need to ensure this is not collapsed into generic AYA narratives	Participant situates isolation relationally and developmentally	Widely echoed across interviews, particularly in relation to missed milestones

Note. This table presents an excerpt of the researcher's reflexive engagement during RTA. The table illustrates how initial reactions, reflexive positioning, and developing observations were actively documented and considered in relation ot the wider data

Appendix I

RTA Generating Initial Codes (Excerpt)



to before your diagnosis?

life different

Participant: Sure. It's pretty different now. Before I got diagnosed, I was in my second year at uni, studying engineering. I was flatting with mates, playing club netball, and working part-time at a retail store. Life was hectic, but in a good way. I had a rhythm, you know? Lectures during the day, training in the evenings, weekends out with friends.

Old activies
routine changes
routines
more time with people
move home
Quieter life.

Participant: Since being diagnosed… everything's slowed down. Like, everything. I've paused my degree, I moved back home with my parents because I couldn't manage flat life anymore, and I stopped working. Now my days revolve around treatment schedules, scans, blood tests, and trying to get through without being too exhausted. A good day might mean I can go for a short walk or catch up with a friend for a coffee. A bad day is just me in bed watching stuff on my laptop or trying to sleep through the nausea.

Paused old routines
New routine
'Get thru day'
negative connotation
new priorities
Shifs in daily life
manage physically? mentally?
finding new routine // Adjusting // Quieter life.
bad = time alone/unwell.
emotional view of days → what value in day. no rest better?

Interviewer: What was the experience of getting diagnosed like for you?

Emotionally off - long duration

Participant: It was rough. I'd been feeling off for a few months—really tired, getting night sweats, weird chest pain. At first I just thought it was stress or maybe a bug. I went to the GP a few times and they thought maybe it was glandular fever or something like that. But then the symptoms got worse, and I noticed this lump on my neck. That's when things started moving faster. I had bloods, then an ultrasound, then a biopsy. I kind of knew something was up, but hearing the actual diagnosis—"Hodgkin lymphoma"—was still a huge shock. I was sitting there with my mum and everything just kind of went quiet in my head.

phy. symptoms
didnt think be cancer themself or professional
pace of tests
Worse symp.
Obvious external symp.
emotional response
Quiet mind// processing
Inital responses
unexpected emotions / lack of

Participant: I didn't cry straight away, which surprised me. I think I was just numb. It was like, suddenly you're not just a student or a young person anymore—you're a cancer patient. It's like everything gets flipped upside down.

new reality
Identity change
rapid identity change// Loss identity

Interviewer: Since then, what has it been like adjusting to life with cancer?

survival mode → adjusting?
- stages
gradual adjust

Participant: It's still something I'm figuring out. I think at first, I was just in survival mode—like, just get through the next appointment, the next cycle. But now that I've been in treatment for a few months, it's kind of sunk in that this is my life for a while. I've had to relearn how to live in this new version of my body and my mind. Even things like eating—I can't eat half the stuff I used to like because it makes me sick. I've lost so much weight, and nothing fits properly. I used to go for runs most mornings, but now just getting up and showered is an achievement some days.

emotional impact
body image? appearance
new self / new identity
old routines
comparing pre-cancer to now reality
changes in what seen as achievements
new perspective
Search for new normal?

#Codes (Initial)
Highlighting ideas, reoccurring patterns to form touch points.

* touchpoints
- loss of autonomy
- Identity change
- Adjustment process
- derailed plans
- Routine change
- Lack of emotional reactions
- Physical Impacts