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DOUBLE DISPARITY: CANCER IN ETHNICALLY MINORITISED YOUNG PEOPLE

Section A: Psychological Outcomes in Ethnically Minoritised Adolescents and Young Adults with Cancer: A Systematic Review
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Major Research Project Summary

Section A is a systematic review of quantitative studies that examined psychological outcomes in ethnically minoritised young people with cancer. The review included twelve studies from the United States. Findings were synthesised narratively and evaluated critically. The evidence was mixed, though suggested emerging evidence that minoritised young people experienced significantly more psychological distress compared to those identified as White. Hispanic youths were consistently identified as a vulnerable group that fared worse in their mental health. Implications relating to clinical practice and future research were discussed.

Section B is an empirical study that explored ethnically minoritised young people's experiences of cancer and cancer care. Nine participants were invited to share stories of their cancer journey, which were analysed using thematic narrative analysis. Themes illustrated the hardship and isolation minoritised young people experienced when navigating the disruptive changes to their sense of identity and social roles from cancer. Cultural narratives highlighted cultural clashes within family, cultural influences on treatment and feeling othered that impacted on their experiences. Cancer care was generally storied positively, though some expressed frustration towards perceived discrimination, a lack of cancer awareness and cultural sensitivity, which led to delayed diagnosis. Clinical implications and future research directions were identified.

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Section A: Psychological Outcomes in Ethnically Minoritised Adolescents and Young Adults with Cancer: A Systematic Review

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Abstract

Background

Ethnic disparities in cancer prevalence, prognosis and health outcomes have been widely documented in adults. However, less is known about the impact of ethnic differences in young cancer patients who present with unique challenges and complex needs along their developmental trajectories. The present review aims to examine psychological outcomes amongst ethnically minoritised adolescents and young adults with cancer.

Method

A systematic search was conducted on PsycINFO, PubMed, Web of Science and CINAHL using terms related to adolescents and young adults, cancer, ethnic minority and psychological outcomes. Quantitative studies of any design that were published after 2000 were included in the review and were screened against the eligibility criteria. Assessment of methodological quality was carried out using a standardised tool. Data were extracted and synthesised narratively.

Results

Twelve studies conducted in the United States were identified. Participants were aged between 14 to 40 years old, had heterogeneous cancer diagnoses, stages and treatment status. The methodological quality of the studies reviewed was mostly moderate to low and the evidence was mixed. Six studies found ethnic disparities in psychological outcomes: the majority demonstrated that ethnically minoritised adolescents and young adults experienced significantly more distress and lower quality of life compared to White peers with cancer. Hispanic young patients, in particular, were highlighted as a vulnerable group that fared worse in their mental health compared to other minoritised youths. Longitudinal data showed that minoritised adolescents and young adults experienced more marked improvement in their psychological health over time in contrast to the Caucasian group.

Conclusion

There is emerging evidence regarding inter-ethnic differences in psychological outcomes amongst adolescents and young adults with cancer. However, the findings are inconsistent, reflecting methodological weaknesses and the complexities of intersectionality impacting on mental health. More attention on cross-cultural research is needed to substantiate these results and to elucidate mechanisms behind these inequalities in order to contribute towards more equitable quality and access to healthcare.

Keywords: Adolescents and young adults, cancer, psychological outcomes, ethnically minoritised.

Introduction

Adolescents and Young Adults with Cancer

Cancer in adolescents and young adults (AYAs) has gained burgeoning attention over the last decade. International oncology working groups have defined AYAs as a distinct population between the ages of 15 to 39 (Aubin et al., 2011; Ferrari et al., 2021). This differentiation has been a much-welcomed move in both academia and clinical practice to acknowledge the unique cancer epidemiology and under-recognition of cancer risks and awareness in this population. Research has shown substantial differences in the biology, aetiology and survivorship of cancer in AYAs, compared to their younger or older counterparts (Tricoli et al., 2016). Whilst this categorisation may be helpful in refining oncology research, the present author recognised that from a psychological perspective, this definition encompasses a wide age range that reduces the heterogeneous experiences of a 15-year-old and a 39-year-old into a single population. This categorisation has implications on the extent of generalisability and comparison drawn from AYAs research across this diverse spectrum. Nevertheless, it represents a pivotal change in providing valuable insights to address AYAs' age-specific concerns that were previously understudied.

The incidence rate of AYAs cancer has inflated markedly by 24% since the 1990s, with the most common types being lymphomas, leukaemia and melanomas (Cancer Research UK, 2021). Despite still being a rare disease, cancer remains one of the leading causes of death in this age range and contributes to the global disease burden (Alvarez et al., 2022). Whilst the survival rate has increased significantly, 86% of AYAs will survive for five years post-diagnosis, it is also the population with the most lagged progress in survival outcomes compared to pre-adolescent children and adults (National Cancer Institute, 2022; Trama et al., 2018). Transitional aged AYAs are also at a formative life stage of undergoing significant physiological and psychosocial development. They face unique psychosocial challenges, such as body image, family planning, financial burdens, disrupted social relationships and occupational opportunities that give rise to complex needs that may not be adequately met by traditional paediatric and adult oncology services (Janardan & Wechsler, 2021). Hence, AYA-targeted research and services have the potential to provide optimised care for their treatment needs and age-related developmental concerns.

Impact of Cancer on AYAs

A multitude of studies have reported elevated levels of psychological distress in AYAs with cancer compared to healthy peers (Sansom-Daly & Wakefield, 2013). Between 30% to 57% of AYAs with cancer reported clinical symptoms of depression, anxiety and post-traumatic stress (Kwak et al., 2013a; Lee et al., 2023). A review examining longitudinal outcomes found that psychological distress was most severe following diagnosis and improved over time (Bradford et al., 2022). On the other hand, some studies have demonstrated enhanced adaptive coping, resilience and post-traumatic growth in AYAs with cancer (Husson et al., 2017a; Kyngäs et al., 2001). Young people have expressed developing a newfound perspective and appreciation for life, as well as finding meaning and purpose that have been linked to better quality of life (QoL) and well-being (Greup et al., 2018).

Despite the breakthroughs in improving survival rates, AYAs survivorship, which refers to the phase of life after completing initial cancer treatment, comes along with its profound challenges as AYAs are left with unmet needs and reduced support after treatment (Millar et al., 2010). In comparison to childhood and older cancer survivors, AYAs are at increased risk of experiencing long-term and late adverse effects, such as fertility challenges, cardiovascular conditions and secondary malignancies (Chao et al., 2016; Chao et al., 2019; Suh et al., 2020). AYA survivors were also found to have less engagement with education and employment along with decreased financial independence compared with healthy controls (Janssen et al., 2022; Sisk et al., 2020). These factors are associated with higher levels of depressive symptoms, anxiety symptoms and lowered self-efficacy (Thom & Benedict, 2019). Over 80% of AYAs experienced clinically significant levels of fear about cancer recurrence (Shay et al., 2016). This finding is corroborated by a population-based study that concluded AYA cancer survivors are at significantly higher risk of developing a psychiatric disorder and a 20% increased risk of experiencing a severe psychiatric episode, including hospitalisation and suicide attempts (De et al., 2021).

Developmental Considerations

The far-reaching impact of cancer is particularly pertinent in young people's lives. Adolescence and emerging adulthood are complex life stages characterized by significant physical, cognitive, emotional and social transitions. Erikson (1968) posited that during these life stages, AYAs have to resolve the developmental conflicts of 'Identity versus Role Confusion' and 'Intimacy and Solidarity versus Isolation', which contribute to one's psychological well-being. The former refers to the navigation of developing personal roles and identities to construct a sense of self, autonomy and independence. The latter focuses on building intimate relationships with others that cultivate meaningful emotional bonds and connections. Yet the disruptions that cancer bring to this developmental trajectory challenge the attainment of these important milestones. For example, AYAs with cancer have pressing medical needs that require dependence on professionals and family, which may compromise their autonomy over life choices and pressure them to deviate from expected life roles (Park & Rosenstein, 2015). Coping with a life-changing illness also threatens the establishment and maintenance of relationships that contribute to feelings of isolation and loneliness (Fox et al., 2023). These psychological impacts as well as the physical and emotional toll of cancer treatment on AYAs are detrimental, meriting special consideration and support.

Cancer Inequalities

Epidemiological analysis on cancer survival rates by race in the United States has shown that the White ethnic group has the highest survival rate of 89.1%, whilst non-Hispanic Black AYAs have the lowest despite having a 25% lower cancer incidence rate than non-Hispanic Whites (National Cancer Institute, 2022). The stark differences have prompted national inquiries into cancer inequalities (Commission on Race and Ethnic Disparities, 2021; Marmot et al., 2020). Whilst the underlying cause behind such disparities remains elusive and poorly understood, factors such as language difficulties, cultural beliefs associated with cancer and structural barriers in healthcare are believed to play a role in these variances (Burnes Bolton et al., 2004; Kagawa-Singer et al., 2010). Emerging studies have investigated ethnic differences in various aspects of the cancer journey, for instance, time and route to diagnosis of cancer, screening participation and service engagement (Abraham et al., 2022; Martins et al., 2013; Martins et al., 2022). However, the trends in ethnic differences are complex due to the vast heterogeneity in cancer types and ethnic groups, thus, findings have been largely inconclusive to confirm or refute the inequalities amongst ethnic groups.

Socially disadvantaged ethnic communities are at an increased risk of experiencing stress and poorer mental health than the majority groups even in the absence of medical illness (Bignall et al., 2019). A meta-analysis of 21 studies found that minoritised adult cancer patients, especially those identified as Hispanic, reported significantly worse psychological distress, symptoms of depression and overall QoL than the White majority population (Luckett et al., 2011). Meyer (2003) proposed the Minority Stress Model for understanding the disproportionate prevalence of mental health difficulties amongst minoritised groups. He postulated that individuals who experience a high degree of stigma, prejudice and discrimination can develop chronic stress responses that lead to poor physical and mental health. The developmental and health predicament faced by AYAs with cancer, compounded with the challenges of identifying as ethnically minoritised are likely to exacerbate their psychological distress and impact on their QoL. Given the national agenda on addressing health inequalities, such as the launch of the Office of Health Improvement and Disparities and the NHS Long Term Plan (NHS England, 2019), comparing outcomes across ethnic groups may provide valuable insights into the impact of ethnic differences on mental wellbeing and drive actions to narrow the gap.

Research Objectives and Aims

To date, there is only one review examining psychological difficulties in ethnic minority adult cancer patients (Luckett et al., 2011), yet none have been conducted in the younger population. Therefore, a review of the literature pertaining to ethnically minoritised AYAs is timely and can contribute to illuminating the systemic issues of racial underrepresentation and disparities. Given the rise in AYAs oncology research in the recent decades, this review aimed to synthesise and critically appraise the evidence base on psychological outcomes amongst ethnically minoritised young people with cancer and to investigate the extent of disparities in outcomes between different ethnic groups. This review also examined other relevant psychosocial measures reported by individual papers, such as QoL.

Methodology

This review was completed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines to uphold the quality and consistency of evidence synthesis. The protocol of this review was registered and published on PROSPERO, the International Prospective Register of Systematic Reviews for Health and Social Care Research (registration number: CRD42023466464). This aimed to promote transparency, quality and reduce the risk of bias in reporting the review.

Search Strategy

A systematic search was conducted on the 8th of June 2023 on the following databases: PsycINFO, PubMed, Web of Science and CINAHL. The development of the search strategy was guided by the PICO framework: (P) population, (I) intervention or exposure for the purpose of this review, (C) comparison group, and (O) outcome as recommended in evidence-based practice (Falzon et al., 2010). The combination of search terms used were grouped under these areas: ‘adolescents and young people’, ‘cancer and oncology’, ‘ethnic or racial minority’ and ‘psychological outcomes’, see Appendix A for the full search terms and strategies for individual databases. The search was limited to studies published in 2000 and thereafter in consideration of the rise in AYAs oncology research instigated by the National Cancer Institute in 2006. Reference lists of included studies and relevant reviews were manually searched to look for further eligible studies.

Inclusion and Exclusion Criteria

Study Design

Studies were limited to those published in peer-reviewed journals in the English language. Quantitative studies of all designs were included. Studies reporting qualitative findings were excluded due to difficulties in drawing comparisons between psychological outcomes amongst ethnic groups without standardised measures. Case studies, case series, dissertations and reviews were also excluded as they tend to have limited generalisability and may not adhere to the same standards of scientific rigour as peer-reviewed papers.

Participants

Participants were AYAs who had been diagnosed with cancer and took part in the study between the ages of 15 and 39. This age range was adopted in alignment with the AYA definition stipulated by the National Cancer Institute (2006). The search included any cancer type or stage, including in remission, and no limitations in treatment status. In studies where the participants' ages ranged from children to adolescence, these were excluded if more than 50% of participants were under 15 years old or had a mean age of diagnosis under 15. This was to ensure that the focus of the review was not overshadowed by findings of AYAs who were paediatric cancer survivors, who may have a different experience to those diagnosed after 15 years old.

Exposure and Comparison

The ethnically minoritised group is considered as the exposure factor in this review. Studies must have included ethnicity analysis comparing outcomes in at least two ethnic groups. The comparison group is the majority group which represents the dominant culture in the country where the study was conducted or any other ethnic groups. Studies that only reported data in majority groups were excluded.

Outcome Measures

The primary outcome of the review is any standardised measures of psychological distress, mental health symptoms or emotional well-being. Baseline data from intervention studies were included, but post-intervention scores were not as experimental trials are not representative of standard care and hence pose difficulty in outcome comparison. Other QoL-related measures were also synthesised if presented in the study.

Study Selection

The search yielded 723 potentially eligible studies and an additional four studies were identified through hand-searching reference lists of included studies and relevant reviews. After removing 207 duplicates, 516 studies were screened by title and abstract. Sixty-three studies were eligible for full-text review and of which, 51 were excluded. Primary reasons for exclusions were participants not within the AYA age range, such as adult or paediatric cancer studies; no ethnicity analysis provided and studies with only one ethnic group. Twelve studies were included in the review. Figure 1 shows the PRISMA flow diagram that depicts the study identification process.

Data Extraction

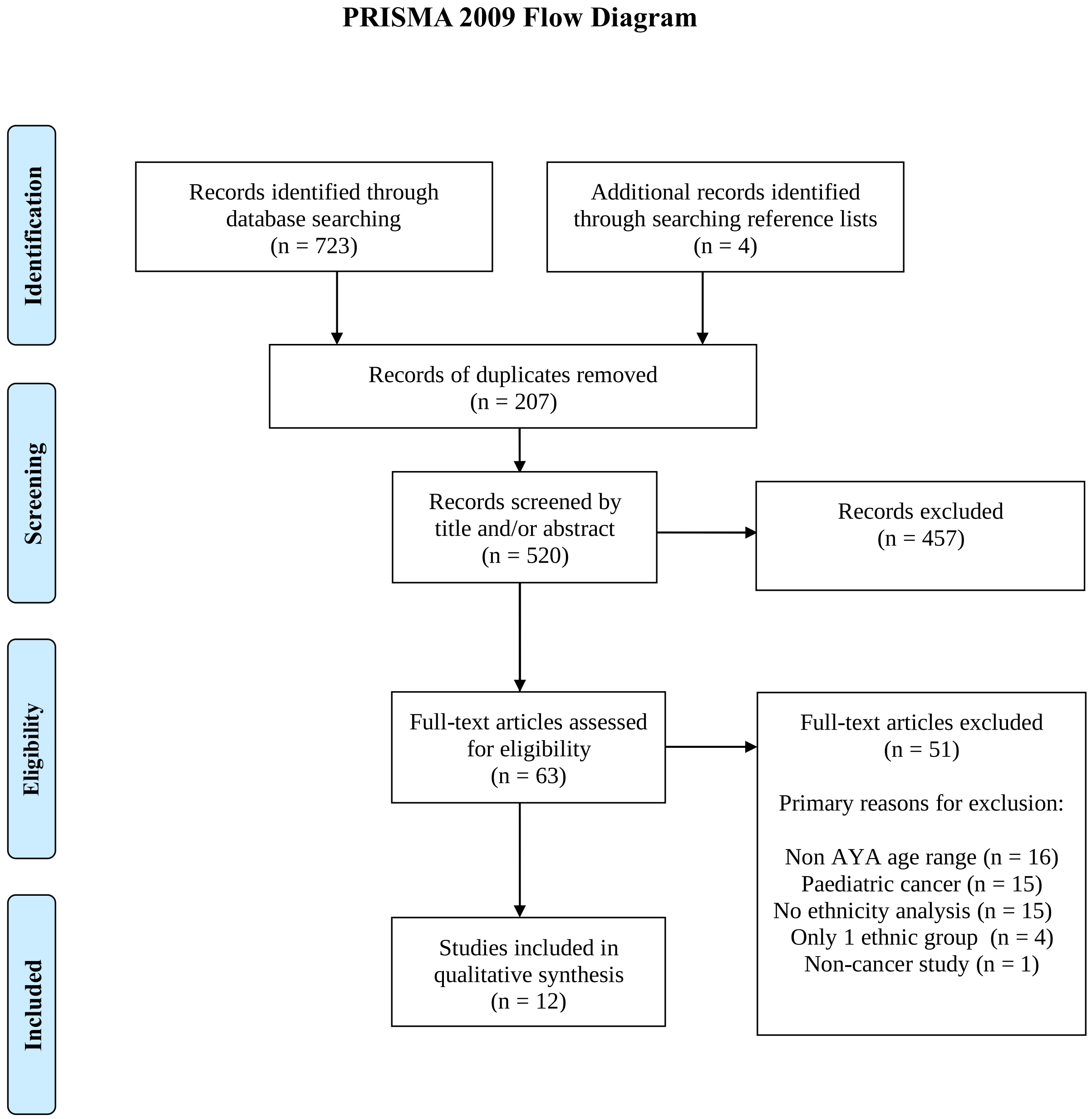
The Cochrane Data Extraction Tool was used as a guide to extract data from the included studies for evidence synthesis. Extracted information included: study setting; study population, participant demographics and baseline characteristics; study methodology; recruitment and study completion rates; outcomes and times of measurement, and results. Due to the heterogeneity in measuring ethnicity and psychological distress outcomes across studies, a meta-analysis was not possible. The data were aggregated descriptively for a narrative synthesis.

Quality Appraisal

Quality assessment of the studies was carried out using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies developed by the National Heart, Lung and Blood Institute (2021). This tool was chosen for its capacity to assess methodological quality for a range of observational study designs. Studies were rated based on criteria covering a range of areas: research question, study population, recruitment methodology, sample size justification, measurement of exposure, timeframe of study, outcome measures, blinding of outcome assessors, follow-up rate and statistical analyses.

Figure 1

PRISMA Flow Diagram Depicting the Screening Process



Results

Study Characteristics

Twelve studies were identified through the eligibility assessment. Four studies appeared to have overlapping datasets as evidenced by the same recruitment procedure through the same institutions during a matching period. Nevertheless, each study reported a different sample size, presented slight variations in demographics and examined diversified research questions and outcome measures, hence, all were included in the review. The overall sample size of included studies was estimated to be 3886 participants (approximate pooled mean age of 27.9). This estimation has taken into account the four suspected duplicate datasets by only including the study with the largest sample size in the calculation to minimise the over-inflation of participant count. More than 1623 participants identified as minoritised, constituting at least 42% of the full sample. All studies were conducted in the United States and recruited participants with heterogeneous cancer types, disease stages and treatment status. Table 1 summarises the main characteristics of these studies. One study looked specifically into distress in the context of COVID-19 (King-Dowling et al., 2023). Another study centred exclusively on female AYA survivors and compared outcomes between those identified as sexual minorities versus heterosexuals (Desai et al., 2021). Only two stated in their main objectives to explore outcomes amongst minoritised ethnic groups (Munoz et al., 2016; Ritt-Olson et al., 2018), whilst the rest aimed to describe outcomes in AYAs generally without emphasis on minority groups.

Table 1

Summary of Included Studies

Study	**Setting**	**Design** **Timepoints**	**Sample Demographics n (% female), Age Range, Mean Age (SD), Cancer Type**	**Ethnic Groups (n)**	**Psychological Outcome Measures**	**Main Findings**
Burgoyne et al. (2015) *Cancer-Related Distress in Young Adults Compared to Middle-Aged and Senior Adults*	USA, hospital-based	Retrospective cross-sectional study	n = 668 (58.7) Age = 18-39 31.1 (6.1) Numerous and heterogeneous cancer types, stages and treatment status	Caucasian (503) African American (101) Hispanic (31) Other (33)	Distress thermometer	**With Bonferroni correction, Hispanics and African Americans scored significantly higher on the distress thermometer than Caucasians.**
Chen et al. (2020)* *Profiles of emotional distress and growth among adolescents and young adults with cancer: A longitudinal study*	USA, multi-sites including three paediatric hospitals and two adult hospitals	Longitudinal cohort study 4 time points: T0 = within 4 months of diagnosis, T1 = 6 months, T2 = 12 months, T3 = 24 months	n = 179 (46.9) Age = 15-39 23.41 (9.09) Numerous and heterogeneous cancer types, stages and treatment status	White (78) Hispanic/Latino (78) Other (21) Missing (2)	BSI-18 PDS PTGI SF-36	**AYAs with high-distress profiles were less likely to be Hispanic/Latino than White, relative to those with resilient-growth profiles.**

DeRouen et al. (2015) *Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer*	USA, population-based	Retrospective, cross-sectional study	n = 484 (36) Age = 18-39 Mean NR, 95% of participants were aged 20 or above. Numerous and heterogeneous cancer types, stages and treatment status	Non-Hispanic White (284) Hispanic (102) Non-Hispanic Black/American Indian/Alaska Native (50) Non-Hispanic Asian/Pacific Islander (48)	SF-12	No statistically significant differences were found in the mental component QoL scores between Hispanic, Black, American Indian, Alaska Native, Asian and Pacific Islander and White AYAs. **Hispanic AYAs had a significantly lower physical component QoL score than White AYAs.**
Desai et al. (2021) *Mental Health Outcomes in Adolescent and Young Adult Female Cancer Survivors of a Sexual Minority*	USA, population-based	Cross-sectional study	n = 1025 (100) Age = 18-40 33.3 (4.9) Numerous and heterogeneous cancer types, stages and treatment status	White (745) African American (29) Asian or Native American (74) Mixed/other (177)	PHQ-8 GAD-7	There was no statistically significant association between depression, anxiety scores and different ethnic groups.
Husson et al. (2017b)* *Health-Related Quality of Life in Adolescent and Young Adult Patients With Cancer: A Longitudinal Study*	USA, multi-sites including three paediatric hospitals and two adult hospitals	Prospective, longitudinal cohort study 3 time points: T1= within 4 months post-diagnosis, T2 = 12 months, T3 = 24 months	n = 176 (44.9) Age = 15-39 23.6 (8.9) Numerous and heterogeneous cancer types, stages and treatment status	White (81) Hispanic/Latino (73) Other (20)	SF-36	No significant differences in the emotional component of QoL scores were found between ethnic groups at all time points.

Kwak et al. (2013b)* *Trajectories of psychological distress in adolescent and young adult patients with cancer: A 1-year longitudinal study*	USA, multi-sites including three paediatric hospitals and two adult hospitals	Prospective, longitudinal cohort study 3 time points: T1= within 4 months post-diagnosis, T2 = 6 months, T3 = 12 months	n = 215 (47) Age = 14-39 23.6 (8.9) Numerous and heterogeneous cancer types, stages and treatment status	White (95) Hispanic/Latino (91) Other (27)	BSI-18	**Hispanic/Latino or other minoritised participants reported significantly higher mean global symptom index scores than White AYAs at baseline.**
King-Dowling et al. (2023) *Psychosocial impact of COVID-19 on caregivers and adolescents and young adult survivors of childhood cancer*	USA, multi-sites including three hospitals	Cross-sectional study	n = 531 (52) Age = 15-29 19.41 (2.6) Numerous and heterogeneous cancer types, stages and treatment status	Non-Hispanic White (347) Black, Indigenous, Hispanic and People of Colour (181)	CEFIS-AYA	**Black, Indigenous, Hispanic and People of Colour had significantly higher distress scores than non-Hispanic Whites.**
Munoz et al. (2016) *Cancer experiences and health-related quality of life among racial and ethnic minority survivors of young adult cancer: A mixed methods study*	USA, hospital-based	Cross-sectional mixed methods study	n = 31 (64.5) Age = 18-39 33.2 (5.1) Numerous and heterogeneous cancer types, stages and treatment status	Hispanic (13) Non-Hispanic Black (9) Asian/Pacific Islanders (8) Mixed (3) Other (5)	FACT-G	**Asian/Pacific Islanders reported a significantly better emotional QoL score than Hispanics. Asian/Pacific Islanders also reported the best overall QoL scores, followed by Black, non-Hispanics and Hispanics.**
Ritt-Olsen et al. (2018)	USA, multi-sites	Cross-sectional study	n = 194 (49.36)	Latino (91)	CES-D PedsQL	**Latinos experienced significantly higher depressive symptom scores**

Depressive Symptoms and Quality of Life Among Adolescent and Young Adult Cancer Survivors: Impact of Gender and Latino Culture	including two hospitals		Age = 15-25 20.75 (2.77) Numerous and heterogeneous cancer types, stages and treatment status	Non-Latino: including African American, White, Asian (103)		**of clinical significance and lower QoL scores than AYAs identified as non-Latinos.**
Smith et al. (2013) *Health-related quality of life of adolescent and young adult patients with cancer in the United States: The Adolescent and Young Adult Health Outcomes and Patient Experience study*	USA, population-based	Cross-sectional study	n = 523 (33.08) Age = 15-39 Mean NR Numerous and heterogeneous cancer types, stages and treatment status	White (285) Hispanic (100) Black (43) Other (56)	SF-12 PedsQL	There was no significant difference in the mental component of SF-12 QoL scores between Hispanic, Black and White AYAs. **Hispanic respondents reported worse physical component of SF-12 QoL than White respondents.**
Zebrack et al. (2014) *Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the*	USA, multi-sites including three medical institutions	Prospective, longitudinal cohort study 3 time points: T1= within 4 months post-diagnosis, T2 = 6 months, T3 = 12 months	n = 215 (46.98) Age = 15-39 23.6 (8.9) Numerous and heterogeneous cancer types, stages and treatment status	Non-Hispanic White/Caucasian (95) Hispanic/Latino (91) African American (11) Asian/Pacific Islander (13) American Indian/Alaska Native (3)	BSI-18	There was no significant association between ethnic groups and assignments to the four distress trajectory groups (Chronic distress, Delayed, Recovery and Resilient). The odds ratio of White versus non-White AYAs in predicting the likelihood of being categorised in the resilient group was also insignificant.

first year following diagnosis						
Zebrack et al. (2015)* *The relationship between post-traumatic stress and post-traumatic growth among adolescent and young adult cancer patients*	USA, multi-sites including three paediatric hospitals and two adult hospitals	Prospective, longitudinal cohort study 3 time points: T1= within 4 months post-diagnosis, T2 = 6 months, T3 = 12 months	n = 165 (46.1) Age = 14-39 22.8 (8.8) Numerous and heterogeneous cancer types, stages and treatment status	White/Caucasian (74) Hispanic/Latino (71) Other (18)	PTGI PDS	No significant differences in post-traumatic stress severity scores were found between White and non-White participants. **Non-White AYAs had a significantly higher score in the new possibilities domain of PTGI.**

* indicates the studies with suspected same datasets, **Bold** highlights findings that reported significant differences between ethnic groups.

Abbreviations: SD, standard deviation; BSI-18, Brief Symptom Inventory-18; PDS, Posttraumatic stress diagnostic scale; PTGI, Posttraumatic Growth Inventory; SF-36, Medical Outcomes Study Short Form-36 Health Survey; NR, not reported; SF-12, Short Form Health Survey; QoL, Quality of Life; PHQ-8, Patient Health Questionnaire-8; GAD-7, Generalised Anxiety Disorder Assessment-7; CEFIS-AYA, COVID-19 Exposure and Family Impact Scales for Adolescents and Young Adults; FACT-G, Functional Assessment of Cancer Therapy-General; Centre for Epidemiologic Studies Depression Scale; PedsQL Scale, Paediatric Quality of Life Inventory

Quality Appraisal

The methodological quality of studies was assessed using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (National Heart Lung and Blood Institute, 2021). Each study was rated and assigned a score for each item: ‘yes = 1 point’, ‘no = 0 point’, ‘not reported = 0 point’ or ‘not applicable = excluded from scoring’. These points were summed and calculated into a percentage that was converted into an overall quality score: below 33% equated to a low quality rating, 34% to 66% corresponded to moderate and above 67% was considered as strong. As all studies in this review utilised an observational design, there are constraints to the extent of methodological rigour that can be achieved when compared to randomised controlled trials. Nevertheless, all studies have their strengths as well as limitations that impact the validity of findings and conclusions drawn from this review. See Table 2 for the evaluation of individual studies and Appendix B for the checklist guidance. Overall, longitudinal studies generally had higher ratings, with Kwak et al. (2018) rated as the strongest, whilst three studies had lower ratings (DeRouen et al., 2015; King-Dowling et al., 2023; Smith et al., 2013). This is due to having a lower participation rate of below 50% and employing outcome measures that were only partially validated for some participants, which increased the risk of selection and measurement bias.

Design

Five studies were longitudinal, though four were suspected to have overlapping datasets. They had sufficient and reasonable follow-up periods spanning from 12 months to 24 months. These studies provided valuable opportunities to examine AYAs’ mood changes over time across different stages of their cancer journey. Although establishing causality is not the focus of this review, longitudinal studies allowed more effective control of confounding variables, which enables a more robust exploration of any trends when making comparisons between ethnic groups. Furthermore, the attrition rates were minimal at follow-up, with three studies under 10% and two approximately 23% dropout.

Conversely, seven studies adopted a cross-sectional design. Despite being efficient and cost-effective in capturing data from a wide diverse population, these findings only provided a snapshot of AYAs' psychological well-being at a single time point, making it impossible to infer relational and temporal causality or to assess changes over time.

Study Objective and Population

All studies had clearly defined objectives and aims. Generally, the study population appeared to be fairly representative of the target population. The majority of studies reported a participation rate of over 50%. Two reported 43% and another two studies omitted this information. However, it is worth noting that those who declined participation or those who were considered too ill to take part were likely to have worse psychological outcomes. It is possible that the experiences of AYAs presenting with more severe psychological distress were not sufficiently captured in the current review. Similarly, participants who could not read or write English were a common exclusion criterion across studies. By excluding this group who could provide valuable data on psychological health in marginalised young people, this poses a risk of bias that limits the representativeness of results in ethnically minoritised communities. Moreover, considerable heterogeneity in cancer diagnosis, severity and treatment received were present in the included studies. Whilst this may strengthen the generalisability of findings across the diverse cancer patient spectrum, this also makes in-depth comparisons across groups more difficult as being at different stages of the cancer journey could impact greatly on psychological responses.

Sample Size and Power

The studies generally had a reasonable sample size. However, they tended to have smaller sample sizes in ethnically minoritised groups and rarely reported power calculations or estimated sample size. Although this does not necessarily constitute a major methodological flaw as observational studies tend to be exploratory in nature, this might weaken the reliability of findings between different ethnic groups due to underrepresentation.

Exposure Classification

Ethnicity was the exposure of interest in this review. However, across studies, ethnic groups were often poorly classified and reported. There was no standardisation as to how ethnicity groups were grouped and some races were clustered together in the analysis as one ‘non-White’ group as seen in King-Dowling et al. (2023), Zebrack et al. (2014) and (2015). This presents as a major limitation in interpreting these studies. The discrepancy in categorization could introduce bias into the analysis, making it challenging to draw meaningful comparisons between groups and to generalise findings. The broad groupings neglected the diversity between ethnic groups and failed to capture the important differences in psychological outcomes amongst minoritised ethnicities.

Outcome Measures

All outcome measures were self-reported by participants. This might raise concerns for response biases where participants may under-report their distress and potentially mask experiences that might be stigmatised in certain cultures (Robinson et al., 2022). Although ethnicity as an exposure factor could not be effectively blinded by outcome assessors, employing multiple means of assessments, for instance collateral reports by family members or clinicians may yield more objective and reliable data.

Most measures used were health-related QoL assessments that contained a mental health component designed to monitor distress in medical patients. It is questionable whether these measures sufficiently encapsulate the wide range of psychological responses in AYAs with cancer as compared to standardised clinical screening tools. For example, Recklitis et al. (2017) assessed the accuracy of Brief Symptom Inventory-18 (BSI-18) in identifying depression and anxiety in young adult cancer survivors compared to the Structured Clinical Interview for DSM-IV. They concluded that the recommended cut-off scores failed to detect a sizeable number of AYA survivors with psychiatric diagnoses. This implies that BSI-18 may obscure the true prevalence of mental health difficulties in this population. Criticisms for some scales, such as the Short Form Health Survey and Posttraumatic Stress Diagnostic Scale have also been voiced by Hagell et al. (2017), as they have not been fully validated across the entire AYA age range. Furthermore, six studies recruited both English and Spanish speaking AYAs (Chen et al., 2020; Husson et al., 2017b; Kwak et al., 2013b; Ritt-Olson et al., 2018; Zebrack et al., 2014; Zebrack et al., 2015). However, it is unclear whether the translated outcome measures employed have been validated in the Spanish language, therefore, weakening the validity and reliability of these results.

Table 2

Evaluation of Methodological Quality

	Burgoyne et al. (2015)	Chen et al. (2020)	DeRouen et al. (2015)	Desai et al. (2021)	Husson et al. (2017)	Kwak et al. (2013)
1. Was the research question or objective in this paper clearly stated?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
2. Was the study population clearly specified and defined?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
3. Was the participation rate of eligible persons at least 50%?	**Yes**	**Yes**	**No** - 43% participation rate.	**Yes**	**Yes**	**Yes**
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? **Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
5. Was a sample size justification, power description, or variance and effect estimates provided?	**No**	**No**	**No**	**No**	**No**	**No**
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**Yes**	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**Yes**	**Yes**
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	**N/A** - cross-sectional design, therefore there was only one timepoint.	**Yes**	**N/A** - cross-sectional design, therefore there was	**N/A** - cross-sectional design, therefore there	**Yes**	**Yes**

			only one timepoint.	was only one timepoint.		
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	**Yes** - data retrieved from medical records	**Yes** - though self-reported	**Yes** - though self-reported	**Yes** - though self-reported	**Yes** - though self-reported	**Yes** - though self-reported
10. Was the exposure(s) assessed more than once over time?	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	**Yes** - although the distress thermometer was a self-report measure, the paper provided psychometric properties of sensitivity and specificity in relation to well-established psychological symptom measures.	**Partially** - SF-36 and PDS have not been validated for the full AYA age range, only validated for adults aged 18 and above.	**Partially** - SF-12 has not been validated for the full AYA age range, only validated for adults aged 18 and above.	**Yes**	**Partially** - SF-36 has not been validated for the full AYA age range, only validated for adults aged 18 and above.	**Yes**

12. Were the outcome assessors blinded to the exposure status of participants?	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.
13. Was loss to follow-up after baseline 20% or less?	**N/A** - cross-sectional design with only one time point.	**Yes** - the attrition rate was about 9.5% at either T2 or T3.	**N/A** - cross-sectional design with only one time point.	**N/A** - cross-sectional design with only one time point.	**Yes** - the attrition rate was 10% after excluding deceased patients.	**Yes** - attrition rate was 8% after excluding 7% of deceased participants.
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	**Yes** - Bonferroni correction was used to adjust for multiple comparisons in determining the differences of means.	**No** - multivariate multilevel multinomial logistic regression models were used to examine associations between demographics and membership in different profiles. Control of confounding variables was not reported.	**Yes** - all covariates associated with the QoL scores were adjusted: age at survey, gender, race/ethnicity, education, type of cancer, symptoms, comorbidities, information needs, impact on control over life, treatment and insurance status.	**Yes** - adjusted for age at enrolment, race, ethnicity and social support.	**No** - univariate analysis, therefore, confounding variables were not taken into account.	**Yes** – multivariate models included sex, race, age at diagnosis, disease severity as well as time-variant variables, such as occupational status, relationships status and treatment status.
Overall Quality Rating	**Moderate**	**Moderate**	**Low**	**Moderate**	**Moderate**	**Strong**

	King-Dowling et al. (2023)	Munoz et al. (2016)	Ritt-Olsen et al. (2018)	Smith et al. (2013)	Zebrack et al. (2014)	Zebrack et al. (2015)
1. Was the research question or objective in this paper clearly stated?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
2. Was the study population clearly specified and defined?	**Yes**	**Yes**	**Yes**	**Yes**	**Partially -** the authors only stated that there were three participating institutions, but did not specify the locations or settings of where these participants were recruited from. The time period, inclusion and exclusion criteria were clearly defined nonetheless.	**Yes**
3. Was the participation rate of eligible persons at least 50%?	**Not reported**	**Not reported**	**Yes**	**No** - only 43% participation rate.	**Yes**	**Yes**
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

5. Was a sample size justification, power description, or variance and effect estimates provided?	**No**	**Yes** - a minimum threshold of 6 participants for each racial/ethnic minority group was decided for the achievement of data saturation within each group.	**No**	**No**	**No**	**No**
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**No** - cross-sectional design, exposures and outcomes were measured concurrently.	**Yes**	**Yes**
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	**N/A** - cross-sectional design, therefore there was only one timepoint.	**N/A** - cross-sectional design, therefore there was only one timepoint.	**N/A** - cross-sectional design, therefore there was only one timepoint.	**N/A** - cross-sectional design, therefore there was only one timepoint.	**Yes**	**Yes**
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.	**N/A** - ethnicity was the exposure factor for the purpose of this review.
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently	**Yes** - though self-reported.	**Yes** - though self-reported.	**Yes** - though self-reported.	**Yes** - though self-reported.	**Yes** - though self-reported.	**Yes** - though self-reported.

across all study participants?						
10. Was the exposure(s) assessed more than once over time?	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.	**No and N/A** for this review as ethnicity remains stable over time.
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	**Yes**	**Yes**	**Yes**	**Partially** - SF-12 has not been validated for the full AYA age range, only validated for adults aged 18 and above.	**Yes**	**Partially** - PDS has not been validated for the full AYA age range, only validated for adults.
12. Were the outcome assessors blinded to the exposure status of participants?	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.	**N/A** - ethnicity is a visible exposure status and this was an observational study, hence participants were not assigned into any groups.
13. Was loss to follow-up after baseline 20% or less?	**N/A** - cross-sectional design with only one time point.	**N/A** - cross-sectional design with only one time point.	**N/A** - cross-sectional design with only one time point.	**N/A** - cross-sectional design with only one time point.	**No** - attrition was about 23.26%	**No** - attrition rate was 23.3%

14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	**No** - comparisons between groups performed via independent samples t-tests and one-way ANOVAs, hence confounders were not adjusted for.	**Yes** - analysis controlled for gender and participants' levels of functioning scores.	**Partially** - T-tests were used to examine differences in scores between ethnic groups, hence confounders were not adjusted for. However, multivariate regression models were used in the analysis between acculturation and depressive symptoms, where age, gender, socioeconomic status and treatment intensity were controlled for.	**Yes** - in the multiple regression models, covariates such as symptom severity, age, gender, ethnicity, education, marital status, health insurance, current treatment and comorbidities were measured and controlled for.	**Yes** - the multiple logistic regression analysis controlled for demographic variables and cancer severity.	**Yes** - the analysis accounted for multiple comparisons and controlled for gender, race, relationship status, age, disease severity and treatment status.
Overall Quality Rating	**Low**	**Moderate**	**Moderate**	**Low**	**Moderate**	**Moderate**

Abbreviation: N/A, not applicable.

Findings Synthesis

Disparities in Psychological Outcomes

Disparities in psychological outcomes between ethnic groups were demonstrated in six studies. The majority highlighted that ethnically minoritised AYAs with cancer experienced poorer psychological health compared to Caucasian AYAs. Burgoyne et al. (2015) only provided data on the mean and standard error of distress thermometer score by ethnicity. The differences in means between groups were hand computed using the Independent Samples T-test, followed by a Bonferroni correction to counteract issues arising from multiple comparisons. The level of significance after the Bonferroni adjustment for multiple comparisons was $p=0.0125$. In the analysis between Caucasian and Hispanic AYAs, the T-test revealed a significant difference in scores, $t(532) = 3.18$, $p<0.01$, with Hispanics reporting significantly higher distress scores than Caucasians. The effect size, as indicated by Hedges' g due to unequal sample size, was moderate with a value of 0.59. Similarly, the comparison between Caucasians and African Americans showed $t(602) = 2.63$, $p<0.01$, suggesting that significantly more distress was reported by African Americans, with a small Hedges' g effect size of 0.29. No significant difference was found between Hispanics and African Americans. Kwak et al. (2013) and King-Dowling et al. (2023) both grouped ethnically minoritised groups into one group and compared outcomes with White AYAs. The former found that minoritised participants reported a significantly higher mean BSI-18 Global Severity Index score as derived from their depression, anxiety and somatization subscales. This is corroborated by the latter researchers, who showed Black, Indigenous, Hispanic and People of Colour as a whole had a higher COVID-19 related distress score than non-Hispanic White AYAs.

A more in-depth comparison between individual ethnically minoritised groups without White participants was provided by Munoz et al. (2016). They illustrated that

Asian/Pacific Islanders reported significantly better emotional well-being scores than Hispanics. This group also described the best overall QoL score, followed by Black, non-Hispanic and Hispanic AYAs. This study lent support to Burgoyne et al.’s (2015) findings that underscored the psychological health of Hispanic AYAs seemed to fare worse than other ethnically minoritised young people, whilst Asian/Pacific Islanders do better.

Similarly, Ritt-Olsen et al. (2018) investigated depressive symptoms and QoL between Latino and non-Latino AYAs as one group, including African Americans, Caucasians and Asians. In addition, they examined the role of acculturation by degree of orientation to the Anglo or Mexican/Latino culture in association with these outcome measures. They demonstrated that Latinos, not only experienced significantly higher levels of depressive symptoms and described lower QoL scores, but also reported more severe presentations that exceeded the clinical threshold when compared to AYAs identified as non-Latinos. Furthermore, analysis of the impact of Latino culture revealed that more acculturated Latinos, who reported a lower Latino and higher Anglo culture orientation, had higher depressive scores. They were also more likely to have symptoms reaching a clinically meaningful threshold. A similar trend was observed for the QoL measure, where lower levels of QoL were described by those identified as more acculturated and less orientated to the Latino culture.

On the other hand, only one study showed that ethnically minoritised groups reported better outcomes. Chen et al. (2020) classified respondents’ profiles based on a combination of distress scores informed by BSI-18 and PDS, as well as post-traumatic growth scores based on PTGI. The four profiles included: distressed (high distress/low growth), distressed growth (high distress/high growth), resilient (low distress/low growth) and resilient growth (low distress/high growth). They found that young people with high distress profiles were more likely to be White than Hispanic/Latino, in relation to those with resilient growth profiles.

The remaining six studies found no significant differences or odds ratios in psychological outcomes between ethnic groups (DeRouen et al., 2015; Desai et al., 2021; Husson et al., 2017b; Smith et al., 2013; Zebrack et al., 2014; Zebrack et al., 2015).

Post-traumatic Stress and Growth Outcomes

No significant differences were observed in the overall post-traumatic stress and growth scores between ethnic groups (Zebrack et al., 2015). Nonetheless, a trend in non-White AYAs, including Hispanics, Latinos and other ethnicities, showed that they reported a significantly higher score in the new possibilities domain of PTGI. This relates to openness to new interests, new perspectives to life and increased adaptability (Calhoun & Tedeschi, 2004).

Longitudinal Outcomes

Kwak et al. (2013) was one of the two papers that analysed the change in distress trajectory by ethnicity from a baseline point of within four months of receiving a diagnosis to one year post-diagnosis. They demonstrated that young people who self-identified as ethnically minoritised were associated with a significant linear decline in their Global Severity Index (GSI) score over time. This implied that minoritised AYAs, despite beginning with a high GSI score at baseline, their scores decreased significantly across one year after diagnosis. However, among White respondents, despite reporting a significantly lower mean GSI score at baseline, their levels of distress did not reduce markedly over one year. Overall, across all minoritised groups, a statistically significant longitudinal downward trend of distress scores was observed across one year. With that said, the decline in distress was weakened by an increase in distress scores, especially anxiety scores, from six months to twelve months after being diagnosed.

Likewise in Husson et al.’s (2017b) study, although there was no significant difference in the baseline measures amongst ethnic groups initially, within-group comparisons over time showed that only Latino AYAs reported a significant improvement in psychological QoL scores over 24 months. This result offered validation to Kwak et al. (2013)'s observation that psychological outcomes in minoritised AYAs appeared to ameliorate considerably compared to their White counterparts regardless of their baseline distress levels.

Other QoL Measures

Two studies revealed ethnic differences in the physical component of QoL scores. DeRouen et al. (2015) and Smith et al. (2013) both found that Hispanic AYAs reported a significantly lower QoL score pertaining to physical health than White AYAs. This corresponds to previous findings in psychological outcomes that highlighted Hispanic AYAs experienced poorer overall outcomes in comparison to White and other minoritised AYAs.

Conversely, one longitudinal trial illustrated that all ethnic groups had a comparable mean physical QoL score at baseline and all groups equally experienced a significant linear improvement in physical QoL scores from baseline to 24-month follow-up (Husson et al., 2017b).

Discussion

The present review explored psychological outcomes in young cancer patients who identified as ethnically minoritised. Despite some mixed findings, six out of twelve identified studies demonstrated that minoritised AYAs reported significantly higher distress levels than White AYAs. This finding appeared to mirror the Minority Stress Model (Meyer, 2003) that highlighted elevated mental health difficulties amongst minoritised groups. The convergence of multiple minority stressors is associated with compounded challenging experiences (Shangani et al., 2020). This could be the case in minoritised AYAs with cancer, where the discrimination they might face based on their ethnic background is compounded on the significant stress and social isolation from cancer, contributing to poorer psychological outcomes. Literature has demonstrated that perceived discrimination is linked to heightened stress responses, distress and is associated with increased unhealthy coping behaviours, such as smoking and drinking (Pascoe & Richman, 2009). Similarly, the adjustment of minoritised groups to the dominant culture’s customs and values was associated with higher levels of psychological distress and anxiety (Da Silva et al., 2017). These factors underline the impact of minority group status on observed disparities in psychological wellbeing.

Amongst the minoritised groups, Hispanic AYAs consistently showed poorer psychological outcomes compared to other minorities. This finding complemented Luckett et al.’s (2011) conclusion that disparities between majority and minoritised patients appeared to be driven largely by those from a Hispanic ethnic origin. A multitude of research in the United States has attempted to illuminate why Hispanic individuals experience poorer health outcomes. Communication barriers even in the presence of interpreters, financial restraints, negative perception of care and clinicians’ attitudes were recurrent themes that were reported (Mayo et al., 2007).

The impact of acculturation on mental health outcomes of Hispanic youths has also garnered attention in the literature and resembles Ritt-Olsen et al.’s (2018) findings in this review. Studies found that acculturation is a risk factor for depression as higher acculturation into the dominant American culture was associated with increased depressive symptoms (Gonzales et al., 2006; Lorenzo-Blanco et al., 2012). Post-traumatic growth amongst childhood cancer survivors was also found to be significantly lower in Hispanic youths who were more acculturated and spoke English as their first language (Arpawong et al., 2013). Cultural orientation to the Hispanic identity appeared to be a protective factor against psychological difficulties (Tobin et al., 2022). Hispanic cultural values emphasize family cohesion, a strong sense of community and discourage conflict (Rivera et al., 2008), which may mitigate the effects of psychological distress. Acculturation, however, is hypothesized to contribute to deterioration in family functioning and closeness as Hispanic values become diluted (Sullivan et al., 2007). Cultural identification intersects with the Minority Stress Model that implies although minoritised groups are confronted with discriminatory challenges, their cultural values could serve as a protective buffer against these stressors and can improve psychological well-being.

On the other hand, the inconclusive findings in this review suggest that there could be other mediating factors at play that influence psychological outcomes. Minoritised groups tend to be a proxy measure for socioeconomic disadvantage, which has direct implications to inequalities in accessing healthcare and insurance. (Ng et al., 2019). Sociodemographic factors, such as low income and unemployment, were associated with diagnostic delays and poorer mental health in AYA cancer patients (Tanner et al., 2023). The lack of financial stability and insurance coverage can influence the quality of cancer treatment and continuity of care, exacerbating worries and distress (Salsman & Kircher, 2022). Studies also demonstrated that AYAs with cancer aged between 20 to 29 years old experienced more psychological distress compared to older AYAs in the 30 to 39 age group (Kirchhoff et al., 2014). Financial toxicity, gaps in care and fertility concerns were attributed to this observed disparity, suggesting that AYAs' experiences vary significantly across the age spectrum (Rosenthal et al., 2023). Similarly, the cross-sectional design in seven studies recruited participants at various stages of cancer and treatment. A review illustrated that certain cancer types and patients who underwent surgery have more favourable psychological outcomes compared to those who were still receiving chemotherapy and radiotherapy, or were experiencing late effects (Tanner et al., 2023). Therefore, the mixed findings could be an artefact of cross-sectional design that fails to account for cancer-related factors which could impact negatively on AYAs' mental health. This underlines the value of longitudinal research in elucidating the dynamic interplay between personal, cancer-related factors and psychological outcomes over time. Moreover, the exclusion of participants experiencing high distress and could not read English may have introduced bias in the findings and contributed to the diverging results. By not capturing the full spectrum of AYAs with distress, findings may have underestimated the true prevalence of psychological distress amongst minoritised AYAs with cancer.

Strengths and Limitations

The present review is the first to date that systematically synthesises and evaluates the literature on psychological outcomes in young ethnically minoritised cancer patients. In light of the global priority in addressing inequalities in cancer care (The Lancet Oncology, 2021), this review contributes to the evidence base by highlighting ethnic disparities that stem early from adolescence. The review is also strengthened by its high transparency and minimisation of bias by adhering to the PRISMA statement (Page et al., 2021) and registration on the PROSPERO public database.

Nevertheless, the findings of this review should be considered in light of several limitations. One important limitation is that all twelve identified studies were conducted in the United States, where healthcare is largely privatised and hence introduces biases related to financial disadvantage that could impact on access to healthcare services and subsequently, health outcomes. This substantially limits generalisability as the papers reviewed failed to capture the vast diversity across ethnic groups and health care services internationally, thus undermining the population validity of findings. Another significant limitation is the unaddressed confounds in several studies, which weakens the validity of the findings as the observed differences may be attributable to confounding factors other than ethnic differences. The inconsistent and flawed reporting of ethnic groups as well as the persistent small sample sizes in minoritised groups across studies have also posed difficulties in drawing comparisons and interpreting inter-ethnic differences. Moreover, differences that exist within ethnic groups, for instance the caste system in South Asia where people are divided into distinct social groups hierarchy with significant social and economic disparities, were not articulated in any of the studies. Furthermore, all studies employed self-reported outcome measures which are prone to response, recall and anchoring biases. Cultural and language barriers may also impact on the accuracy of responses in minoritised young people.

As the majority of studies identified did not intend to examine ethnic differences as a primary objective, it is possible that some studies with the relevant analysis and findings were obscured in the main body of reports and were missed whilst undergoing the screening procedures by abstract. Lastly, amongst the few longitudinal studies, four out of five were suspected to have originated from the same research trial. These over-represented data may be prone to sampling bias, leading to questionable scientific rigour and restrict the generalisability of findings to broader contexts.

Clinical Implications

Findings implied that ethnically minoritised young people with cancer are at risk of experiencing poorer psychological health compared to their White peers. It is important that evidence-based psychological support is offered as part of the integrative package of care alongside medical treatments. Longitudinal studies revealed that psychological well-being tends to be at its worst following diagnosis, then fluctuate around six to twelve months and gradually improve over time. This suggests more comprehensive psychological assessments beyond simply self-reporting emotional QoL that measure low mood, anxiety, other psychological difficulties and related support should be offered immediately following diagnosis. Psychosocial assessment should be routinely evaluated at critical points throughout AYAs’ cancer journey, for instance at diagnosis and at regular intervals thereafter, capturing their mental wellbeing at initiation of treatment, during, end of treatment and transition to survivorship to ensure AYAs’ changing needs, motivation and engagement over time are accommodated. Previous research has identified barriers to accessing psychological services in AYAs with cancer, for instance, a lack of accessible, appropriate and integrated support, especially in post-treatment survivorship (Holland et al., 2021). Likewise, Lu et al. (2021) summarised barriers and facilitators for mental health service use amongst minoritised adolescents. They found that besides personal factors, therapist and cultural factors, such as ethnic match and relationship with clinicians, therapeutic attributes and acculturation all influenced marginalised youths' engagement in services. Professionals should receive routine training in enhancing cultural competence and maintain sensitivity in cultural awareness whilst providing care. Promoting clear and effective communication, interpersonal control, and showing warmth, respect and care have been underlined as fundamental elements of culturally sensitive care, which predicted improved health outcomes, treatment adherence and satisfaction (Tucker et al., 2011).

Moreover, findings conducted in the United States have identified that Hispanic or Latino young people were most at risk of experiencing poorer mental health. Yet, in the context of the UK where there is currently no specified ethnic category for Hispanic or Latino individuals recorded in the government census and hospital databases, little is known about their experiences living in the UK. This raises questions as to the extent to which difficulties that Hispanic youths face are culture bound within the United States in relation to the systemic prejudice towards Latin Americans, or whether this represents a broader phenomenon amongst Hispanic migrants living in other Western countries. The added complexity of intersectionality, where different forms of social factors, such as poverty and migration, compound themselves and contribute to marginalisation, all of which should be taken into consideration in understanding young people's experiences and informing support plans. Clinicians should be mindful not to simply assign minoritised AYAs to the 'other' ethnic group without attending to their ethnic identity and overlook the associated difficulties they may face. Clinicians could also explore AYAs' cultural orientation and their extent of acculturation using standardised measures, such as the Bicultural Youth Acculturational Questionnaire (Kukaswadia et al., 2016), which may be useful in understanding the impact of cultural influences underlying health behaviours and outcomes, thereby informing support that strengthen resilience.

On a macro-level, services could initiate community involvement and collaborative projects with marginalised young people to empower them to voice their needs and influence decision making processes from the bottom up to improve services. This joint alliance could advocate for cancer awareness in minoritised groups, decrease cultural stigma and build trust towards the healthcare system, which are pivotal in dismantling systemic barriers to accessing services and contribute to better patient experience.

Research Implications

Despite emerging literature highlighting ethnic disparities in cancer, research focusing on the experiences and needs of ethnically minoritised AYAs is scant. There needs to be amplified efforts in recruiting ethnically minoritised young people to take part in research to enhance visibility and representativeness. Special attention must be given to the way that ethnicity data are recorded which does not reduce the heterogeneity in each ethnic group. Addressing these limitations in future research may include adopting standardized criteria for ethnicity classification, for instance, aligning with the national census ethnicity categories, and avoiding overly broad groupings, such as 'non-White', to improve the accuracy and applicability of findings. Intersectionality with factors like gender and socioeconomic status also need to be explored. Future research could benefit from examining a broader scope of psychological domains as some studies only relied on the emotional component of QoL as an outcome measure. For example, other psychological difficulties beyond depression and anxiety could include substance abuse, trauma, obsessive-compulsive disorder as well as positive outcomes, such as self-esteem, resilience and post-traumatic growth. The use of a clinical interview could also overcome biases in self-reported questionnaires and facilitate a more culturally sensitive approach to accommodate individuals from diverse ethnic backgrounds.

Given that AYAs' emotional states will likely fluctuate along their cancer journey, more longitudinal data could elucidate the long-lasting impact of cancer on AYA survivors and could further delineate the changes in psychological outcomes over time from the point of diagnosis, during active treatment and transitions into post-treatment survivorship. Understanding the trajectory allows clinicians to tailor more personalised care at different stages of their cancer journey to meet AYAs' evolving needs.

In addition, although oncology research has recognised AYAs as a unique population, the wide age range spanning across 24 years meant that the idiosyncratic experiences encountered by AYAs across the spectrum may not be fully captured. Younger adolescents are likely to experience a different journey in contrast to older young adults who are faced with diverging developmental tasks and demands. Further breakdown of age groups in the analysis could elucidate more nuanced patterns and allow a more comprehensive understanding of how different age cohorts are impacted psychologically. Similarly, expanding research into other Western and non-Western countries would foster cross-cultural understanding, strengthening the reliability and generalisability of findings. More international research has the potential to influence global agenda and policies in dismantling systemic racism within healthcare.

As the majority of studies in AYAs oncology research are quantitative in design, the richness of data that qualitative methodologies bring is often overlooked, especially given the dearth of attention on minority groups. Further qualitative research focussing on a narrower age range is warranted to shed light on the experiences and needs of minoritised AYAs with cancer and related facilitators to access support. In-depth accounts of minoritised young people’s cancer journey could potentially illuminate factors contributing to these ethnic disparities and elucidate issues relating to the intersectionality of culture, social determinants, inequalities in access and racial discrimination.

Conclusion

This review synthesised and appraised the findings of 12 studies that examined psychological outcomes in young cancer patients from ethnically minoritised backgrounds. The findings extended the work of Luckett et al. (2011) in highlighting ethnic disparities in psychological outcomes amongst the younger population. Despite some mixed findings, there was evidence that suggested ethnically minoritised AYAs, especially those identified as Hispanics or Latinos, reported higher levels of distress as compared to their White counterparts. Longitudinal trials supplemented that, despite starting with poorer psychological well-being at baseline, minoritised AYAs seemed to experience a more substantial improvement in their mental health over the course of 12 to 24 months follow-up than Caucasian AYAs.

These findings are limited by several methodological issues, for instance flawed classification of minoritised groups and uneven sample sizes. Further research is warranted to contribute to the scant evidence base in cross-cultural research and to elucidate possible reasons behind such disparities in the hope of addressing structural racism and promoting culturally sensitive healthcare.

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Section B: Experiences of Cancer and Cancer Care amongst Ethnically Minoritised Young People in the UK

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Abstract

Background

Service user experience studies have found poorer experiences of cancer care and lower satisfaction amongst ethnically minoritised groups. Whilst significant strides have been made in understanding cancer experiences in adults from minoritised populations, there exists a knowledge gap in understanding how cancer impacts on ethnically minoritised young people, many of whom are faced with complex developmental challenges, and their experiences of care. This study aimed to understand the experiences of cancer and cancer care amongst ethnically minoritised young people in the UK.

Methods

Nine young people aged between 16 to 24 with heterogeneous cancer diagnoses and stages who self-identified as belonging to eight different minoritised ethnic groups were interviewed about their experiences of cancer and cancer care. Participants' stories were analysed using thematic narrative analysis.

Results

Findings identified three core narratives overarching 12 themes. Young people's cancer experiences illuminated common themes of feeling Dismissed, Shock and Turmoil, Grieving Self and Changes, Isolated and Helpless, Adapting in Adversity and "Changed for the better" and. Cultural narratives revealed diverging views towards family support and involvement amongst minoritised youths. Cultural influences on treatment options and feelings of othered also complicated their cancer experiences. Participants' stories suggested that apart from a protracted journey to diagnosis, minoritised youths generally reported positive experiences of cancer care. Receiving personalised, accessible care and experiences of feeling seen were valued.

Conclusion

The findings shed light on cultural influences on minoritised young people's experiences of cancer and care. Implications on strengthening cultural sensitivity and visibility were highlighted. Future research may be helpful to hone into minoritised cancer experiences at specific stages of one's cancer journey including survivorship across more diverse socio-cultural contexts and how systemic factors may impact on the provision of culturally competent care.

Keywords: cancer experience, cancer care, adolescents and young adults, ethnically minoritised.

Introduction

Cancer health disparities across ethnic groups have been widely documented, prompting a closer examination into the intersectionality between cancer and ethnicity (Delon et al., 2022). Low awareness of cancer symptoms, low participation in screening programmes, clinical trials and delayed help-seeking behaviours were more likely to be observed in ethnically minoritised groups (Waller et al., 2009). Research has investigated factors contributing to these disparities. A review conducted in the United States highlighted that structural and socioeconomic factors, such as limited healthcare access due to lack of insurance and geographical barriers, contributed to diagnostic delays and poorer outcomes among minoritised groups (Zavala et al., 2021). Education and income were found to mediate the relationship between ethnic groups and cancer survival rates (Kehm et al., 2018). Cultural and language difficulties were identified as additional barriers to accessing services, interpreters and communicating with clinicians, contributing to poorer patient experiences (Karliner et al., 2011). Cultural beliefs and stigma associated with cancer have also been shown to influence aspects of one’s cancer journey, for instance barriers to help-seeking, adjustment to diagnosis, treatment compliance and coping strategies (Gray et al., 2014).

Critical Race Theory

Despite efforts to understand the factors underlying cancer health disparities, ethnic disparities in health outcomes continue to persist. The intersectionality between ethnicity and cancer disparities could be understood through the lens of Critical Race Theory (CRT). CRT centres the role of racism at both systemic and interpersonal levels in health inequalities (Ford & Airhihenbuwa, 2010). It posits that structural discrimination embedded in the healthcare system intersects with social determinants of heath, contributing to the disproportionate risks in health outcomes amongst minoritised groups. As such, cultural competence in healthcare is highlighted as an important factor in addressing barriers to accessing services, which has direct impact on survival rates and quality of care (Gehlert et al., 2021). CRT has been increasingly used as a guiding theoretical framework in research for understanding racial-ethnic variations in patient care experiences and amplifying the voices of marginalised populations to address racial disparities (Graham et al., 2011; Mitchell et al., 2022). UK national studies have highlighted lower satisfaction and poorer care experiences reported by minoritised patients (Bone et al., 2014; Pinder et al., 2016). Higher levels of mistrust towards healthcare professionals were also noted amongst ethnic minorities (Bustillo et al., 2017). In particular, non-White and younger patients consistently reported inferior quality of care compared to older adults (Bone et al., 2014; Furness et al., 2017). This suggests the need to understand the experiences of minoritised young people's cancer journey to achieve equitable care.

Young People with Cancer

The transition from childhood to adulthood is a pivotal developmental stage where teenagers and young adults (TYAs) navigate the crises of 'identity' and 'intimacy' to establish their personal identity and committed relationships (Erikson, 1968). Yet, the arrival of chronic illness interferes with their social, occupational roles and is perceived as a biographical disruption that threatens self-coherence (Bury, 1982). This initiates a meaning making process referred as narrative reconstruction by Williams (1984), where individuals renegotiate identity and reconstruct a new sense of order in the world that contributes to an adaptive growth. McAdams's narrative identity theory (1988) added that through constructing life stories, individuals can integrate past experiences to create a coherent sense of self and navigate life transitions. This has influenced the movement towards narrative-based medicine, which shifts from dominant medical perspectives to prioritising patient's narratives as a resource to understand and deliver patient-centred care (Kalitzkus & Matthiessen, 2009).

Research has explored the unmet needs of TYAs with cancer. Fertility concerns, the need for age-appropriate information, communication, and social interactions were frequently quoted (Bibby et al., 2017). Access to financial and emotional support were highlighted as significant service needs (Galán et al., 2018). Correspondingly, Teenage Cancer Trust (2021) found that over 50% of young people with cancer reported poor mental health and felt they needed psychological support. However, 15% of respondents did not have access to support, revealing a concerning gap in psychosocial service provision for young people. Adolescence and young adulthood are a period of vulnerability for mental health risks and a period in which adversity can substantially influence future health and quality of life trajectories (Monasterio et al., 2016). Exploring young people's cancer experiences could enhance support structures and improve their well-being.

Moreover, research has shown that ethnically minoritised young cancer patients are more likely to have additional unmet needs, poorer quality of life and prognosis than the White ethnic group (Moke et al., 2019; Murphy et al., 2021). Keegan et al. (2012) found that minoritised youths were more likely to have at least six or more unmet needs than non-Hispanic Whites relating to recurrence concerns, treatment options and financial support. Having more unmet informational or service needs was in turn associated with poorer physical and mental quality of life (DeRouen et al., 2015; Smith et al., 2013). This underscores the adverse impact of ethnic discrepancies in needs and service provisions that warrant attention. Multiple studies also demonstrated that young minoritised patients were less likely to take part in studies than White patients (Bellizzi et al., 2012; Harlan et al., 2011). This highlights minoritised TYAs' voices are underrepresented in research and presents a knowledge gap that demands attention to explore their experiences. This population is faced with a 'double disparity', where they struggle with challenges of cancer at a transitional age in tandem with barriers associated with identifying as ethnically marginalised (Munoz et al., 2016). Through undertaking the section A review, it was apparent that little qualitative research has been conducted into how racially marginalised youths makes sense of their cancer, its impact and their cancer care. This underlines the limits of current literature in understanding the differential and compounded impacts created by structural differences.

Rationale and Aims

This research endeavoured to bridge the knowledge gap by exploring minoritised young people's experiences of cancer with a view to improve the quality of care. This reflects NHS values of 'respect and dignity' and 'compassion' by understanding their feelings and amplifying their voices to promote empowerment. By gaining insights, improvements can be driven to provide more representative care, aligning with values of 'commitment to quality care' and 'improving lives'. Findings have implications for improving the care experience through increased cultural understanding and informing training on strengthening cultural awareness and competence.

This present study aims to understand the cancer stories experienced by ethnically minoritised TYAs through the following research questions:

1. What stories do ethnically minoritised TYAs tell about their experiences of cancer?
2. How are cultural narratives depicted in minoritised TYAs' cancer stories?
3. What stories do minoritised TYAs tell about their perceived barriers and facilitators to cancer care?

Methods

Design

A qualitative design was employed using individual interviews. An expert by experience was consulted in the design of the project, the language and accessibility of participant materials.

Ethical Considerations

This study was approved by an NHS Research Ethics Committee and the Health Research Authority. The recruitment site confirmed its capacity and capability to deliver this study in June 2023.

Informed consent was sought from all participants prior to the interviews. Voluntary participation, anonymity and confidentiality were emphasised. Participants were assured that they were not obliged to answer all the questions and had the right to stop the interview or move away from topics they found uncomfortable. A debrief space was offered at the end of the interview to discuss anything that had arisen and to offer some breathing or grounding techniques if the participants became distressed. Participants' care teams were also notified of their participation and if concerns emerged regarding participants' psychological wellbeing.

Participants

Purposive sampling was adopted to recruit TYAs with cancer who self-identified as belonging to an ethnically minoritised group through clinicians working in an NHS TYA Cancer Service as well as through social media and cancer charities to reach a more diverse and representative sample across the UK (see Table 3). No defined sample size has been established for qualitative research (Vasileiou et al., 2018). To capture in depth accounts of personal experiences, nine participants with a mean age of 20.3 years were recruited, of whom eight were female. Table 4 shows participants' demographics.

Table 3

Inclusion and Exclusion Criteria

Inclusion Criteria
1. TYAs between 16 to 25 years old with a formal diagnosis of cancer.

This age range aligns with the UK service structure and clinical guidelines (National Institute for Health and Care Excellence, 2005).

2. Self-identified as belonging to an ethnically minoritised group

Ethnic minorities are defined as all ethnic groups other than the White British group, which includes White ethnic minorities (Office for National Statistics, 2015). However, for the purpose of this study, the White ethnic group was excluded as a whole to hone into the experiences of minoritised participants who position themselves as racially different to the White group. It must be emphasised that the rationale for this is not to undermine the experiences of White ethnic minorities, rather the researcher would like to highlight the lived experiences of racially minoritised youths accessing cancer care, which aligns with the adult and quantitative literature that underlined inequalities in patient experiences between White and racially minoritised groups (Bone et al., 2014; Trenchard et al., 2014). It is also important to note the difference in terminology between 'ethnically minoritised' and 'racially minoritised'. 'Ethnically minoritised' is a broader term that refers to groups distinguished by shared cultural heritage, customs and language, whilst 'racially minoritised' generally refers to groups identified by shared physical characteristics or ancestry. For the purpose of this study, these terms have been used synonymously to reflect the shared experiences of marginalisation and discrimination faced by these groups.

3. English speaking

It was important to ensure clear and effective communication during the interview to avoid narratives getting misinterpreted or lost.

Exclusion Criteria

1. White British and White ethnic minoritised groups.

2. TYAs who were significantly emotionally distressed that participating in the study could further exacerbate their distress.

Table 4

Participants' Demographics

Pseudonym*	**Age Range**	**Gender**
Jessica	21 – 25	Female
Glee	16 – 20	Female
Ximena	16 – 20	Female
Rose	21 – 25	Female
Kyra	16 – 20	Female
Adam	21 – 25	Male
Jasmine	21 – 25	Female
Amber	21 – 25	Female
Riley	16 – 20	Female

Note. * Names have been changed to protect participants' identities.
All participants had heterogeneous cancer types and received treatment in NHS hospitals. Six participants were born in the UK, two were born in America and one was born in Middle East Asia. Two participants identified as Latinas, the rest identified as: Arab, Black Caribbean, Black Caribbean and White, Black African, Filipina, Nigerian Brazilian and Pakistani.

Procedure

Eligible participants were given an information sheet and offered the opportunity to ask questions regarding the study. Following consent, they were invited to complete a demographics questionnaire. All participants opted to attend the interview online via Microsoft Teams. Interviews were conducted between August and November 2023 with an average duration of 77 minutes. Interviews were recorded on an encrypted dictaphone and transcribed verbatim. Following the interview, participants were given a debrief sheet about accessing support and a £10 voucher to thank them for their participation.

Interview

The interview schedule was developed in consultation with my supervisors who work with TYAs with cancer. A pilot interview was conducted to ensure the questions were suitable and accessible to young people, with adjustments made accordingly. The schedule acted as a guide that covered three areas pertaining to the research questions: cancer experiences, cultural narratives and cancer care (see Appendix J). Kim (2015) suggested that a narrative interview should elicit a process of story-telling and have minimal influence from the interviewer. As recommended, the interview followed her two proposed phases: the narration phase encouraged participants to tell their story without interruption from the interviewer and the conversation phase allowed interviewer to ask questions for clarification and to elicit additional narratives.

Data Analysis

Narrative inquiry is well suited in learning about the stories TYAs experience on their cancer journey. Thematic narrative analysis (TNA) was chosen for its emphasis on the content for eliciting ‘what’ participants’ illness stories are about (Riessman, 2008), whilst attending to structural elements informed by Frank’s (1995) typology of narratives to understand how TYAs constructed their stories and identities (Table 5). TNA enables the identification of similarities and differences across stories and elicits illness narratives in the context of other intersecting plotlines in one’s life, such as families and cultures. It also offers rich insights into how cancer care is experienced by minoritised TYAs, seeking to legitimise the voices of this marginalised population. Moreover, as ethnicity is a complex social construct that is self-defined, context specific and subjectively meaningful to each individual

(Ford & Harawa, 2010), TNA was chosen over other qualitative methodology for situating and understanding people’s lived experiences within their socio-cultural contexts.

This study referenced TNA methodologies from Hjulstad et al. (2023) and Riessman (2008). A narrative unit constituted of participants’ illness stories, hence accounts were preserved and analysed as a whole unit rather than fragmented to reduce risk of losing meanings in the stories. The process involved five stages: (a) interviews were transcribed and “cleaned up” to remove dysfluencies, (b) familiarisation of narratives through re-reading, (c) coding narrative segments and developing core narratives for each participant, detailing its narrative features, such as emotional tone, form and plot, to situate their stories, (d) organising coded narratives into themes, and (e) identifying similarities and differences in themes within and between participants’ accounts.

Table 5

Summary Table of Narrative Features

Narrative Tone	The attitude and emotional feeling conveyed by listening to the story.	
Narrative Form (Gergen & Gergen, 1986)	Progressive	The story progresses towards a goal.
	Stable	The story of events remain unchanged from an evaluative position.
	Regressive	The story moves away from a desired state.
Narrative Plot (Frank, 1995)	Restitution	The narrative sees illness as a temporary interruption and highlights a resolution to the problem with hope to return to a ‘normal’ state.
	Chaos	The narrative loses sense of order, meaning and imagines life never getting any better and chaos will continue endlessly.
	Quest	The narrative contains transformative elements, describing illness as a challenge to learn new lessons and meanings.

Epistemological Position

Narrative approaches are rooted in social constructionism, which emphasises that reality is socially constructed though language, discourse and meaning making (Clandinin & Connelly, 2000). The researcher positions as a critical realist and adopts the stance that whilst certain aspects of reality are fixed, our understanding of the world is influenced by subjective perspectives and experiences (Willig, 2012). We view the world and live through the stories told by others and ourselves (Murray, 2015), hence reality emerges from the stories told.

Quality Assurance

Several measures were taken to strengthen the validity of this study. First, a reflexive interview was carried out to enhance my reflexivity in exploring my preconception and assumptions about this topic to minimize biases on data interpretation (Appendix L). A reflective journal was maintained throughout to facilitate self-reflection, document any subjectivities and enhance methodological transparency (Appendix M). Supervision was utilised to discuss coding decisions to improve themes validity. Lastly, the results were grounded in direct quotes to ensure transparency and rigour. Participants were also invited to take part in respondent validation, where they could comment on the accuracy and resonance of findings to strengthen credibility. Though, no responses were received by the submission date.

Results

The narratives of nine participants were summarised individually to present a core narrative alongside its narrative features. A cross-analysis between participant narratives identified common themes. Similarities and differences across narratives were discussed.

Table 6

Individual Core Narratives

Overview of Narrative	**Emotional Tone, Form and Plot**
Jessica's story of ambivalence Jessica's story began with returning home for Christmas holiday, only to be disrupted by a diagnosis of cancer. She described a real sense of guilt and burden on the family as she felt she brought disruption to people's lives. She also spoke of her struggles whilst navigating life with this disruption, for instance putting life on hold and making lifestyle changes. Ambivalence was a central theme that penetrated throughout her narrative. She expressed gratitude for her family's support and active involvement in her care, but felt overwhelmed from hearing different opinions and views. She was given the autonomy to make decisions regarding her treatment, but the prospect of this responsibility weighed heavily on her, as she feared the unknown consequences it might have on her future, especially in relation to fertility and bearing children which are considered essential for women in her culture. Jessica's narrative is regressive in that she contrasted the superior services and support she received back home to services in the UK. Whilst she acknowledged the differences in healthcare systems, she expressed disappointment with the	The emotional tone was rushed, anxious and worried. A regressive narrative of chaos.

care in UK, describing a stressful service transition and feeling like she was *"at the bottom of the priority list"*. A sense of chaos was present throughout her stories of life disruption, service experiences and future prospect. As she has a rare cancer, the limited treatment options available translated into a sense of helplessness and hopelessness as she struggled to find *'cure'* to return to health. *"I'm kind of left with no options, which I currently feel here in the UK. So surgery in the beginning, my oncologist said "Ohh, I wouldn't recommend it. It could come back so much more worse and it could come back as 8 different tumours instead of 1. But if you want it, we can offer it." But when I got rejected from these trials, she was like "ohh, why don't you consider surgery?" And I'm like, but because that's the only option, not because it's recommended you know. At this point I think this is what I'm dealing with right now and I'm kind of in between things where "I recommend this, but you can't have it", "I don't really recommend surgery, but you can have it."*	
Glee's story of powering through Glee told a story of resilience and restitution, capturing her journey from feeling overwhelmed, struggling with acceptance, to moving on with cancer. She spoke of the challenges of physical changes from cancer and treatment as well as a persistent fear of re-occurrence that could impact on her future.	The emotional tone was matter of fact, pragmatic and stoic.

Despite these struggles, she showed unwavering determination to regain control of her life with the support of her mother and friends. Glee also storied her experiences of care as very positive and supportive, fueling her aspiration to become a radiologist to help others. Her acceptance of her illness showed that she was able to live a life with and beyond cancer. *‘‘I just had to accept that it's a part of me now and I get on along with it and just do everything I can in my power to make myself feel better rather than just dwelling on it every day, just thinking, cancer, cancer, cancer, cancer, when I could have good thoughts and try and get along with things.’’*	A progressive narrative of restitution.
Ximena’s story of survival Ximena's story communicated the harrowing difficulties of being a refugee whilst battling cancer in a foreign country. She storied her experiences of cancer in a passive tone, detailing her symptoms and the medical procedures in a factual way where she simply followed along the doctors' instructions. She also voiced a cultural narrative that cancer was thought to be passed on from family members. Restitution plot dominated Ximena’s story as she expressed a strong wish to become *“normal again”,* discussing changes to her body, being sick, friendships, and adjusting to her new life in a foreign country. She also shared the challenges of not being able to speak English well that led to experiences of discrimination	The emotional tone was poignant, helpless, detailed in facts. A progressive narrative of restitution.

and made her hesitant to meet new people. Nevertheless, she storied her experience of care as being very positive, well supported and felt that she was important to the clinicians. She aspired to become a doctor of oncology to help other people like herself. *‘‘When I come outside the hospital, I didn't want to go outside. I want to stay there and I say all days to my mom in the hospital that I want to die. Because it is no was normal Ximena. It was a different Ximena….I don't like to be sick. I want to be normal.’’*	
Rose’s story of frustration and grievance Rose storied her journey to diagnosis as one full of obstacles and a fight to be heard and seen. Her narrative captured the struggles of navigating through the physical changes in her body and the cultural clashes between her family during her cancer journey. She spoke of the lack of understanding about cancer in the Black community and the discrepant views in treatment between cultural beliefs and Western medicine. Her narrative was storied as a constant battle to fight for her needs against the healthcare system and her family. This quest eventually led her to live a life beyond cancer and to give back to the communities that helped her. Whilst she storied her cancer care as supportive, she advocated	The emotional tone was of anger, frustration and resentment. A progressive narrative of quest.

for more cultural visibility and sensitivity in cancer services: *"when people talk about race and people factor that into care, it's a beautiful thing that happens"*. *''It's taken a whole other month to figure out what was happening and if anyone had done a simple blood test, CT scan or had taken a second to pay attention to me and my pain, I wouldn't have spent a month in hospital trying to save my eye and my life all at the same time. Like I could literally have been dead in a few weeks if I stayed in (town name).''*	
Kyra's story of who am I? Kyra's story offered an account centralising on the disruption cancer brings to her self-identity and peer relationships. Her narrative directed our attention to the feeling of isolation as a person from mixed heritage, explaining that she did not fit in ethnic categories, nor do either cultures see her as the same. The compounded impact of being mixed and ill with cancer amplified her identity crisis and isolation. She spoke of the importance of her hair as a major part of her identity and the impact of losing her hair, including lowered self-esteem and social stigma. Having experienced her own hardship led to a changed mindset of gratitude and having more sympathy for other people. She storied a positive experience of cancer care and described feeling seen from meeting people and receiving gifts that aligned with her	The emotional tone was lonely and confused. A progressive narrative of restitution.

cultural identity. Although there were elements of chaos as Kyra described her identity crisis, her story was largely restitution as she described being in remission now and returning back to school. This highlights that narratives can evolve along different stages of participants' cancer journey and intersecting narratives can co-exist in TYAs' stories. *''I hated school cause I only went in on certain times and I haven't been in for ages and people noticed things…someone asked me if I died because there was a rumour that I got run over by a horse… then someone texted me did you die?''*	
Adam's story of growth through adversity Adam's story is an explicit quest narrative as he communicated his cancer journey as a challenge to become a better self. Cancer clarified new priorities in his life. He described a changed mindset in life to cherish time and health as well as gaining a new sense of purpose and meaning. He storied the hardest part of his journey as being seen as vulnerable, expressing a wish to be *'at the best of his game'* and independent. Redemptive elements were present throughout his narrative, for instance his eczema cured as a result of chemotherapy, getting into university from extenuating circumstances despite disruption to his education, and involving in cancer advocacy work. He expressed a passion to share his insights from	The emotional tone was confident, optimistic and proud. A progressive narrative of quest.

cancer and influence others: *“I do a lot of charity work for them and help. I also am on the Teenage Cancer Trust youth advisory group… It was the best decision of my life because I met so many amazing people. It's taken over my life basically. I'm just doing so much for them, and they're doing so much for me”*. Family support was a major part of his cultural narrative. He portrayed his experiences of care as very well organised, and highlighted the importance of personalised care and emotional support. *‘‘I’m not the same person at all from before, completely different. My mindset is different. I see things different. It changed me completely, I think for the better. I think I needed that kick.’’*	
Jasmine’s story of *‘cancer was my full time job’* Jasmine’s story is a quest narrative. She marked her cancer journey as a learning opportunity to use her voice and power. She described her struggles of not being taken seriously when seeking medical help and the lack of cancer awareness amongst healthcare professionals, which led to a delayed diagnosis. She shared how cancer stripped her of her identity through losing her hair and putting her life on hold, including the loss of financial stability and relationships. The adversity, nonetheless, changed her outlook on life to be more adaptable and grateful, fueling her to use her voice and knowledge to raise cancer awareness.	The emotional tone was stoic, accepting and reflective. A progressive narrative of quest.

Cultural narratives relating to ethnic parents surfaced in her account, highlighting the cultural clash in expressing and processing emotions in her family, which led to feelings of invalidation. She also spoke of the advantages of having medical professionals from the same ethnic backgrounds which eased language barriers and felt more relatable. *“I feel quite confident to talk about my journey because I don't think it's anything to be ashamed of. I feel like having experienced this has given me a lot of knowledge and power that I wouldn't have had prior to this...When you go through something so traumatic, your voices, your power should be used in the best way.”*	
Amber’s story of adaptability and superpower Amber storied the beginning of her cancer journey as frustrating and disappointing as she was not taken seriously or listened to. She storied the hardest part of this journey was feeling lost after her treatment, describing having to grieve her old self whilst navigating changes in a new life and new identity. Isolation was highlighted as a recurring theme with regards to her experiences at hospital in the context of COVID, being on an adult ward and unable to find others who could relate to her culturally. Nevertheless, Amber’s story exemplifies a quest narrative as she storied her illness as a transformative	The emotional tone was calm, composed and resilient. A progressive narrative of quest.

force. She described seeing her ability to get through cancer as a *“superpower”* that enables her to take things in her stride. Her narrative of cancer care was positive, emphasising the importance of meeting other people of colour as a fundamental part of her support system. *‘‘I kinda just look at it as my superpower, which probably sounds crazy, but no, I do, I look at it as that because being a Black person, you already have to deal with stigmas or stereotypes … sometimes people just judge you by your name... So I kind of just use the fact that I've had cancer, I use that as my strength and I look at it, if I can get through that, I can get through anything and I can achieve anything that I want.’’*	
Riley’s story of a 20 year old with an “*old person disease*” In Riley's narrative, sarcasm was used heavily to frame her cancer journey as a frustrating, disappointing and isolating one. She narrated her experiences of service mistakes, including waking up during medical procedures, declined referral to a TYA specialist centre and delayed treatment. She also highlighted isolation as an international student away from family and being an outlier for having a rare cancer type for her age. The hardest part for her was the pressure of making medical decisions that weighed heavily on her and adjusting to lifestyle changes as a result of cancer. Nonetheless, she expressed acceptance	The emotional tone was lively, sarcastic and forthcoming. A progressive narrative of restitution.

towards this new normality and described efforts to restore her ‘*healthier looking body’*, reflecting a restitution narrative: *“I like coping with it with humour and it’s better to laugh at the situation than cry about it, in my opinion. I prefer laughing about it”*. Riley found her experiences of cancer care very helpful, underlining the importance of tailored care and peer activities. She also wished for more cultural sensitivity in hospital experiences and adaptations in improving language barriers in services. *‘‘It felt really unfair and why me of all people? especially pancreatic cancer, like why? Like such an old people disease? Even when I meet people, it can be quite isolating, 'cause they all have lymphoma or melanoma. Like all my friends, they all know people that have the same cancer.’’*	

Table 7

Table of Themes Development

Cancer Experiences	
Themes	**Sub-themes**
Dismissed	Not listened to/taken seriously Fighting for medical attention Mistrust Swift medical attention
Shock and turmoil	Shock Delayed realisation Fear for the future Burden and guilt
Grieving self and changes	Physical destruction/debilitating Losing hair = loss of self Appearance change and insecurities Upsetting/traumatic Lifestyle changes Heightened anxiety Putting life on hold o Career/education disruption o Plans on hold o Financial hardship Fear of re-occurrence Feeling lost post treatment
Isolated and helpless	Isolated Loss of relationships Unsupported Untrodden path with uncertainties Discrimination COVID isolation
Adapting in adversity	Keeping occupied Maintaining normality Staying informed Family & Friends Charities/Peer support Professionals Spirituality Being open to talk Resilience and perseverance

Changed for the better	Changed mindset New priorities Empowerment Gratitude Living beyond cancer Giving back
Cultural Narratives	
Family: support or burden?	Family oriented and supportive Food as care Involved but overwhelmed Cultural clashes o Cultural attitudes/scrutiny o Cultural views of treatment o Managing emotions Changed relationship
Feeling othered and lonely	Different and alone Away from family & home
Cultural influences	Cultural cancer perspectives Mistrust Limited treatment options Fertility and bearing children
Facilitators and Barriers of Cancer Care	
Personalised and accessible care	Age-appropriate facilities Personalised Responsive and flexible Accessible support Good communication
Feeling seen	Cultural visibility and sensitivity Peer support network Emotional support Supportive Listened to and respected Ethnic minoritised clinicians shared understanding Agency and choice
Overlooked and lost	Mistakes Communication gaps Lack of cultural sensitivity Inaccessible support Rude and uncaring Patronising Invalidating

Cancer Experiences

All participants began their stories when they first noticed signs and sought medical attention.

Dismissed

Six participants described their experiences of presenting to services and were "*not taken seriously". Their concerns were "not listened to"* and reported repeated visits where they were dismissed back home.

> *"She told me maybe I'm stressed, or it's anxiety. I felt like I wasn't being taken seriously because she wanted me to go home with just painkillers, but I knew something was wrong... so I asked to speak to a doctor, and at this point I was really distressed, crying, feeling a bit invalidated."* – Jasmine

Rose expressed frustration at the limited medical attention she received. She linked her experiences to news reports of discrimination faced by Black people in hospitals, citing higher mortality rates and different treatments.

> *"Not a single person checked my eye pressure, no CT scan, no MRI scan or just a simple blood test whatsoever…I even had to argue with them to get them to prescribe me stronger painkillers."* – Rose

Some began harbouring mistrust towards the system.

> *"They don't take me seriously and I don't trust what they say either."* – Rose

Amber attributed her experiences to her young age, but also alluded to a running theme of perceived discrimination within her family, where members felt unheard by doctors which delayed diagnosis.

> *"It wasn't really taken seriously, I think cause of my age, I was so young as well…my grandmothers both passed of pancreatic cancer, both of them were back and forth from the doctors as well and the doctors testing for everything but cancer, saying "oh it's their*

bowels", but it just wasn't, they weren't listening and they didn't run the right test that they needed." – Amber

Narratives that diverged from this were Adam, Glee and Jessica, who described more obvious symptoms that received rapid medical attention. Jessica was the only person who was diagnosed in her home country and contrasted the difference in healthcare systems that enabled her to present at the specialist service in the first instance.

Shock and Turmoil

All participants described the *"shock"* upon receiving the diagnosis. Some expressed fear and confusion, while others revealed strength and determination that emerged in the face of uncertainty. For some, it spurred a need to make sense of why they had cancer.

"I just couldn't believe it 'cause I've always been so healthy my whole life." – Riley

For Glee, Kyra and Adam, the delayed realisation only came after they saw others' reactions that prompted them to recognise the severity of their condition.

"When I saw my parents cry, cause both my parents are very strong minded… When I saw them, then I realised how serious it was." – Adam

For many, this marked a pivotal point in their life that heralded anxieties and uncertainties about the future.

"I was scared because I didn't know the extent, I didn't know what was gonna happen. I didn't know what I was gonna be on. And then I was started worrying about, am I gonna lose all my hair? What's gonna be the complication?" – Glee

Jessica described feelings of guilt that her diagnosis has *"burdened"* and *"triggered"* the family as she shared her family history of cancer.

"I was more anxious about my parents' reactions. My dad, his mom had a really tough cancer journey. So I kind of felt like I was a trigger at this point...I feel like I was just disrupting the whole mood." – Jessica

Grieving Self and Changes

All participants spoke about the emotional turmoil of grieving their former self and navigating changes brought about by cancer. They described the physical destruction from intensive treatment and the side-effects that continued to linger post-treatment.

> *"If I was in rugby now, I'd snapped in half… I miss that healthier looking body. Now I'm much more frail, like my muscles have shrivelled up and dried."* – Riley

Jasmine, Glee, Adam and Kyra articulated the impact of losing their hair which represented the loss of their identity and confidence. This led to feelings of insecurities about their appearance and self-esteem.

> *"It changed my self-confidence a lot because I lost my hair. Before I had really long hair and I was a girl that was really attached to her hair and it just felt like I lost a big part of my identity. Even though my hair is grown back, it's still a constant reminder of what's happened and all the trauma that I went through."* – Jasmine

> *"I felt really ugly all the time 'cause my hair and I just felt like crap."* – Adam

Rose echoed the sense of loss, insecurities and grieved the confident person she was.

> *"When I try to do things that I used to enjoy before, I had a life, I was a person…I was confident. I literally cried when going out because I find it so hard to be in social situations."* – Rose

For Ximena, the change was so overwhelming that she struggled to reconcile her identity.

> *" I want to die… because it is no was (it was not a) normal Ximena. It was a different Ximena."* – Ximena

Many described the hardest part was adjusting to the life changes as cancer became their *"full time job"*. For some, this meant prioritising their health and changing the way they socialised, which left them isolated.

> *"I can't count on everyone knowing that they have to stay away from me if they're sick…*

I miss just being able to eat, and now I have to think about what I eat." – Riley

All participants shared disruptions to their lives that meant they had to put their life on hold and became unable to fulfil their expected social roles.

"I'm not gonna go back as normal and I'm not gonna do the interview that I thought I would." – Jessica

For Jasmine and Rose, their occupational disruption led to financial hardship which compounded onto the arduous challenges they were already facing.

"`My expenses went up ten folds, my income went down straight away… I had no saving… I had travelling costs and costs for my mum and all of that was a burden weighed down on me." – Rose

Amber and Rose attempted to make sense of their new reality, but felt lost in finding their identity, purpose and place in the world after treatment.

"What am I? Where does my life go now? What am I doing now? … because it changes you so much, you don't really know who you are. – Amber

Many also shared heightened anxiety and a fear of re-occurrence that pervaded their life.

"I'm scared of headaches now, 'cause I'm thinking, is it growing?" – Glee

For older participants, the anxiety centred around ambivalence in treatment options and the implication it has for future prospects, which weighed heavily on them.

"I couldn't even decide if I want ice cream or nachos at the cinema. How am I meant to decide if I want this procedure…when you don't know which one's gonna be better and which one's gonna potentially save your life?" – Riley

Isolated and Helpless

Isolation was a theme that penetrated across all narratives. Adam and Amber described being hospitalised during COVID which kept them physically isolated. Many highlighted the disconnection from peers and felt excluded from the typical trajectory of TYA lives.

"It was like being back in COVID, but it was only me on lockdown and everyone else was free to do whatever they wanted." – Riley

Some spoke about the lack of representation in age and ethnic background in cancer support groups they attended that exacerbated their feelings of isolation.

"Nobody looks like me. Nobody's my age. No one's my skin colour, even when they are my skin colour, they're not my age…So there's no one I can relate to and that makes it so lonely." – Rose

For Jessica and Riley, having a rare cancer further marginalised them as they navigated an untrodden path fraught with uncertainties.

"*It can be quite isolating…they all know people that have the same cancer."* – Riley

"Because it's such a rare tumour, very little is known about it. A big part of it is I feel like I'm just experimenting and that is not very reassuring. There's not much research out there saying what will happen." – Jessica

Rose, Jasmine, Amber and Riley reflected on the loss of relationships whilst going through cancer as peers failed to understand and support them. Sentiments of resentment were shared, though they were able to recognise real friends who *"stepped up"* for them.

"Young people love to go out, go on party. So I feel like a lot of my friends chose to do things like that, over staying with me in the hospital or keeping me company because they probably didn't understand how it feels to be stuck in a hospital room for five days straight….I lost a few friends whilst I had cancer, but it was for the better." – Jasmine

Similarly, Adam, Riley and Jasmine felt unsupported by their school and workplace, which left them feeling disappointed and helpless.

"My teachers didn't consider at all what I had gone through…and he gave me a terrible grade." – Adam

For Ximena, experiences of discrimination due to her refugee status and language barriers scarred her from meeting people.

"English it is not my first language…and some people bullying to me... I was scared to talk to another person." – Ximena

Adapting in Adversity

All participants emphasised the importance of family and friends who supported them through cancer.

"My brother and my dad shaved their heads and that would make me feel a bit better." – Kyra

Many appreciated charities and healthcare professionals that gave emotional as well as practical support. Glee, Rose and Kyra also mentioned spirituality as a source of comfort. Some described personal resilience that enabled them to power through the difficult times.

"It's really easy to get into the slump…then feeling sorry for myself. But being sad doesn't change anything, and I was thinking might as well try to enjoy the time I do have and do things to better myself." – Riley

"Even after my operation, I said I need to get up and do the work even though I was still recovering. I need to do it just to try and pass the year." – Glee

Keeping occupied and maintaining normality were discussed as distractions and ways to regain some sense of control.

"I guess trying to keep as much of a normal life as I could, even though nothing was normal anymore." – Riley

Some shared that being open to talk about their experiences allowed them to *"unpack"* and make sense of their feelings. Amber added that *"taking one day at a time"* and staying informed helped as *"sometimes the not knowing is worse."*

"Changed for the better"

All participants, except Jessica who had not started treatment, shared a changed outlook on life that led to positive changes and growth. Jasmine, Adam and Amber reflected on how volatile and precious life was, urging them to make the most of every opportunity, be grateful and not take things for granted.

"Life's so short, I just go for it" – Amber

New priorities emerged: *"I really prioritise my health now a lot more and mental wise, I use my cancer to make me keep going basically, I just want to be healthy all the time."* – Adam

Others spoke about personal growth, such as feeling more matured, understanding and adaptable. Enhanced resilience was also highlighted.

"I use that (cancer) as my strength… if I can get through that, I can get through anything and I can achieve anything that I want." – Amber

Empowerment was described by Ximena, Glee, Jessica and Adam as rejecting vulnerability, seeking independence and living a life beyond cancer.

"Normally I go in wheelchair. But now I want to go alone to the college and I go with the crutch alone." – Ximena

"I didn't like how everyone just felt sorry for me all the time…I just wanted to be seen the same as everyone. – Adam

Participants also spoke about taking meaningful actions to influence others. Ximena and Glee aspired to become healthcare professionals to help people with cancer. Rose, Jasmine and Adam shared acts of *"giving back"* via charity work and becoming cancer ambassadors to raise awareness.

"When you go through something so traumatic, your voices, your power should be used in the best way." – Jasmine

Cultural Narratives

All participants discussed intersections between family and their culture, though their narratives diverged greatly.

Family: Support or Burden?

Adam, Glee, Ximena, Kyra, Amber storied their large families as supportive and helpful. Cancer brought their families closer together and facilitated better relationships. Food was highlighted as a form of expressing care.

> *"My family now is more like together."* – Ximena.

> *"When you're not well, everything is solved via food. So every day I would have a different auntie coming to my house and dropping off a whole tray of food."* – Adam

Jessica and Riley resonated with feeling cared for, but also expressed ambivalence around the *"over caring culture"* which at times increased pressure on them.

> *"The culture is very family oriented. So having my family involved... that adds to the pressure…it only makes me more indecisive of what I wanna do."* – Jessica

By contrast, Rose and Jasmine described cultural clashes leading to difficult family dynamics that burdened them on top of cancer. Rose spoke of the frustration from the *"television view of cancer"* in her community, which required her to fight for her preferred care.

> *"They were trying to make me drink soursop tea…But it can interfere with chemotherapy. So I had to have that fight and battle with my family members, saying "I'm not going to try soursop tea... I understand that somebody's auntie who's tried it…but this is not how I want to do it". That was super frustrating… having to justify my medical care to people… people within the African and Black community don't trust big Pharma …and "chemotherapy is killing you", which is really heart-breaking because… I needed that chemotherapy to stay alive."* – Rose

Both echoed that the perceived societal scrutiny of ethnic parents at times compromised participants' needs.

> *"My mum cares a lot about what other people think rather than how I feel, so she wouldn't want someone to see me crying in my hospital bed when I'm in their presence because she's worried about how she might look as a mum."* – Jasmine

Jasmine added that she struggled to confide in her parents due to their incongruent *"emotional intelligence"*, which meant her *"emotional needs weren't necessarily met"*.

> *"Ethnic parents aren't really open to the idea that a young person could be depressed or anxious because to them, your stresses are really minor in comparison to what they experience. If I would say to my mum, "I'm so depressed", she'd be like "why? what do you have to be depressed about, you're still young, you don't have a house, you're not paying a mortgage" and it would become a competition of who's going through the worst thing."* – Jasmine.

Their stories underscored the complex interplay between acculturation and familial relationships within minoritised communities. Acculturation exacerbated tensions within the family unit as traditional cultural beliefs clashed with Western views and contributed to conflicts.

Feeling Othered and Lonely

Participants described feeling lonely as they struggled to meet people culturally similar to them whom they could relate to, which underlined the lack of racial representation in cancer communities.

> *"I've gone to support groups out there…but 9 times out of 10, I'm probably the only Black person in the room. It was difficult because none of them relate to me. Sometimes it just helps to have someone, talk to someone that looks like you, because there's certain things that can go unsaid."* – Amber

"I was terrified, I hadn't come across any cancer survivors, let alone a Black person who survived cancer." – Rose

For Kyra, being of mixed heritage exacerbated this loneliness as she felt torn between her racial identities and did not feel belonged to either group.

"I feel like none of those (ethnic categories) fit me 'cause I don't think people see me as that... just separated from the other kids." – Kyra

For participants born outside the UK, loneliness was more pronounced as they were physically separated from their families and left to navigate their cancer journey on their own.

"They're surrounded with their family. And I'm kind of here and my family is not here." – Jessica

These examples illustrated that as cancer shattered participants' sense of self and derailed their lives, their need to belong and find support within their ethnic communities became increasingly crucial to feel safe.

Cultural Influences

For Adam, Kyra, Jasmine, Riley, whose cultures were deeply intertwined with religion, cancer was viewed as a challenge from god. Adam, who ascribed to these views and believed that *"it will make you a better person"* found it helpful in coping with his illness. Others, however, rejected these views as whilst it served to reassure their families, it was *"not always what I wanted to hear"* and wished for more understanding.

"I always hear "God puts his strongest soldiers through the hardest battles". But sometimes you just want your feelings to be validated and understand that you're going through a hard time." – Jasmine

For Jessica and Rose, cultural considerations weighed heavily on their treatment options.

> *"Getting married, having kids is such a big cultural thing…chemo will affect your fertility…but that's stuck with me more, it's definitely on the bottom of the list for a treatment option."* – Jessica

Rose conveyed fear of the limited treatment options for her cancer type amongst minoritised populations that could compromise survival:

> *"Because I'm an only child, and even if I'm not an only child, even as a relative donor, it's not always the case that you can get a match. And I think the likelihood of... the statistics around Black people on the stem cell transplant list is extremely low…I'm just living my life, hoping that this fucking thing never comes back. But if it does come back, I know that the other option is just fucking terrifying… I have no option but to use the donor register and it could take me years to find a match because the rate of it (stem cell transplantation match) is so low for people from ethnic backgrounds, especially Black people."* – Rose

These stories demonstrated the diverse ways in which participants' culture and ethnic identity shaped their perception of cancer, support and available treatment options. These cultural narratives spoke to TYAs' need to feel heard, held and for their plight to be acknowledged.

Barriers and Facilitators of Care

All participants storied their overall experience of cancer care as positive. However, for some, care in the initial stages of diagnosis, were disappointing.

Overlooked and Lost

Six participants described their concerns were *"not taken seriously"*, which reflected the lack of TYAs cancer awareness amongst professionals. For some, this late diagnosis impacted on their prognosis, treatment and life options.

> *"Everything was quite overlooked at… when you look at the symptoms of lymphoma, the symptoms I had really aligned. So the fact I got told twice it was nothing and I got sent home with just painkillers, when I had a really big tumour in my chest... the lymphoma I had was*

really aggressive, I had to start my treatment straight away. So I never got to see a fertility doctor.” – Jasmine.

Rose, Amber and Riley underlined clinicians’ lack of cultural sensitivity in care that led them to be overlooked.

“(Doctor) came to show me pictures of White people with styes and infected cysts and said how these looked the same to what I have and basically just told me to look out for bruising and redness around the eye. But I am Black and my eyes are black. Bruising in a White person would obviously look very different from bruising in a Black person with Black complexion.” – Rose

“I think the hardest part was just getting diagnosed. I know it's the universal experience of olive skinned people…When I got jaundice … 'cause I'm like a different skin tone to most people here, so it looks different on me.” – Riley

Jessica, Ximena and Riley expressed frustration from service mistakes.

“They wanted me to redo my biopsy because they lost my biopsy slides…I started crying because I was just frustrated… cause you know appointments being lost, referrals being lost in the hindsight is not too bad. But for me to redo a whole biopsy, like no.” – Jessica

Communication gaps highlighted by Kyra and Riley left them uninformed and confused.

“When I got diagnosed, I knew what it was, but I didn't understand, I’d rather they explained… Before my surgery, I remember I would cry a lot 'cause I didn't understand…and I think no one explained any.” – Kyra

“One of the (charity) representatives came to see me and told me something about infertility because of chemo, and I didn't know that, no one told me that, no doctor told me that.” – Riley

Adam, Amber, Jasmine and Riley narrated encountering clinicians who were uncaring and patronising, which left them feeling disrespected and invalidated.

"I was like the youngest person there, but they (nurses) didn't seem that understanding or there wasn't much support from them... in that moment, that was all I needed, just someone to be like, are you OK?" – Amber

"He just treated me like a kid, like I was dumb, but also very mean… Before I could even finish answering his questions, he was just moving on to the next one. And at one point, he was asking me my prognosis and if they had high hopes for me because there was no point doing the fertility preservation if I was going to die." – Riley

Feelings of frustration and helplessness permeated these stories of care experiences that left participants feeling unseen, disregarded and unsupported. This added stress and became barriers to receiving effective care.

Personalised and Accessible Care

All participants spoke to the importance of personalised care and appreciated support that tailored to TYAs' specific needs.

"Her (nurse) skin colour was similar to mine. So she was like, "our bodies, scars can heal in this way, and this type of scar can be more common in our skin type"…the scar would have been a very obvious area in my chest. So as a young woman, you'd want that area pretty… I think that was really specific and helpful…She even told me the name of the kind of scarring that it could come up as. I Googled it, like very specific and personalised. I think personalised care is a good word for it." – Jessica

"They were helping me find places that would help me with visa and things like that, that are more specially tailored to me. – Riley

Jasmine and Riley expressed that having age-appropriate facilities lightened them up during difficult times of treatment.

> *"It was specifically for young people, they had a room where there was games, game boards, PlayStation, things to draw and paint on… So even though you're in hospital, you have some means to entertain yourself...so that was definitely helpful."* – Jasmine

Adam added that building personal connections with TYAs through conversations can enhance their experience of care.

> *"Get to know them a bit more personally rather than just be like, "oh, you're here for this treatment"… because when you're very personal with someone like that, it makes the whole experience a lot better."* – Adam

Most participants highlighted accessible support and communication as facilitators in care that promoted a sense of control.

> *"If I need support, if I need to change appointments, who would be the best person to contact and not have to go through the general thing. So a feeling of direct support."* – Jessica

> *"If I need any help, she would reply me quickly. Like I remember as soon as I got the hives… she literally replied to me, I don't think it was an hour, like they're very on the ball."* – Glee

> *"Everything was explained to me really well, so I wasn't taken by surprise or I knew what to expect."* – Amber

Jasmine and Riley spoke about extending the accessibility of support beyond hospital settings and suggested written aids to overcome language barriers.

> *"Having that support outside of the hospital whilst you're not there would be helpful. So even if it was like a phone call or a house visit, or arranging to meet up outside of when you have treatment would be helpful."* – Jasmine

> *"Medical words are so difficult to understand. It'd be nice if someone could translate into regular people language… if she had it written…it would be there…Sometimes I wish you could put on subtitles on people."* – Riley

Feeling Seen

For many, having emotional support and a peer support network that shared similar experiences and cultural heritage were storied as instrumental in fostering connection, validation, hope and eased feelings of social isolation.

> *"I met another girl who had the same type of cancer as me and she was Black, and I think that was helpful, because someone here had been through what I've been through and also (looked) like me."* – Kyra

> *"It would have been beneficial to get some emotional support and I know at the first appointment, the oncologist offered that, but I never heard anything about it again."* – Jessica

Rose and Amber echoed this and felt that clinicians should acknowledge their differences and take responsibility in connecting TYAs to relevant communities.

> *"I wish healthcare professionals would educate themselves more to help…Like "all you might be going through something different, I don't understand this, but there's this group of people that might" because … being a Black woman does make this experience different. And I think from there, it was on the onus on the professionals to go out of their way to find (support)."* – Rose

Similarly, Jessica, Rose, Kyra, Amber, Riley and Jasmine highlighted the importance of cultural sensitivity in care that helped them feel seen and more relatable.

> *"We got these dolls…and it was my kind of skin colour and hair colour and I just think that was nice. I think that was more important to me, just being seen."* – Kyra

> *"Having a wig that represented what I looked like before… no matter the texture of your hair, the length of your hair, they tried to make that possible."* – Jasmine

For Rose, Jasmine and Jessica, encountering minoritised clinicians promoted a sense of comfort, safety and facilitated a shared understanding that reassured participants.

> *"I had so much mistrust in the healthcare system, that was really important that I had Black women within…They were really important in helping me to feel seen, to feel known, to know what to say and I felt comfortable."* – Rose

Cared by a team who was *"nice", "friendly", "supportive"* and *"keep you in their best interest"* was appreciated by all participants. Ximena, Rose, Kyra and Amber spoke of being treated with respect and taken seriously that made them feel valued.

> *"Clinicians bringing themselves down to my level… when I'd be on the bedside, they'd come down and they'd speak to me face to face. That was extremely powerful."* – Rose

Staff promoting choice and agency enabled participants to feel more empowered when their illness have stripped them of their autonomy and control.

> *"They're gentle, they don't treat you like you're like useless, like you can't do anything."* – Kyra

Discussion

This study aimed to explore minoritised TYAs' experiences of cancer and cancer care through TNA. The findings offered insights into how cultural influences shape the needs of minoritised youths to inform personalised support. Findings will be discussed in relation to the research questions, relevant literature and implications.

What Stories do Minoritised TYAs Tell about their Cancer Experiences?

Findings from this study illustrated protracted journeys to diagnosis in line with the literature. Gibson et al. (2013) examined young people's pre-diagnosis experience and revealed that repeated GP visits were disappointing as concerns were not acted upon. They highlighted common beliefs that ‘young people do not get cancer’ led to symptoms being minimised. The lack of awareness is likely compounded by subtle symptom nuances and perceived ethnic and age discrimination in minoritised youth, prolonging the diagnostic delay.

Findings highlighted the emotional turmoil experienced by TYAs in relation to the biographic disruption from cancer. Kim et al.’s (2016) meta-synthesis illustrated the intertwining nature between developmental characteristics and emotional struggles. They found that disruption to fulfilling normative social roles evoked feelings of distress, guilt and uncertainties. Identity formation was further compromised by physical changes that affect self-image and a reduced sense of control and autonomy. Findings aligned with Erikson’s (1968) psychosocial theory in emphasising the development of identity through exploring different roles and social interactions. The disruption from cancer led to ‘role confusion’, mirroring participants’ accounts of *“feeling lost”.* The theme ‘isolated and helpless’ resembled the literature in demonstrating that the life adjustments TYAs faced left them feeling socially excluded from peers (Drew et al., 2019). The isolation was exacerbated by diminished social support, which was associated with poorer psychological well-being (Fox et al., 2023). This underscores the importance of peer network and emotional support at this developmental stage.

Williams’s (1984) idea of narrative reconstruction explored the cognitive reorganisation in relation to self, life and the society to reconstruct a sense of order from the illness-induced disruption. This resonated with participants’ narratives of keeping occupied and maintaining normality as ways to regain control. The theme “changed for the better” reflected the collective strength and resilience gained through adversity for most participants and supported evidence that demonstrated better wellbeing than healthy peers in survivorship

(Jörngården et al., 2007). Participants' narration in this study may have been therapeutic and promoted the meaning-making process (Atkinson & Rubinelli, 2012).

All participants who completed treatment and progressed towards remission held progressive narratives, whilst Jessica who was still deciding treatment had a regressive chaotic narrative. It is possible that as perceived life threat diminished in remission, participants were no longer focussed on surviving, enabling them to delve into the meaning-making process (Sansom-Daly & Wakefield, 2013). Furthermore, Jessica received private healthcare services at home contrasted with the limitations in NHS services, which reinforced her regressive narrative.

How are Cultural Narratives Depicted in TYAs' Cancer Stories?

Whilst cultural stigma and taboo around cancer were frequently reported in adult literature (Ridge et al., 2023), such narratives did not present in this study. Not disclosing cancer was storied as not wanting to burden others, rather than avoid shame. This could suggest increased cancer knowledge in newer generations of minoritised populations intersecting with the impact of acculturation may have mitigated negative consequences related to stigma.

Findings highlighted discrepancies in how TYAs experienced family involvement as influenced by cultural perspectives. Whilst most valued family support, two participants found it burdening. Huang et al. (2022) examined family coping amongst racially minoritised groups and underlined effective family communication as adaptive coping. Maintaining harmony and comfort were prioritised in some cultures, which led to communication avoidance. This resonated with Jasmine and Rose's stories of cultural clashes that led to feelings of invalidation and frustration. These accounts are consistent with Bronfenbrenner's (1979) ecological systems theory in highlighting how different levels of interrelated systems shape our development. Findings emphasised the way TYAs storied their support were positioned within their socio-cultural context in the microsystem with their family and cultural influences in the macrosystem.

Cultural identity exacerbating loneliness was a recurring theme across narratives. The lack of representation in cancer communities resembled adult research, which reinforced feelings of ‘othered’ and left TYAs feeling unsupported (NHS England, 2020). A desire for better cultural visibility was communicated by participants to challenge the dominant culture of whiteness and foster validation.

What Stories do TYAs Tell about Their Perceived Barriers and Facilitators to Care?

Overall, participants described a positive experience of cancer care. Personalised and accessible care was identified as important facilitators to care. This aligned with patient feedback reporting more favourable care experiences in specialist TYA centres than adult centres (Furness et al., 2017). The provision of age-appropriate care suited to young people’s psychosocial needs, such as entertainment facilities of video games, computers, boardgames and access to a youth worker, along with clear communication and information provision were highlighted as key elements to good quality care. Prior research also found that individuals who indicated having their informational and service needs met were less likely to report fear of reoccurrence (Shay et al., 2016). This suggests accessible care can promote psychosocial wellbeing.

Additional factors influencing participants’ perceptions of care included cultural sensitivity and feeling seen as opposed to being overlooked and minimised. Participants’ diagnostic experience reflected ‘whiteness’ as the default in services, which failed to acknowledge cultural diversity. This ‘colour-blindness’ perpetuated structural inequalities in health outcomes and care experiences in minoritised populations (Cunningham & Scarlato, 2018). A recent review highlighted the centrality of affective relational elements in patient-professional interactions amongst racially minoritised people (Ridge et al., 2023). Feeling connected, not ‘othered’ and recognising the whole person with their socio-cultural circumstances were valued. Examples of these were cited by TYAs in the present study, where their cultural heritage was recognised through receiving dolls and wigs that aligned to their identity. Patient-perceived cultural sensitivity of professionals was linked with improved adherence to treatment recommendations (Tucker et al., 2011). This implies systemic approaches that display cultural appreciation and interpersonal warmth can create safety and connection for minoritised TYAs whilst promoting adaptive health behaviours. These narratives fit with the attachment theory that suggests in threatening situations, individuals are motivated to seek proximity and safety from a secure base (Bowlby, 1969). TYAs’ need to be held, heard and seen could be understood as attachment behaviours in helping them regulate and anchor their stories, whilst they navigate turbulent cancer challenges. Likewise, peer contacts and emotional support were highlighted as important by all participants. These areas were consistently identified as important needs in TYAs literature which reflect the fundamental tasks of constructing identity and social belonging at their developmental stage (Bibby et al., 2017). A sense of shared identity provides validation and reduce feelings of isolation.

Limitations

Many participants were recruited from London which presents a sampling bias weakening the generalisability of findings. Vast differences exist across and within cultures which could not be fully elaborated. The gender imbalance with predominantly female participants meant that masculine cancer narratives and its impact were limited. Moreover, excluding those who do not speak English undermines the representativeness of findings and may further marginalise youths with language barriers. Valuable data from those who potentially encounter more difficulties along this cancer journey may have been missed.

Clinical Implications

The diagnostic obstacles reported point to the need to challenge Eurocentric approach of care, attending to ethnic nuances in symptom manifestation and how distress and support are experienced in individual’s socio-cultural context. The cultural narratives emerged from this study indicate that exploring the impact of cultural clashes and family communication may be helpful and suggest value in family sessions. Similarly, clinicians’ acknowledgement of their cultural position and differences to minoritised youths may facilitate engagement and trust. Current psychological assessment should be reviewed to ensure they capture the full spectrum of psychological outcomes relevant to ethnically minoritised youths. Measuring constructs such as cultural orientation, acculturation, family support and experiences of discrimination may be beneficial in gaining a comprehensive understanding of TYAs’ psychosocial needs situated within their socio-cultural background. Findings also highlighted TYAs’ need to be heard, seen and understood. Fostering a safe therapeutic rapport through relational skills of active listening and validation appears crucial in transforming TYAs’ care experiences. Establishing a secure base in therapy may support TYAs to mourn their losses and facilitate the meaning making process in narrative reconstruction as participants described narrating their experiences as helpful.

Minoritised TYAs’ narratives underlined a desire to connect and relate. Group interventions connecting ethnically diverse TYAs could foster a sense of community and support. Services could launch more community based initiatives to connect TYAs to minoritised cancer networks and groups in the community. These cross-sector collaboration has the potential to build minoritised community trust, hear underrepresented voices to address barriers to access support, improve service quality and reduce health disparities.

Future Research

As shown in this study, TYAs’ evolving needs and challenges continue beyond remission, hence exploration of their survivorship experiences is warranted. Recruiting more male participants from diverse regions and delineating the impact of acculturation on TYAs’ experiences could allow a deeper understanding of how cancer and coping mechanisms are experienced in different socio-cultural contexts. The voices of marginalised youths with language barriers need to be heard. Research may benefit from exploring clinicians’ perspectives of working with minoritised TYAs to highlight any challenges or structural resistances to providing equitable care.

Conclusion

The findings reflected the hardship and post-traumatic growth experienced by minoritised TYAs with cancer in line with the wider literature. Cultural narratives relating to feeling othered, family support and treatment options appeared to complicate their experiences. Personalised and accessible care, peer support and experiences of feeling seen were highlighted as key facilitators to cancer care. Findings underscored the importance of cultural sensitivity and visibility in services.

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Section C: Appendices of Supporting Materials

Appendix A: Search Strategy

<table>
<tr><td>Population

AYAs aged 15-39 with cancer of any type or stage, including in recovery</td><td>Youth
Young pe*
Teen*
Young patient*
Adolescent*
adolescence
Young adult*</td><td>AND</td><td>Cancer*
oncology
Neoplasm*
Tumo*
Malignanc*
Carcinoma*
Sarcoma*
Leukaemia
Lymphoma
Hodgkin disease
Melanoma
Osteosarcoma</td></tr>
<tr><td colspan="4">AND</td></tr>
<tr><td>Intervention/Exposure

Ethnically minoritised</td><td colspan="3">Ethnic
Ethnic* minorit*
Racial*
Race
Minorit*
cultural
multiethnic
Multicultural
Culturally diverse
cross-cultural
Migrant*
Immigrant*
Emigrant*
Refugee*
Black
Asian
Hispanic
Latin*
African
People of colour
(Ethnic OR rac* OR cultural OR cross-cultural) AND (difference* OR variation* OR comparison* OR disparity OR diversity)</td></tr>
<tr><td>Comparison</td><td colspan="3">Majority group that represents the dominant culture in the country where the study was conducted and any other ethnic groups.</td></tr>
<tr><td colspan="4">AND</td></tr>
<tr><td>Outcome

Psychological distress measures</td><td colspan="3">(Psychological OR emotional OR mood OR mental) AND (outcome* OR distress OR disorder* OR illness* OR health OR wellbeing)
Distress
Anxiety
Depression</td></tr>
</table>

	Unmet need*
Inclusion Criteria	• Searches were limited to papers published in peer-reviewed journals in the English language • Published from 2000 and onwards • Quantitative studies of all designs – primary data only • Studies with ethnicity analysis of outcomes between at least two ethnic groups
Exclusion Criteria	• Case studies, case series, dissertations, reviews were excluded • Not in English • Studies that only reported data in majority groups • Studies without comparing outcomes in different racial groups – at least two.
Databases	1. PsycINFO 2. PubMed 3. Web of Science 4. CINAHL **<u>* search using abstract as opposed to all fields *</u>**

PsycINFO (Multi-field search)

Headings:

1. Neoplasms

Abstract

2. Cancer* OR neoplasm* OR tumo* OR malignanc* OR carcinoma* OR sarcoma* OR leukaemia OR lymphoma OR Hodgkin disease OR melanoma OR osteosarcoma OR oncology
3. 1 or 2
4. (Psychological OR emotional OR mood OR mental) AND (outcome* OR distress OR disorder* OR illness* OR health OR wellbeing)
5. Distress OR anxiety OR depression OR unmet need*
6. 4 or 5
7. Youth OR young pe* OR young patient* OR teen* OR adolescen* OR young adult*
8. Ethnic OR ethnic* minorit* OR racial* OR race OR minorit* OR cultural OR multiethnic OR multicultural OR culturally diverse OR cross-cultural OR migrant* OR immigrant* OR emigrant* OR refugee* OR Black OR Asian* OR Hispanic* OR Latin* OR African* OR People of colour
9. (Ethnic OR rac* OR cultural OR cross-cultural) AND (difference* OR variation* OR comparison* OR disparit* OR divers*)
10. 8 or 9

Limits

- English only
- 2000 onwards
- Adolescence and Adulthood

Final Search: TOTAL = 98

PubMED

MeSH Terms

1. Neoplasms

Title/Abstract

2. Cancer* OR neoplasm* OR tumo* OR malignanc* OR carcinoma* OR sarcoma* OR leukaemia OR lymphoma OR Hodgkin disease OR melanoma OR osteosarcoma OR oncology
3. 1 or 2
4. (Psychological OR emotional OR mood OR mental) AND (outcome* OR distress OR disorder* OR illness* OR health OR wellbeing)
5. Distress OR anxiety OR depression OR unmet need*
6. 4 or 5
7. Youth OR young pe* OR young patient* OR teen* OR adolescen* OR young adult*
8. Ethnic OR ethnic* minorit* OR racial* OR race OR minorit* OR cultural OR multiethnic OR multicultural OR culturally diverse OR cross-cultural OR migrant* OR immigrant* OR emigrant* OR refugee* OR Black OR Asian* OR Hispanic* OR Latin* OR African* OR People of colour
9. (Ethnic OR race OR racial* OR cultural OR cross-cultural) AND (difference* OR variation* OR comparison* OR disparit* OR divers*)
10. 8 or 9

Limits

- English only
- 2000 onwards
- Adolescent (13-18) + young adult (19-24) + adult (19-44)

Final Search: 3 and 6 and 7 and 10 = 180

CINHAL

Subject Headings

1. Cancer OR neoplasms

Abstract

2. Cancer* OR neoplasm* OR tumo* OR malignanc* OR carcinoma* OR sarcoma* OR leukaemia OR lymphoma OR Hodgkin disease OR melanoma OR osteosarcoma OR oncology
3. 1 or 2
4. (Psychological OR emotional OR mood OR mental) AND (outcome* OR distress OR disorder* OR illness* OR health OR wellbeing)
5. Distress OR anxiety OR depression OR unmet need*
6. 4 or 5
7. Youth OR young pe* OR young patient* OR teen* OR adolescen* OR young adult*
8. Ethnic OR ethnic* minorit* OR racial* OR race OR minorit* OR cultural OR multiethnic OR multicultural OR culturally diverse OR cross-cultural OR migrant* OR immigrant* OR emigrant* OR refugee* OR Black OR Asian* OR Hispanic* OR Latin* OR African* OR People of colour
9. (Ethnic OR rac* OR cultural OR cross-cultural) AND (difference* OR variation* OR comparison* OR disparit* OR divers*)
10. 8 or 9

Limits

- English only
- 2000 onwards
- Adolescent (13-18) + adult (19-44) (S9)

Final Search: 3 and 6 and 7 and 10 = 45

Web of Science

Abstract

1. Cancer* OR neoplasm* OR tumo* OR malignanc* OR carcinoma* OR sarcoma* OR leukaemia OR lymphoma OR Hodgkin disease
2. (Psychological OR emotional OR mood OR mental) AND (outcome* OR distress OR disorder* OR illness* OR health OR wellbeing) OR distress OR anxiety OR depression OR unmet need*
3. Youth OR young people OR young person* OR young patient* OR teen* OR adolescen* OR young adult*
4. Ethnic OR ethnic* minorit* OR racial* OR race OR minorit* OR cultural OR multiethnic OR multicultural OR culturally diverse OR cross-cultural OR migrant* OR immigrant* OR emigrant* OR refugee* OR Black OR Asian* OR Hispanic* OR Latin* OR African* OR People of colour
5. (Ethnic OR rac* OR cultural OR cross-cultural) AND (difference* OR variation* OR comparison* OR disparit* OR divers*)
6. 4 OR 5

Limits

- English only
- 2000 onwards

Final Search: 1 and 2 and 3 and 6 = 400

Appendix B: Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

This has been removed from the electronic copy.

Appendix C: Letter of NHS Ethics Favourable Opinion

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Appendix D: Letter of HRA Approval

This has been removed from the electronic copy.

Appendix E: Email Confirmation of Capacity and Capability from Recruitment Trust

This has been removed from the electronic copy.

Appendix F: Participant Information Sheet

Participant Information Sheet

Research Study: Experiences of cancer and cancer care amongst ethnically minoritised young people in the UK

My name is Lynette Chan and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study about your experiences of cancer. Before you decide whether to take part, it is important that you understand why it is being done and what it would involve for you. Talk to someone about the study if you wish.

What is the purpose of this study?
I would like to understand the experiences of cancer amongst young people from ethnically minoritised backgrounds. Having cancer can be very distressing, yet there is little research looking into the challenges and unmet needs these young people face. I am interested in learning from your personal experiences to help us understand better ways of supporting you and others in the service.

Why have I been invited?
You have been invited to take part in the study by your clinician. We are hoping to invite around 8-10 young people aged between 16-25 years old who self-identity as belonging to an ethnic minority group to take part.

What do I have to do?
First, you will be asked to fill in a brief questionnaire about your basic information. You will then be invited to attend an interview with me to talk about your experiences of having cancer, cancer care and your views on how your ethnic background might influence your cancer journey. The interview will last about an hour, but this may be shorter or longer depending on how much you would like to share. You can choose to do the interview in one session or across two sessions online via a video call at whichever date and time you prefer. What we talk about will be recorded using an audio-recorder, so only our voices will be on record to allow me to listen back to our conversation.

Do I have to take part?
It is up to you to decide whether you would like to join the study. If you choose to take part, I will ask you to sign a consent form and with your permission, I will inform your GP and care team in the Teenage and Young Adult Cancer Service that you are participating in this study. Even after signing this, you can choose to withdraw and stop the interview at any time, without giving any reason. This will not affect the quality of care you receive in any way.

What are the possible benefits of taking part?
I cannot promise the study will benefit you directly, but the information we get will help us understand better the experiences of cancer amongst ethnically minoritised young people. This may help us provide better support for marginalised young people accessing services.

To thank you for your time and participation, you will be given a one-off payment/voucher of £10 following the interview. If you choose to have the interview at (HOSPITAL NAME), you can also be reimbursed for your travel expenses with receipts (up to a maximum of £10).

What are the risks of taking part?
You might find that some of the questions in the interview might be quite difficult, distressing and could bring up upsetting feelings. It is important to look after yourself; if you feel there are things that are too difficult to talk about, please let me know. You can take breaks at any time during the interview if you feel overwhelmed. You can also choose not to talk about certain things or stop the interview altogether.

What happens after the interview?
All information collected from you during the research will be kept strictly confidential. However, if you tell me that you might harm yourself or someone else might be harmed, I will have to inform your care team and share this information with them. They will then decide whether your parents/guardians/carers should also be informed if they are concerned. The recording of our interview will be kept securely in a password-protected memory stick. After the interview, the recording will be typed up in words as a pseudonymised transcript (using a fake name to protect your identity) and the original recording will be destroyed. After the study finishes in 2024, the university will keep the transcript on an encrypted CD in a locked cabinet for 10 years. After this, the data will be destroyed.

How will we use information about you?
We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you. If you choose to withdraw, we would like to use the data already collected about you up to your withdrawal. However, if you are not happy with this, please let us know on the consent form (item 9).

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch

- by asking one of the research team
- by sending an email to lc943@canterbury.ac.uk, or
- by ringing us on 01227 927110.

What will happen to the results of the research study?
If you would like to (this is optional), I would like to invite you to comment on the results of the research to see if it matches with what you told me. If you feel I have got something wrong, you can ask me to change it. The results of this study will be written up in a report submitted to the university as part of the assessment for my training. The report is also hoped to be published in a scientific journal. None of your personal details will be mentioned in any reports or publications, but it may include anonymised quotes from our interview.

Has the study been reviewed and approved?
All research has to be reviewed by an independent group of people called a Research Ethics Committee to protect your rights. This study has been reviewed and approved by the NHS Research Ethics Committee and Canterbury Christ Church University.

Questions, concerns or complaints?
If you have any questions or concerns about any aspect of this study, please do not hesitate to contact me and I will do my best to address your concerns. If you would like to make a complaint about the research, you can contact Dr Fergal Jones, Research Director of Clinical Psychology Programme, Salomons Institute of Applied Psychology at 01227 927110 or fergal.jones@canterbury.ac.uk.

Thank you for taking the time to read this information sheet and considering to take part.

Lynette Chan Email: lc943@canterbury.ac.uk

Trainee Clinical Psychologist
Salomons Institute for Applied Psychology

Appendix G: Recruitment Poster

MAKE YOUR VOICE HEARD

YOUR VOICE MATTERS!

We want to hear about your experiences of having cancer and cancer care to help improve your care

People of Colour

Black

Asian

Brown

Mixed Heritage

Are you

- **YOUNG PERSON** with experience of **CANCER**
- **16 – 25 years old**
- From **ETHNICALLY MINORITISED** background & speaks English

WHAT DOES IT INVOLVE?

- Tell us about your experiences of cancer and cancer care in a 1:1 interview
- Only takes an hour
- Anywhere, online, anytime you decide

YOU DESERVE BETTER CARE,
HELP US MAKE A DIFFERENCE

Join to receive **£10 voucher**

Scan this QR code to find out more and SIGN UP

Lynette Chan
✉ lc943@canterbury.ac.uk
☎ 07888 317477

NHS

[redacted]

Canterbury Christ Church University

IRAS: 322167 | Version 2: 03/07/2023

Appendix H: Consent Form

Consent Form

Experiences of cancer and cancer care amongst ethnically minoritised young people in the UK

If you would like to take part in this project and agree to the information below, please initial all the boxes and sign below.

1. I have read and understood the information provided in the information sheet dated 16/05/23 (version 4) for the above study. I have had the opportunity to think about the information, ask questions and have had these answered. ☐
2. I understand that taking part in this study is voluntary and I can withdraw my consent at any time without giving any reason, and this will not affect the quality of care I receive in any way. ☐
3. I give permission for the interview to be audio recorded using a voice recorder and to be transcribed (written up) by the researcher. ☐
4. I understand that other members of the research team may view the pseudonymised (given a fake name to protect your identity) transcript. I give permission for these people to have access to the recorded data in anonymous form. ☐
5. I agree that anonymous quotes from my interview may be used in published reports of the study findings. ☐
6. I understand that although the interview is confidential, my information may need to be shared with my care team/parents/guardians/carers if there is any risk concerns about my safety or the safety of others. ☐
7. I agree to take part in this study. ☐
8. I agree that I can be contacted after the interview for the purpose of 'respondent validation' (this means to confirm that the research findings match with what I said in my interview). ☐
9. If I decide to withdraw from the study, **I agree/do not agree** (*please delete as appropriate*) for data already collected about me up to this point to still be used.

10. I give permission for my GP and care team at the (HOSPITAL NAME) Teenage and Young Adult Cancer Service to be informed of my participation in this study and for support to be provided if required.

	YES	NO
I would like to receive a summary report of the project findings.	☐	☐

If 'YES', please provide your e-mail: …………………………………………………………

Name of Participant: ……………………………………………………… Date: ……………………………………..

Signature of Participant: …………………………………………………

Appendix I: Demographics Questionnaire

Participant Information

Confidentiality and Anonymity: *All answers will remain confidential and will be anonymous if included in the write-up of this research project.*

1. Name: ____
2. Age: ____
3. Gender: ____

4. Choose one option that best describes your ethnic group or background:

Asian or Asian British

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, please describe: ________________________________

Black, African, Caribbean or Black British

☐ African
☐ Caribbean
☐ Any other Black, African or Caribbean background, please describe: ______________

Mixed or multiple ethnic groups

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed or multiple ethnic background, please describe: ________________

Other ethnic group

☐ Arab
☐ Any other ethnic group, please describe: ____________________________________

5. Country of birth: ________________________________
6. At what age did you arrive in the UK? ________________________________
7. How long have you been living in the UK? ________________________________
8. What is your first language/mother tongue? ________________________________

9. What is your education level?

☐ No formal education qualifications
☐ GCSEs or equivalent
☐ A levels or equivalent
☐ Diploma or equivalent
☐ Degree
☐ Master’s degree or higher qualifications
☐ Others, please describe: ____

10. What is your cancer diagnosis? ____

11. At what age were you diagnosed? ____

12. What country were you diagnosed in? ____

13. What treatment are you currently receiving? ____

14. What treatment have you received previously? ____

15. GP name and address ____

Thank you for completing this questionnaire.

Appendix J: Interview Schedule

Interview Schedule

Introduction

I would like you to tell me about your story since being diagnosed with cancer, including all the experiences that have been important to you personally. I am going to listen to your story and I will also ask some questions about the things you tell me so that I can have a good understanding of your experiences. If there are any questions you do not want to answer or would like to take a break, please just let me know.

1. Cancer experiences

Is there an expression or term you prefer to use to describe your illness?

(use participant's language thereafter)

- Could you tell me about the time you first became unwell (when you first noticed something didn't feel right)?
- Could you tell me the time when your doctor told you about your diagnosis?

- What was it like for you?
    - Prompt: How did you feel? What did you think? What did you do to cope?
- How does cancer affect you and your everyday life?
    - Prompt: self (emotionally/behaviourally), daily life, work/school, interests, social, relationships
- What are some of the changes that have happened in your life through having cancer?
- What was the hardest part about having cancer?
- Has cancer or your treatment changed the way you see or feel about yourself? If so how?

2. Cultural narratives

How would you like your ethnicity to be referred to?

(use participant's language thereafter)

- Tell me anything relating to your ethnic/cultural identity that has been particularly relevant to you during your cancer journey?
- What stories or ideas have you heard about cancer or treatment from your ethnic/cultural background?

- How do you cope and manage living with cancer and being a young person from ethnically minoritised background?
- Has your ethnic/cultural background made you feel different to other young people with cancer? If so how?

3. **Cancer care/Accessing services – medical follow ups, psychological/holistic support**
    - Can you tell me about your experiences of your cancer care?
    - *(IF person was diagnosed in their home country) How is cancer care service any different in your home country?*

- Do you feel your ethnic/cultural background has an impact on the care you received, if so how?
    - Could you tell me about any positive aspects/challenges you might have experienced in your care in relation to your ethnic identity?
    - Do you feel that your experience of care has taken into consideration for your cultural needs and age?
    - Any cultural needs you felt was absent?
- How could cancer care and support be more helpful to you as someone coming from an ethnically minoritised background?
    - What would be a positive change to the care you receive?
    - How would you like things to be done differently?
    - How could your cultural needs have been met better?

Is there anything else you feel would be important for me to know about your experiences?

INTERVIEW ENDS

How are you feeling, how did you find the interview?
Is there anything I can do for you now?
Do you feel you might want to talk to anyone else about how you are feeling?

Appendix K: Debrief and Support Sheet

Debrief Form & Looking After Yourself

Research Study: Experiences of cancer and cancer care amongst ethnically minoritised young people in the UK

Thank you so much for speaking with me today. It is normal after the kind of conversation we had today to feel down, upset or drained. This should pass soon. It is important to look after yourself over the next few days.

The purpose of this study was to understand the experiences of cancer amongst young people from ethnically minoritised backgrounds. Having cancer can be very distressing, yet there is little research looking into the challenges and unmet needs these young people face. We hope by learning from your personal experiences through this interview, it can help us understand better ways of supporting you and others in the service.

Here are some things you can do over the next few days to look after yourself:

- Talk to a friend/family member - Sometimes, just talking to someone you trust can be a big source of support and comfort. You could also let them know how you would like them to support you, such as taking a walk or watching a movie with you.

- Do something relaxing and enjoyable - Activities like listening to music, watching a movie, taking a walk in the park, or doing some light exercise can help you relax.

- Have a cry - When you are down, it can feel like “getting on with it” or ignoring things is the best way to feel ok. Taking some time to yourself to acknowledge your difficult experiences and painful emotions might help make sense of things and help you feel better.

What if I need extra support?
If you find these feelings don’t pass, or if you feel distressed, you can access additional support in the following ways:

- Helpful websites - The following websites can be useful sources of information and support
  https://mindovercancer.org.uk/
  https://jtvcancersupport.com/
  https://www.themix.org.uk/
  https://www.mind.org.uk
  https://www.papyrus-uk.org/

- Speak to your clinicians in the Psychological Medicine Team or the Teenage and Young Adult Cancer Service at (HOSPITAL NAME) for support

- Make an appointment with your GP - Your GP is a good first point of call if you think you could use some extra support. They can talk to you about the things you're struggling with and will be able to refer you to the most helpful service for your needs.

What if I need help right now?
If you feel like you need immediate support, the following services might be able to support you:

- HOPELINE 247 – Call 0800 068 4141 / Text 0786 003 9967 (24 hours every day)
- Samaritans – Call 116 123 (24 hours every day)
- SANEline – Call 0300 304 7000 (4 pm – 10 pm every day)

If you feel that you can't keep yourself safe, you can always attend your nearest Accident & Emergency Hospital or contact Emergency Services (999) where support will be available.

What happens now after the interview?
All information collected from you during the research will be kept strictly confidential. However, if you tell me that you might harm yourself or someone else might be harmed, I will have to inform your care team and share this information with them. They will then decide whether your parents/guardians/carers should also be informed if they are concerned. The recording of our interview will be kept securely in a password-protected memory stick. The recording will then be typed up in words as a pseudonymised transcript and the original recording will be destroyed. I will make sure that I will not write your name or anything else that can identify you. Anonymised quotes from our interview might be used in my final report, though your name will not be identified.

If you have agreed to be contacted after the interview for the purpose of 'respondent validation' in the consent form (this means to confirm that the research findings match with what you said in your interview and this part is **optional**), I will contact you and send you a copy of the findings for your review later. You can comment on the findings, add or edit any information that you feel is more accurate to your experiences.

If you have indicated that you would like to receive a summary report of the project findings in the consent form, this will be emailed to you via the address you provided earlier after the study is completed. If you change your mind, you can always let me know by emailing me.

Questions, concerns or complaints?

Thank you again for taking part. If you have any questions or concerns about any aspect of this study, please do not hesitate to contact me and I will do my best to address your concerns. If you would like to withdraw your data, please let me know now or contact me later. If you would like to make a complaint about the research, you can contact Dr Fergal Jones, Research Director of Clinical Psychology Programme, Salomons Institute of Applied Psychology at 01227 927110 or fergal.jones@canterbury.ac.uk.

Lynette Chan Email: lc943@canterbury.ac.uk

Lead researcher & Trainee Clinical Psychologist

Thank you for your time to take part in this study.

Appendix L: Reflexive Interview

Reflexive Interview

Interviewer: So I thought maybe we could start by you explaining your research topic.

Researcher: My project's on cancer experiences in young people from ethnically minoritised background. Do you want to know more about how it's done or like, why I've come up with the topic as such?

Interviewer: Yeah, you could start with explaining a little bit how you became interested in that particular topic.

Researcher: Yeah, it's quite an interesting process. It's kind of a combination of experiences I've done in both settings, so one is the young people population, where I've always been interested in and a population that I've always wanted to work clinically and in research. And I came across something in the MRP fair about young people with cancer and that linked with my experiences working as an AP in a palliative care unit, which is quite different obviously because you're working with older adults in the terminal phrase of the illness. And what I found really interesting was the cultural, I guess the cultural perspectives of cancer. Because when I was working, I was back home and in the Chinese culture, there is a lot of unspoken things about cancer. A lot of stigma, and I think during my work there, I saw a lot of interesting ideas that people have about cancer and how that's really impacted on how they receive their care or also how the family members provide care or support. So I just found that to be quite an interesting topic that seemed to fit in quite well in the context of cancer and young people, but also thinking specifically at the ethnically minoritised perspective that could link into the cultural ideas that I was interested in, so that's kind of a mix of both that came together. Yeah. So that's how the project came about.

Interviewer: And what sort of things did you notice about those cultural ideas and how they influenced people's experience of cancer when you were working?

Researcher: I think back then, because I was working with older adults, there was a strong idea that it is contagious. There were ideas I heard from the patient and he was telling me how his wife sort of keep him in this room, just himself and they don't really go in there and he was just kept isolated in that space and he didn't get spoken to and people just bring him food and that's it. I was quite shocked by how he was being treated and it really struck me the idea of, you know, a person is just being left to die, like, literally. And he was really ill and you imagine how hard he was feeling physically, but also emotionally just being, like, shut out. So that was a strong memory that I had from that cultural perspectives. I think it's the idea that it's contagious, but also, you know, good deeds and bad deeds, like whether you've accumulated enough good deeds or bad deeds that have led to a certain outcome, and that's a punishment of some sort, if you had done something that was deemed to be inappropriate or wrong. So Yeah, I think these are kind of the main ones that I had.

Interviewer: When you started preparing for this study, what did you learn from the literature? How did that inform your thinking about this topic and what you might find out?

Researcher: Yes, I guess it's a bit different because when I was working back home, we were centralised in the Chinese, Asian culture. But when I'm doing research, first of all, a lot of the research was done in Western countries. There was basically not much research done in Eastern countries and even in my critical review right now, about psychological outcomes in ethnically minoritised young people with cancer and everything was from the US. So that in itself is striking that it's not being spoken about or research at all in Eastern countries, but also how different they are. Because there is such huge diversity of ethnicities and the beliefs are just very different. So it's just trying to make sense of all the different things that people could believe and also how, so say if a person was born outside the UK and then moved over versus someone who was born here, where they're more acculturated and that also seem to make a difference. So I think it's learning about the different ideas and the nuances of these differences.

Interviewer: Was there anything that stood out to you about maybe particular groups or how you described people who have moved to the UK or a Western country compared to those who are from minoritised backgrounds born in these countries.

Researcher: There's only a few studies that looked into acculturation and that's mainly looking at Hispanic Latinos versus those born in the US. Actually a lot of studies were saying how the more acculturated you are, so the more distant you are from your original background, the quality of life is worse. Your mental health is worse. So that's the finding that's been quite consistent in literature that I've been seeing. I'm quite interested in why that is and something about coping, ways of coping and you know, how you seek help. I wondered how they all played a part.

Interviewer: And in terms of your own project, do you remember what sort of assumptions you had, or maybe ideas about what you might find out?

Researcher: I suppose when I was told about this project in the research fair, they talked a bit about the background that people from ethnically minorities background seem to have a poorer experience. So that's something that's always been talked about, how there's systemic racism in the NHS and the healthcare system that inherently already have this bad view. And you already think I might get quite negative things from people from minoritised background, so that was an assumption that I had, that they have poor quality of life, poor experiences of care.

Interviewer: Mm hmm. Did you think about specific groups within that broad group of people who fall into the minoritised category, I suppose?

Researcher: I haven't really thought very deep about it initially, but now that you've asked that question, I think what came to mind is perhaps people identifying from Black cultures probably will have worse experience, but also somehow people from Asian countries probably won't share even if they struggle, or even if they do have poor experiences, they probably will be less likely to share that information with other people, or to even do research and fill in questionnaires that elicit those information.

Interviewer: It sounds like it’s informed by your own background and understanding why people might approach these sort of questions that way.

Researcher: Yeah, I think both from the things I've been learning from the course about the treatment of Black people, but also I guess specifically in Asian, I think that people generally do keep to themselves. They're less opinionated, or they tend not to share that sometimes, even if they have certain feelings about things. When I was doing my QIP, I was asking people to give their feedback on the experiences of psychological therapies and how they found the whole process, and there was one client who was Chinese. And she was like, oh, I don't want to cause trouble. I don't really have anything to say. It's all good. And then she just hung up. And that's such an accurate picture of people from home where they just, even if things weren't right, we just kind of get on with it and you don't tend to cause trouble or raise things to keep the peace.

Interviewer: What do you think underlies that reluctance to express? Maybe negative views or opinions?

Researcher: I think there's something about us being a very collectivistic culture where you've been brought up that I guess you don't really talk about anything to anyone else outside your family in terms of things that you're going through. So I think there is that narrative about keeping things within your family. Everything should be dealt internally, without affecting other people.

Interviewer: Mm hmm. Yeah. So there is something about keeping things private and within your close circle. And I think what caught my attention is that when you were talking about that Lady you had a phone conversation with, she said something about getting into trouble. I don't know if you had any thoughts about that sort of perception that by disclosing too much, you might get into trouble or do something that won't be well received.

Researcher: Yeah, and I guess when she said it, there's an assumption that there is something that she didn't like about it, because if she'd liked things about it, she wouldn't feel the need to say, I don't want to cause trouble. It feels like when a person says things that's opposite from the main narrative, people tend to stay away from that. So I think it's the idea that, oh, if I say something that's criticising you, if it doesn't fit with what everyone else think, you don't want to raise trouble. And I guess not wanting to criticise people, it's also another thing. Also feeling that if you raise a comment that would lead to actions and not wanting to go through that trouble.

Interviewer: So the idea of not wanting to criticise someone else because it would cause perhaps some discomfort for them, but also it might involve you.

Researcher: Yeah, I think both sides about like affecting other people. So if you say that, that might snowball into something, but you also don't want to be involved in this, you want to keep yourself out of trouble. So I think that's definitely the two in there.

Interviewer: OK. So can I ask you a little bit about where you are at now with your study? I know that you have some interviews

Researcher: Yep. So I've done a few interviews. Still recruiting for a couple more. I feel like maybe it hasn't elicited as much cultural narratives as I would imagine. I think individual people might have had some views around that, but the majority of people didn't really have that much cultural views. Probably because they're quite young first of all, but also most of them were born in the UK. So the whole culture narratives thing didn't come through as strongly as I imagined. But equally, most people just found services helpful. I don't think anybody really criticised the system or the care that they received. So again that's a bit opposite to what I imagined when I had those assumptions, thinking that people would be struggling and they'd be coming on to share negative experiences.

Interviewer: Mm hmm. What did you think they might criticise when you started interviewing them?

Researcher: Maybe there was something about cultural sensitivity that was not really thought about, for example patients where their cultural needs haven't been met. So for example wigs or breast implants that weren't their own skin colour. But the young people that I'm interviewing and none of them mentioned any of that. And they didn't think they were treated any differently to other people.

Interviewer: Mm hmm. And could you say just a little bit about your sample?

Researcher: Yeah. So I'm recruiting people from 16 to 25 who were diagnosed at this age. So people who only just had cancer quite recently in the middle of that adolescence trajectory and self identifies as from ethically minoritized background. And there's not really a restriction in terms of the type of cancer, whether they're going through treatment or not.

Interviewer: And those people that you've managed to recruit, what does that sample look like?

Researcher: A lot female, actually, and the age range is quite a good coverage. In terms of like ethnicity, it was quite a range actually, got quite a good mix of ethnicity, but not Chinese though. I think I've got like 6 different ethnicities. But also very female heavy, I've only got 1 male so far.

Interviewer: What do you think might be different between men and women?

Researcher: There's already been a lot of stats that said ethnically minoritized men have lowest participation rates in trials, so I think that definitely fits what I'm seeing. I did ask the service I'm recruiting from and wondered what was the demographic spread in the original pool of people and she was like pretty equal. So it's interesting how the females tend to sign up and more keen to share. But again, that probably ties in with what we already know about men tend not to perhaps share experiences or talk about emotional difficulties. That's probably quite in line with the theories that we've been hearing about men‘s way of coping.

Interviewer: I actually have a couple of questions and they're quite different. The first one is about how you feel you might have influenced the interviews, the recruitment process, I suppose, thinking just about your own background and you are female from Hong Kong that might have some impact on participants.

Researcher: Yeah, recruiting by a poster with my surname, people would be able to associate my name as someone who's not from the UK. But I actually also did a cringey video of myself talking about this study so they could put a face to the project and that was played at the service events. And I guess seeing someone who's also ethnically minoritized may feel more fitting, like link in better in a way versus a White person who comes in to talk about ethically minoritised experiences. So that might make potential young people feel more comfortable sharing their experiences with me because I might have had similar experiences.

Interviewer: I was also particularly interested in the interview process itself. How you feel like participants might have responded to you.

Researcher: I think 'cause my interview is separated into three sections where the first is about cancer experiences. And then the second part focuses on the cultural narratives, and the third is about cancer services. I find more difficult to elicit responses with the cultural bit because I think a lot of people found it difficult to answer. So I think that part I found a bit more difficult to get information from, and I may or may not have tried to maybe ask in a different way to try to get more, but I think most of the time they just said not much, then we just move on. So that's a bit different from when they talk about cancer experiences because I'm just listening completely. I'm not trying to intervene I guess.

Interviewer: Yeah. What would you attribute that difficulty to elicit participants ideas about culture, specifically in relation to cancer?

Researcher: There is one thing about them being quite young and I think people who grew up in this generation might already have a lot more awareness about cancer. Most of them were born in the UK so stories have kind of developed and this is no longer as stigmatised as before and there's just a lot of charities about young people with cancer. Now there are specialised teenage young adults centres, so I think it's just the times have changed and there's just more awareness of it. And I guess a lot of people that I interviewed, their parents were also probably brought up in the UK. I haven't actually asked that, but a lot of them just seem more acculturated, they have lived here their whole life. So I think the whole idea of cultural ideas is probably not as present when they're more distant from their family culture.

Interviewer: Mm hmm. And how have you found the experience of being an interviewer and running into that difficulty, that you would first explore cancer experience more generally, and then the other part would be around culture. And that sounds quite difficult. Like to elicit some kind of thinking and reflection on those sort of things? What was that like for you as the interviewer?

Researcher: I think initially I did find I had to do a bit more work because I think for the first section, I normally just ask tell me about your story and they can just talk for like 10-15 minutes without me having to interrupt. But I think in the section about culture, very often they are like I don’t know, so I ended up having to ask more prompting questions to try to ask different areas. But I think generally if they can't really think of anything, I’d normally just leave it. So sometimes I worry about not having enough information or data. But again, that shouldn't really be something that I worry too much because that's maybe their experience, is that they don't have any and they don't feel like that had affected anything. And I think the ways that some people have shared the cultural influence were quite different from what I imagined. Some people talked about it wasn't really cultural stigma, but how cultural family ties are really important and how that was really helpful through the journey. So it wasn't a negative side of culture that affected the journey, it was more like a positive kind of view. So that was quite interesting one.

Interviewer: Mm hmm, and that was unexpected for you that more positive side.

Researcher: Yeah. I was expecting kind of stigmas and like myths. But I think it was interesting that he brought up that point and I was like, OK, actually, I hadn't thought of it. And I think that opened me up a bit.

Interviewer: Yeah, it made me wonder if there is something about those cultural narratives being a lot more implicit and not necessarily like immediately accessible because perhaps they are not as like negative or positive, it's just something that is sort of underneath.

Researcher: Yeah, I think you're absolutely right. I feel like with young people, it's a very different because the parents are taking care of the 16 year old young person. I think a lot of things just become more implicit, or it doesn't come to them as an explicit cultural thing. It was just something that their parents did in their view, perhaps. Yeah.
I remember at one of the Salomon's lecture, this guy said cancer was like the C word. Like people wouldn't talk about it. It was that hidden C word. But these days, people do talk about cancer and people want to talk about cancer because we want people to be aware of it and do more screening and do more kind of preventative work and how that narrative has changed. And I think that definitely relate to this generation where there's a lot more information out there, and there's a lot of health consciousness around that.

Interviewer: How have you found the interviews? Thinking about yourself. Has it been challenging? Has it been enjoyable or something else?

Researcher: I’ve really enjoyed listening to the experiences 'cause they come from such different backgrounds, you can get really different perspectives on their experiences and in a way even though I was expecting that they might have a poor experience, I was glad that they all found the care experiences really nice and helpful and felt that they had the support that they needed. But yeah, I think it's definitely heavy, because you're listening to these really young people and then you think back to when you're 16, you were just kind of fooling around. And these people have gone through so much like, the amount of pain in their body, but also like internally the things that they have to go through is unimaginable. And we can really see how they kind of bounce back, a lot of them have talked about how now it's changed their perspective completely, but also it's always going to be in the background and this impact is going continue their entire life.

Interviewer: So yeah, something about the resilience and having to make really difficult choices that most people don't really have to face ever.

Researcher: Yeah. And a lot of them did get quite emotional when I was doing the call with them, but I'm very glad a lot of them have found it helpful, a few of them have said that actually talking to me and being able to process it here was quite helpful.

Interviewer: I think we will have to finish soon. I don't know how you feel about this. If it was helpful or something is missing.

Researcher: No, I think it's really helpful. I haven't really done this before, but I think it's really made me think a lot about my assumptions and where they came from and you mentioned how I do the interview, I think that's going to make me more mindful to stay more open and not leading questions. I think I've had these thoughts scattered around my head before , but I think it's now at the forefront of my mind and it's more present, it's quite helpful.

Interviewer: I'm glad. I don't know your methodology, how much reflection is needed. But if you want to do another one once you finish all the interviews and before the analysis, something changes in your own thinking. You can let me know.

Researcher: Thank you so much. And you've been such a great interviewer. And you also made me think about things that I hadn’t noticed, so Thank you.

Appendix M: Excerpts from Research Diary

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Appendix N: Annotated Transcript

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Appendix O: Themes Development from Individual Narratives

Dismissed	Shock and turmoil	Grieving self and changes	Isolated and helpless	Adapting in adversity	"Changed for the better"
Family: support or burden?	Feeling othered and lonely	Cultural influences	Personalised and accessible care	Feeling Seen	Overlooked and Lost

	Patterns	**Quotes**
Jessica	Fear for the future	*"All I was thinking of was change, like how things will change, how life will be different if it was a certain. I think a lot about change and how things would have, how things would be different in any kind of each part. That's something I think about a lot."*
	Burden and guilt	*"that kind of guilt of every other day we're going somewhere. They're also in their own free time, contacting people, sending them my scans, just feeling like it was taking up a lot at the time of space and time as well."* *"I was more anxious as well about my parents' reactions. My dad...his mom had a really tough cancer journey and she passed away from breast cancer and his other family members. So I kind of felt like I was a trigger at this point."*
	Heightened anxiety	*"everyone gives you their opinion and you know, you're indecisive as it is..being more anxious and having the pressure of deciding treatment wise."*
	Putting life on hold	*"At this point, I was like putting off interviews...So at this point, that aspect of change, thinking okay I'm not gonna go back as normal and I'm not gonna do the interview that I thought I would go back and do."*
	Isolated	*"sometimes you don't really feel included if you go to a general Cancer Support group."*
	Untrodden path with uncertainties	*"because it's such a rare intermediate tumour, very little is known about it. A big part of it is I feel like I'm just experimenting and that is not very reassuring."*
	Maintaining normality	*"I wanted to feel a sense of normality by going out and enjoying things, feeling like I was in a break. I think it was nice to have that aspect of don't ask me any questions about my health."*

	Charities/peer support	*I do join a lot of peer support groups on Facebook and like social media specifically for desmoid, which I find helpful.*
	Family oriented and involved Overwhelmed	*"The culture is very family oriented. So having my family involved and when I'm talking family, I'm not just talking my mum and my dad, I'm talking my grandparents (laugh) being involved and because they're medics as well, I think that adds to the pressure, we all just wanna be hands in help out with what kind of treatment you get."*
	Different and alone	*"I think of them, ohh they're kind of surrounded with their family. And I'm kind of here and my family is not here."*
	Fertility and bearing children	*"because of the way I grew up, the way I see my culture, if certain treatments would affect my fertility, I guess that would also play a part."*
	Accessible support	*I feel like in (city), I had that direct contact but not here. So I feel like your experience depends a lot on the service and I'm glad I've had that service, cause sometimes it's reassuring... it's just busy here (laugh).*
	Good communication	*"every oncologist and clinician I work with here has been extremely like sensitive and helpful...and just relayed information helpfully, sent me notes of what we spoke about every time."*
	Shared understanding	*"I think she's (oncologist) like South East Asian...And I think that was something she brought up quite a few times when we were considering treatment like her from herself, not just from me, about the fertility pregnancy side of things... She's like, ohh, I see you're not married, but if you ever want to get married and have kids (laugh), I wouldn't recommend this because this will affect you in this way... it was nice, because it was like an unspoken thing that she knows of and it's in the back of my head. But she kind of confirmed it."*
	Peer support network	*"you're in contact with a lot of patients, if you do a support group or a support network with the same people in the same service. that would kind of be very helpful, like being very specific with the support I think."*
	Mistakes	*"I had a telephone appointment a few weeks ago, I think the oncologist forgot to call me and I had to call the hospital, reminding them that I have an appointment like an hour ago."*

Dismissed
Shock and turmoil
Grieving self and changes
Isolated and helpless
Adapting in adversity
"Changed for the better"
Family: support or burden?
Feeling othered and lonely
Cultural influences
Personalised and accessible care
Feeling Seen
Overlooked and Lost

Glee	Shock	*"it was just a shock because I remember I was coming out all happy and then I just started crying and me and my mum, we cried together."*
	Heightened Anxiety	*"I'm more worried about myself. And I just worry about different things, like just daily lifestyle, like I just make sure I'm always feeling well. I just have to pump down tablets now to make sure I'm not either feeling sick or just something's going wrong."*
	Fear of re-occurrence	*"I'm scared, Like if she does take me off at the end of this year, like, what if this side decides to kind of grow again?"*
	Isolated	*" I just stopped socialising a little bit...and I just kind of kept to myself...I couldn't reach my full potential because of… ill that and I knew I couldn't be the same as when I had like nothing when I was just well... I just felt kind of different because not everyone's like this. "*
	Keeping occupied	*"rather than sitting at home..., go for a walk or just do some garden. Sit indoors all day, like I don't mind in the evening, but not all day in, especially college. Like on a Monday, I'll just try and do something. I just don't like it because I would just sit in bed over thinking. I don't want my whole life to be revolved around like cancer."*
	Gratitude	*"even though I do have cancer, it could be worse because I remember I saw like a girl... and she was in the bed and I was like…At least even I've got this, at least I can walk, like at least I can… Still, I'm still mobile, even though I'm struggling. There's some people who can't walk, who have lost eyesight, ear."*
	Responsive and flexible	*"(oncologist) literally replied to me. I don't think it was an hour, like they're very on the ball. Even my mum was saying the care that you get there, they're very fast, like they won't make you wait…days... unless it's like maybe the weekend, and even then they're very on the ball."*
	Supportive Listened to and respected	*"when you come in, obviously asking how your day is...or you're comfortable when you're like there and just supporting you. Like there'd be no rudeness, if you know what I mean, like, they'd all like keep you in their best interest of how you are and make sure you're okay before they do anything and make sure you've taken everything."*

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	Inaccessible support	*"I do have a nurse like number that I can call, but I feel like every time we've called, I don't think it's a straight number or it's not easy to access cause I'm sure she said call if you need it. So sometimes it's not easy to get through to her."*
Ximena	Not listened to/taken seriously	*"my mom and my auntie told the ambulance. And the ambulance say sorry, we are very busy. We don't have, we cannot give- send one ambulance."*
	Physical destruction/debilitating	*"I was…like this 'Aahhh'. And I say to auntie, I have very headache. I don't, I cannot. And that day I cannot move. I cannot talk. My mouth was like this. I cannot see."*
	Appearance change and insecurities	*"In the hospital that I want to die, because it is no was normal Ximena. It was a different Ximena, and that was difficult."*
	Discrimination	*"to be for me happy, having friends, but here in London I don't have friends...they was laughing because my first language it is not English and I don't speak good.*
	Charities/peer support	*"we have a foundation that they try to make happy to the person that have like cancer and they gave gift. And I like."*
	Family & Friends	*"When I no happy, my mom tried to make me happy...my friend of (hometown), they always call me. They always try, they always ask me for how I am."*
	Empowerment	*"normally I go in wheelchair. But now I want to go alone to the college and I go with the crutch alone."*
	Giving back	*"I want to be a doctor on oncology to help people like me."*
	Changed relationship	*"My family now it is more like together."*
	Away from family & home	*"I think that sometime I want to be in my country"*
	Cultural cancer perspectives	*"She's (grandmother) saying that, she passed the tumour (to me) because she was sick."*
	Accessible support	*my nurse of oncology, she say always that you feel like bad, You need me right at any time, I always going to be …with you and that.*
	Supportive	*"I love the Doctor of oncology and the Doctor of Epilepsy. They are so sweet with me. For example the doctor of epilepsy, they was worry because I say that I want to die and she go and buy me tickets to go to see frozen the musical."*

Dismissed	Shock and turmoil	Grieving self and changes	Isolated and helpless	Adapting in adversity	"Changed for the better"
Family: support or burden?	Feeling othered and lonely	Cultural influences	Personalised and accessible care	Feeling Seen	Overlooked and Lost

	Mistakes	*"I didn't like when they give me more medicine that it is not mine…that day the nurse give me more medicine than normal… normal I take 900... And that day give me three tablets of 600 ...and that was the reason that I have many headache."*
Rose	Not listened to/taken seriously	*"I never heard back cause they had already closed my case. So next day I went straight to A&E and after waiting for like 7 hours, they were like that looks like a stye. No further checks, no nothing and just sent me home."*
	Fighting for medical attention	*"I went back to A&E again and this time my friends all came along with me… like wanting to advocate for me because everyone around me saw how bad my eye was and was basically worried sick for me. My friends were all like …are you sure you are telling them how serious this problem is and… like how much pain you are in. Erm… and I was like trust me girl, I have not emphasised or repeated myself enough to get them to see me properly."*
	shock	*"I could not believe it… like I was in shock thinking, they must be joking… you know, this could not be happening to me."*
	Appearance change and insecurities	*"My body's changed. I was on steroids and I went from being …going to the gym four or five times a week, very toned …to being the biggest I've ever been …putting on 20 kgs...the body that I have now…the insecurities I have now, I've never, ever, ever in my life experienced. "*
	Feeling lost post treatment	*"what is my next step now? What does my life mean now? Where do I want to go?"*
	Loss of relationships	*"my friends held me down, but in the midst of that, there were also people that I have loved so much in my life and had to drop everything for them, and that's not what they did. And I have to battle with myself all the time of do I hold people to the same standard as everyone?"*
	Being open to talk	*"when I do tell my story and I speak to people about my story, I'm able to kind of unpack."*
	Spirituality	*"a lot of Africans do pray so that was something that was really helpful."*
	Living beyond cancer Giving back	*"They've given me lots of volunteering opportunities…that is kind of just helped me live a life outside of cancer, do you know what I mean and do little things but still give back to that, because that's important to me, to give back to."*

Dismissed	Shock and turmoil	Grieving self and changes	Isolated and helpless	Adapting in adversity	"Changed for the better"
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	Cultural clashes	*"the way that I wanted my treat-, like my care from my family and my friends was not the way my mom wanted it…she felt herself that she was being watched by people."* *"I had to enforce those boundaries myself, which was really, really painful, really hard to do because there was a culture clash between me and my mum and the way that she would handle stuff and the way that my aunties and uncles will handle things and the way that I would handle things."*
	Overwhelmed	*African culture is so…The problem is it is a positive and negative... Like when people are calling me all the time and trying to check up on me, they were concerned in those moments that was really helpful. At the same time, it also was very overwhelming.*
	Different and alone	*"I was terrified, I hadn't come across any cancer survivors, let alone a Black person who survived cancer."*
	Limited treatment options	*"Because I'm an only child, and even if I'm not an only child, like even like a relative donor, it's not always the case that you can get as a match. And I think the statistics around like black people on the stem cell transplant list is extremely low, so for somebody that's got a blood cancer, knowing that this potentially could be the option...is just f*** terrifying."*
	Mistrust Ethnic minoritised clinicians	*"Because I had so much mistrust in the healthcare system… that was really important that I had black women within. Like Black nurses that looked like me, that were looking after me at that time to help me feel more comfortable, and that then helped me repair those feelings and was then able to make me feel a bit more comfortable."*
	Cultural visibility and sensitivity	*"more visibility on black issues specifically, there's a girl that I know who's had breast cancer, and when they talked about getting breast implants after, those are not her colour."*
	Agency and choice	*"They tried to give me as much choice 'cause once you've been diagnosed, that's it. All your choices, that your agency, your everything away from you."*
	Listened to and respected	*"It was very different to the doctors that would just come talk, ask me questions, go. But when a doctor really came …and treated you like a proper human being...sometimes you just feel like your hospital number, but then the people that really came down to talk to me and to have that more one-on-one time and come down to my level was so incredibly moving and good for me."*
	Lack of cultural sensitivity	*"He was basically trying to explain how my presentation fit with what a White person might look like."*

Dismissed	Shock and turmoil	Grieving self and changes	Isolated and helpless	Adapting in adversity	"Changed for the better"	
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Kyra	Not listened to/taken seriously Mistrust	*"I have really long and heavy periods, like not just ke 2 weeks, like two months of just every day and like a lot. And then I started to swell at my stomach. And we went to the GP. And this is part of the reason I don't really like my like GP. And they said there was nothing wrong. And I was like, I don't really like trust them."*
	Losing hair = loss of self	*"I love my hair and it's just like a part of who I was and then…When it came back and it was short, I just didn't feel the same, like I couldn't style it.*
	Putting life on hold	*"And I didn't go to school when I was sick. So I don't know how I would have dealt with going to school...it would have been horrible. I don't think I could have gone to school."*
	Fear of re-occurrence	*"I think it makes me like a bit paranoid...like I'm scared of it happening again."*
	Isolated	*"I hated school 'cause I only went in on like certain times and I haven't been in for like ages... someone asked me if I died?"*
	Unsupported	*"when I went to school with like, a wig...then this girl like lifted out my hair and I was like…horrible, like one of the worst like things that happened...She just came up to me and like lifted at my wig and pulled it away."*
	Family & friends	*"my brother and my dad, Oh my dad's already bald, but like they shaved their heads."*
	Spirituality	*"they're really like religious and I guess like cause of that, I always thought I was gonna be OK."*
	Changed mindset	*"I feel like I was kind of mean at the school and maybe I still, I still am like, I'm quite understand with people, but I feel like I have more sympathy maybe...I try and think about like why someone might be…being like the way they are…I think I am less like judgemental."*
	Different and alone	*"It's like difficult for me to put... on all the forms it's like… Like African, or it's like mixed, like African and white. And I feel like none of those… like fit me 'cause I'm not like…I don't think like people see me as that."*
	Cultural cancer perspectives	*"when you like saying it, Oh yeah, but God is with you. Like it's not always what I wanted to hear."*
	Supportive	*"The nurses just made my time better. Like I liked them and I thought they were nice. I think that was helpful that could just help me…get through whatever it was."*
	Peer support network	*"I met another girl who had the same type of cancer as me. And she was black, and I think that was helpful. Because it was like someone here had been through what I've been through and was also like me."*

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	Communication gaps	*"I knew when I got diagnosed, I knew what it was, but I didn't understand, I'd rather they explained. And when I was before my surgery, I remember I would cry a lot 'cause I didn't understand and I think no one explained any."*
Adam	Swift medical attention	*"I called my GP... he said I want you to come in person...I went ended up having a blood test and ultrasound on the same day, all in one day. And they said you need to stay overnight because they want to do a biopsy in the morning. So literally straight away, they didn't waste any time ."*
	Shock Delayed realisation	*"When I saw my dad cry, I was like, Oh my God, this must be serious... I didn't think much of it until I like saw my parents react to it."*
	Physical destruction/debilitating	*"The whole time I was vomiting like, I had nothing to vomit and I was still vomiting bile. And I even got home after the hospital and I was still vomiting for hours. I just remember that day. It was the worst day ever. Like the last day of my cycle."*
	Appearance change and insecurities	*"I felt really ugly all the time 'cause my hair and I just felt like crap."*
	Isolated	*"people just don't understand if they haven't gone through it."*
	COVID isolation	*"I wasn't allowed to have my parents with me 'cause it was lockdown cause of COVID. So I was basically on my own."*
	Family & Friends Keeping occupied	*"I used to watch movies with my friends remotely. So I'd share my screen and put a movie on, and we'd just watch it together... I relied on my friends a lot. They kept me busy and distracted. So yeah, I spoke to my friends all the time."*
	New priorities	*"I really prioritise my health now a lot more... I just want to be healthy all the time."*
	Giving back	*"I'm actually an ambassador for (charity name). So like yesterday... I presented on stage. I was on the panel."*
	Empowerment	*"I usually just deal with things and get on with it. But yeah, I did feel a little bit down... but I still powered through it. And I kind of use it to keep me going every day...I want to be better than ever."*
	Living beyond cancer	*"I literally had no hair and I was still really weak. But as soon as I had enough hair to look like I hadn't have treatment... I got a job at a restaurant."*

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	Family oriented and supportive	*"I've got 30 people that I can just go and chat to anytime, that they will message me. Everyone calls me every day. So many calls from different aunties and stuff... it really kept me going. So I'm glad I have that whole support background."*
	Food as care	*"In Pakistani culture...when you're not well, everything is solved via food. So every day I would have a different auntie coming to my house and dropping off a whole tray of food. It was very nice. I did love it."*
	Cultural cancer perspectives	*"my uncles and aunties and grandparents always recommending me things like oh drink this, drink that, you'll be better soon...I've heard like crazy stories of people being cured of their cancer from doing like things like that, but obviously it didn't work for me 'cause I had to have chemo anyway."*
	Personalised	*because when you're very personal with someone like that, it makes the whole experience a lot better.*
	Peer support network	*"it was amazing. It was the best decision of my life because I met so many amazing people...I wouldn't have met anyone that had gone through the same thing as me if I didn't go to that."*
	Emotional support	*I think someone to talk to more, but definitely like someone more up front. You know someone you could just sit down and have a chat with to get through it,*
	Inaccessible support	*" a lot of other people had someone that they could talk to. I don't really have anyone like that. I don't know if I wasn't just offered it or something. But yeah, there was something definitely missing."*
Jasmine	Not listened to/taken seriously	*"I felt like I wasn't being taken seriously because she wanted me to go home with just painkillers, but I knew something was wrong."*
	Shock	*"It was just like a really big shock and I think it took a lot of time to accept it and it was a very emotional part of the journey. Cause you never think like as young as you are that you'd hear that you have cancer, cause often like, we just associate cancer to old people."*
	Losing hair = loss of self Upsetting/traumatic	*"I was a girl, that was really attached her hair and it just felt like I lost a big part of my identity. Like, even till today, even though my hair is grown back, it's still like a constant reminder for me of like what's happened and like all the trauma that I went through."*
	Lifestyle changes	*"The change in my everyday life was the hardest for me."*
	Putting life on hold	*"I was out of work from April. But being out of work, also means you don't have the same income that you had before. Andlike I had a lot of expenses to pay for."*

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	Unsupported	*"sometimes I would be in the hospital...because I didn't attend some meetings... my work was trying to give me a disciplinary meeting which I think was really unfair considering my whole situation. So that made me feel like my work didn't value me or understand like, the severity of my situation."*
	Loss of relationships Unsupported Isolated	*"I had a boyfriend, but I feel like he wasn't really understanding of my situation, along with a lot of my other friends...Like young people, they love to go out, go on party, holidays and stuff... they probably didn't understand how it feels to be like stuck in a hospital like room for five days straight. Like you can't even go outside."*
	Professionals	*"So her and another young people worker called (name), like I used to talk to them a lot when I spent time in the hospital."*
	Changed mindset	*"my outlook on life has changed a lot, like realising how volatile life can be and how quickly things can change your circumstances. And it made me realise as young people, erm we often take our health for granted...it's also matured me like mentally and like understanding and in understanding like, in life like you really have to be able to adapt and adjust to certain situations because a lot of things can be out of our control."*
	Empowerment	*"I feel like having experienced this has given me a lot of knowledge and power that I wouldn't have had prior to this."*
	Cultural clashes	*"I feel like that's just cause how they was brought up. They wasn't brought up to necessarily feel your emotions and understanding, like why you feel certain emotions and how to soothe those emotions as well...she (mum) would discourage me from crying. But if I don't cry, then I'm not releasing my emotions."*
	Different and alone	*"To be honest, like when I was in hospital, I did notice like I never really like meet anyone similar to me."*
	Ethnic minoritised clinicians	*"a lot of nurses in (hospital name) are like predominantly Filipino, so it was like when I would meet these nurses and they would like see that I'm also Filipino, it kind of brings like a comfort...Like it breaks the barrier between them and my parents. So like they would speak in Tagalog to my parents."*
	Age appropriate facilites	*"in the hospital on that third floor, because it was specifically for young people, they had a room where there was games, game boards, PlayStation, things to draw and paint on. So even though you're in hospital, you have some means to pass time or do something to entertain yourself."*

Dismissed	Shock and turmoil	Grieving self and changes	Isolated and helpless	Adapting in adversity	"Changed for the better"
Family: support or burden?	Feeling othered and lonely	Cultural influences	Personalised and accessible care	Feeling Seen	Overlooked and Lost

	Shared understanding	*"it was like an ice breaker knowing you and a lot of your nurses are from the same culture and the same country."*
	Cultural visibility and sensitivity	*"they was like very catering towards having a wig that represented what I looked like before, and they didn't rule out anything, no matter like the texture of your hair, the length of your hair."*
	Patronising	*"there has been times in the hospital, when my cousins they would stay overnight and I feel like we would be treated like school children...I feel a bit patronised or treated like a school child, like I was in a school environment."*
Amber	Not listened to/taken seriously	*"it was a bit frustrating just 'cause I knew something was up, but they wasn't taking it seriously...so it was like why? why not just listen?"*
	Shock	*the world just stopped for a while...it really just felt like my world was ending right there and then, it was very difficult.*
	Lifestyle changes	*"because I'm so tired sometimes I just have to like stay in and... even just doing regular things, like doing like your weekly shop or something, sometimes I can't do as much as I did before."*
	Feeling lost post treatment	*"what am I? Where does my life go now? What am I doing now? ... because it changes you so much, you don't really know who you are and it's sort of like, I'm mourning the person that I was because now I look at everything so much differently... even physically I'm different."*
	Loss of relationships	*"I have lost some friends along the way...like it'll filter out your friends and sort of separate your real friends. I think the friends that I lost along the way... they either couldn't deal with it or they just didn't take it seriously."*
	COVID isolation	*"It was still COVID. So my parents couldn't come in with me or nothing. So they just literally had to drop me off at the hospital and that was really tough, that was a really tough day."*
	Maintaining normality	*"I kind of try and make everything sort of the same, so it's helped me cope with the changes that have happened as well."*
	Staying informed	*"letting me know what was gonna happen next helped as well, 'cause it was the fear of unknown and not knowing 'cause I just thought it was the end."*

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	Changed mindset	*"I used to be a really shy person and talked myself out of doing things. But now I just feel like life's so short, I just go for it. Anything I want to do, I just do it."*
	Empowerment	*"I use that (cancer) as my strength and I look at it, if I can get through that, I can get through anything and I can achieve anything that I want."*
	Cultural clashes	*"my dad...he wouldn't want to show me his emotions or how he feels. But I've had to tell them like it helps and it's good just to let it out...I'd much rather you just show me how you feel at that time than try and hide it 'cause it can make you feel worse trying to hide or trying to hold down the emotions."*
	Different and alone	*"All support groups and stuff that I have been to, I've only met like a couple Black people, like being one of colour. So I find myself actively looking for people that's been through the same thing as me that I can relate to."*
	Cultural cancer perspectives	*"I've met some black people who don't believe in getting treatment or things like that... having met people who have told me use natural remedies instead. Like it can be a bit confusing as well."*
	Good communication	*"everything was explained to me really well so I wasn't taken by surprise or I knew what to expect or what was coming up."*
	Peer support network	*"maybe make an event or just a group, especially for Black people or just minorities, it would be nice to just have that there, just for us where you're gonna meet people just like you, of the same background as you."*
	Lack of cultural sensitivity	*"it was also difficult because one of those relate to my kind of hair, my natural hair. So it's sort of trying to explain those things, it can be a bit awkward sometimes, they just didn't understand."*
	Rude and uncaring	*"just in that moment I felt like they didn't really care or wasn't bothered that much."*
	invalidating	*"the respond is that, you know, you're so young, so it won't be nothing too serious and it kind of made you feel a bit silly for worrying."*
Riley	Not listened to/taken seriously Fighting for medical attention	*"I noticed they didn't really like take me very seriously at first, I could tell that they expected to send me home, so I demanded for a blood test."*
	Shock	*"I've led a pretty healthy life...Didn't really drink that much, didn't smoke. I've never smoked. So it was a bit of a big shock."*

Dismissed | Shock and turmoil | Grieving self and changes | Isolated and helpless | Adapting in adversity | "Changed for the better"
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Lifestyle changes	*"My relationship with food has changed so much. I love food, but I can't eat some of the things I loved anymore...it's a lifestyle change that I have had to make, which I am not happy about."*
Appearance change and insecurities	*"I look back at pictures of me from a year ago and I looked so healthy... I miss my body that was strong."*
Putting life on hold	*"it's hard to plan trips and things when you have chemo every two weeks and then appointments in the between and all that stuff."*
Isolated	*"I will most likely not find someone like that because of how rare it is at this age. So that's also been a big struggle at the start, felt very isolating and lonely."*
Unsupported	*"It was hard to convince them (university) to come back actually, they kept telling me I could not come back to university. They told me they could not accommodate me, but they never asked me what accommodations I wanted or needed."*
Maintaining normality	*"I was just looking forward to coming back to uni and I guess trying to keep as much of like a normal life as I could, even though nothing was normal anymore."*
Charities/peer support	*"We have an events coordinator, with Teenage Cancer Trust, she's great. She's amazing... She makes events every single month."*
Changed mindset Empowerment	*"It's just being sad doesn't change anything. And I was thinking might as well try to enjoy the time I do have and do things to better myself."*
Food as care	*"food is a big thing in my culture, we tend to bond a lot over food."*
Away from family & home	*"something difficult is not being able to travel back home for the holidays right now and see my family, which is really sad."*
Cultural cancer influences	*"Tried to do some baking, which was hard because my mom fell into the whole sugar feeds cancer thing. So it was hard to bake stuff with no sugar."*
Cultural cancer influences	*"a lot of family members who are telling me it was in God's plan and stuff like that. And it's to reassure themselves and make themselves feel better. But I don't always appreciate some of the comments they say about it being like, my faith or God intentionally did this to me."*

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	Age-appropriate facilities	*"Go to a teenage and young adult centre, so that's been very helpful. I don't think going to a regular hospital would have been as helpful, just because they have a lot more support targeted towards young people."*
	Personalised	*"they were helping me find places that would help me with a visa and things like that, that are more I guess specially tailored to me."*
	Supportive Agency and choice	*"all the nurses are absolutely amazing. They support me, my mom, my boyfriend. They always give options. Like anything you have, any sort of issue you can go to them and they'll do their best to fix it."*
	Mistakes	*"they rejected my referral, which was not meant to happen. Apparently that's bad and not supposed to be a thing. Apparently what happened is that they didn't see my age, they just kind of saw pancreatic cancer and just shoved me away. So that was a mistake on their part."*
	Communication gaps	*"one of the representatives came to see me and told me something about infertility because of chemo, and I didn't know that, no one told me that, no doctor told me that."*
	Rude and uncaring Patronising	*"he's just like here attacking me and making me feel like I'm some crazy girl trying to do this procedure (fertility preservation) So it was very traumatic for me…then he was just like, do you want me to send in the nurses to deal with you?"*

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Appendix P: Findings Summary for Participants

Dear [participant's name],

I hope this letter finds you well. Thank you for taking part in my research and sharing your stories with me. My research was interested in the experiences of cancer and cancer care in ethnically minoritised young people. I met with 9 young people and have been analysing the interviews. I would like to share a summary of these findings and if you have any feedback for me, I would love to hear from you. I have included below a short summary of the story you told me, as well as some ideas and common themes that came out across different people's stories. I have also added direct quotes from what people have said in the interview to help illustrate these findings.

The questions I was curious about were:

1. What stories do ethnically minoritised young people tell about their experiences of cancer?
2. How are cultural narratives depicted in ethnically minoritised young people's cancer stories?
3. What stories do ethnically minoritised young people tell about their perceived barriers and facilitators to cancer care?

Interview Summary

[Individual interview summary of each participant]

Themes from Cancer Experiences

Dismissed: Participants spoke about their experiences of getting diagnosed. Many described repeated visits to the doctors and felt their concerns were not listened to or taken seriously .

"I felt like I wasn't being taken seriously because she wanted me to go home with just painkillers''

Some related this to perceived discrimination that led to them being dismissed and harboured mistrust towards the healthcare system. Others related this to their young age and professionals' lack of awareness in cancer amongst young people that contributed to a delayed diagnosis.

Shock and turmoil: Everyone expressed the shock and emotional turmoil they experienced upon receiving the diagnosis. This then prompted some to reflect on their health and try to make sense of why they had cancer. Many shared the overwhelming sense of uncertainties and anxieties about the future which frightened them.

"I was scared because I didn't know the extent, I didn't know what was gonna happen. I didn't know what I was gonna be on. And then I was started worrying about, am I gonna lose all my hair? What's gonna be the complication?"

Some people described feeling guilty as they felt having cancer has burdened the family. This guilt then transformed as a need to stay strong for the family and protect them from further distress.

Grieving self and changes: All participants described the physical and emotional toll that cancer and the treatment had on them. For some, losing their hair was a profound moment that represented the loss of their identity and self-confidence that was shadowed by increased anxiety and insecurities about their appearance, body image and self-esteem.

"It changed my self-confidence a lot because I lost my hair… it just felt like I lost a big part of my identity."

Many agreed that adapting to the life changes from cancer was the most difficult part of their journey. Some reported feeling lost in finding their identity, purpose and place in the world after treatment ended. The side-effects from treatment, uncertainties about future and the fear of re-occurrence continued to pervade their life which caused psychological distress.

Isolated and helpless: Isolation was strong theme that appeared across all participants' stories. Many commented on the disconnection from peers as their lives diverged from a typical young person's path. Some spoke of the lack of representation in age and ethnic background in support groups that made them feel very lonely. For a few, having a rare cancer made them feel like an outlier when others shared the same cancer. Some also reflected on the loss of social relationships, lack of support from school or workplace through this journey that left them feeling disappointed and helpless.

"Nobody looks like me. Nobody's my age. No one's my skin colour, even when they are my skin colour, they're not my age…So there's no one I can relate to and that makes it so lonely."

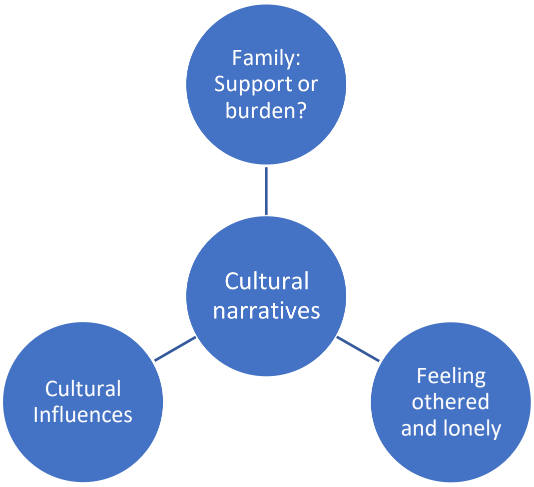
Adapting in adversity: Family and friends were emphasised as important support that got them through cancer. Charities and healthcare professionals were described as helpful in supporting them with emotional and practical support. Some also commented on spirituality as a source of comfort. Keeping occupied and maintaining normality were discussed as distractions from cancer and ways to regain control of their life.

"I guess trying to keep as much of a normal life as I could, even though nothing was normal anymore."

"Changed for the better": Participants who had completed treatment shared positive changes and growth from their cancer journey. New priorities and mindset towards life emerged, whilst personal growth in maturity, adaptability and resilience were shared. Some spoke of empowerment through seeking independence, living a life beyond cancer and taking meaningful actions to influence others.

"When you go through something so traumatic, your voices, your power should be used in the best way."

Themes from Cultural Narratives



Family: Support or burden?: Most participants were grateful for their family's support and commented that cancer brought them closer. Food was echoed by many as a way of showing care. Some people appreciated their family's involvement, but felt the overwhelming support at times increased pressure on them. Others described their family's involvement as a burden as they experienced cultural clashes in ways of processing emotions and diverging views of cancer treatment with their community, which resulted in frustration and stress.

"The culture is very family oriented. So having my family involved… that adds to the pressure…it only makes me more indecisive of what I wanna do."

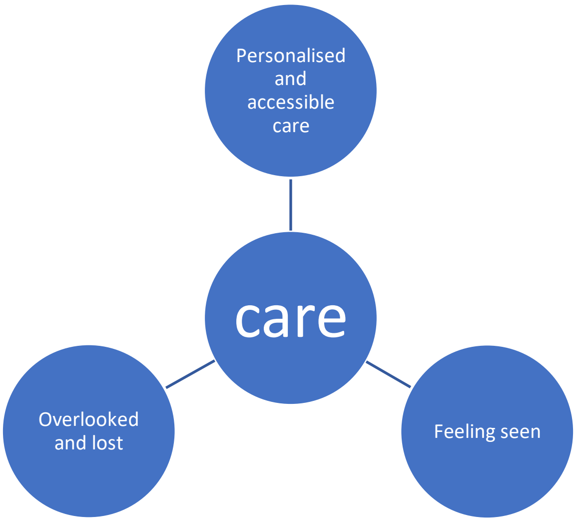
Feeling othered and lonely: Many described struggles of finding people whom they could relate to culturally in support groups, which left them feeling lonely. Loneliness was exacerbated for those whose family were abroad as they were left to navigate their cancer journey on their own.

"I've gone to support groups out there…but 9 times out of 10, I'm probably the only Black person in the room."

Cultural influences: Participants commented on the intersection between religion and their culture and shared narratives of cancer as a challenge from god. Some found it helpful in coping with their illness, whilst others rejected these views as they felt it only served to reassure their families, and young people wished for their feelings to be validated. Other cultural considerations, such as the importance of fertility and scarce minoritised stem cell donors, also impacted on treatment options.

"I always used to hear "God puts his strongest soldiers through the hardest battles". But sometimes you just want your feelings to be validated and understand that you're going through a hard time."

Themes from Facilitators and Barriers to Cancer Care



Participants described their overall experience of cancer care as positive, though some were disappointed at the prolonged journey of diagnosis. Some felt that the lack of cultural sensitivity and not being taken seriously led to delayed diagnosis that impacted on their prognosis. Some expressed feeling overlooked as they shared stories of upsetting clinician interactions, service mistakes and communication gaps that left them frustrated, invalidated and uninformed.

Personalised and accessible care that tailored to young people's needs were valued. Many highlighted the importance of emotional support and peer support that shared similar experience and cultural background fostered connection, hope and reduced feelings of isolation. Cultural visibility and sensitivity in care helped them feel seen and promoted a sense of comfort and reassurance.

These ideas are broadly what stood out to me from hearing nine people's stories and may not necessarily reflect your own personal experience. I would be interested to hear your thoughts on these results and whether you think they fit with your lived experiences. I hope this research can help us understand better ways of improving young people's cancer experience. If you would like to get in touch or if you still have not received your £10 voucher, please feel free to email me on lc943@canterbury.ac.uk.

Finally, I would like to thank you for taking the time to participate in this research project. It was a real privilege to listen to your stories and I was truly struck by your strength and resilience.

Warm wishes,

Lynette Chan
Trainee Clinical Psychologist

Appendix Q: Summary Report to NHS Ethics Committee and Trust R&D

Dear Research Ethics Committee/Trust R&D,

I am writing to share a summary of the findings on my research project exploring experiences of cancer and cancer care in ethnically minoritised young people in the UK. Nine minoritised young people were invited to share their cancer experiences and their stories were analysed using thematic narrative analysis. Common themes were shared across people's stories. I have added direct quotes from what people have said in the interview to help illustrate these findings.

The research questions I was interested in were:

1. What stories do ethnically minoritised young people tell about their experiences of cancer?
2. How are cultural narratives depicted in ethnically minoritised young people's cancer stories?
3. What stories do ethnically minoritised young people tell about their perceived barriers and facilitators to cancer care?

Cancer Experiences Themes

Dismissed: Participants spoke about their experiences of getting diagnosed. Many described repeated visits to the doctors and felt their concerns were not listened to or taken seriously .

"I felt like I wasn't being taken seriously because she wanted me to go home with just painkillers.''

Some related this to perceived discrimination that led to them being dismissed and harboured mistrust towards the healthcare system. Others related this to their young age and professionals' lack of awareness in cancer amongst young people that contributed to a delayed diagnosis.

Shock and turmoil: Everyone expressed the shock and emotional turmoil they experienced upon receiving the diagnosis. Many shared the overwhelming sense of uncertainties and anxieties about the future which frightened them.

"I was scared because I didn't know the extent, I didn't know what was gonna happen. I didn't know what I was gonna be on. And then I was started worrying about, am I gonna lose all my hair? What's gonna be the complication?"

Some people described feeling guilty as they felt having cancer has burdened the family. This guilt then transformed as a need to stay strong for the family and protect them from further distress.

Grieving self and changes: All participants described the physical and emotional toll of cancer and the treatment had on them. For some, losing their hair was a profound moment that represented the loss of their sense of identity and self-confidence that was shadowed by increased anxiety and insecurities about their appearance, body image and self-esteem.

"It changed my self-confidence a lot because I lost my hair… it just felt like I lost a big part of my identity."

Many agreed that adapting to the life changes from cancer was the most difficult part of their journey. Some reported feeling lost in finding their identity, purpose and place in the world after treatment ended. The side-effects from treatment, uncertainties about future and the fear of re-occurrence continued to pervade their life which caused psychological distress.

Isolated and helpless: Isolation was strong theme that appeared across all participants' stories. Many commented on the disconnection from peers as their lives diverged from a typical young person's path. Some spoke of the lack of representation in age and ethnic background in support groups that made them feel very lonely. For a few, having a rare cancer made them feel like an outlier when other people shared the same cancer. Some also reflected on the loss of social relationships, lack of support from school or workplace through this journey that left them feeling disappointed and helpless.

"Nobody looks like me. Nobody's my age. No one's my skin colour, even when they are my skin colour, they're not my age…So there's no one I can relate to and that makes it so lonely."

Adapting in adversity: Family and friends were emphasised as important support that got them through cancer. Charities and healthcare professionals were described as helpful in supporting them with emotional and practical support. Some also commented on spirituality as a source of comfort. Keeping occupied and maintaining normality were discussed as distractions from cancer and ways to regain control of their life.

"I guess trying to keep as much of a normal life as I could, even though nothing was normal anymore.''

"Changed for the better": Participants who had completed treatment shared positive changes and growth from their cancer journey. New priorities and mindset towards life emerged, whilst personal growth in maturity, adaptability and resilience were shared. Some spoke of empowerment through seeking independence, living a life beyond cancer and taking meaningful actions to influence others.

"When you go through something so traumatic, your voices, your power should be used in the best way."

Cultural Narratives Themes

Family: Support or burden?: Most participants were grateful for their family's support and commented that cancer brought them closer. Food was echoed by many as a way of showing care. Some people appreciated their family's involvement, but felt the overwhelming support at times increased pressure on them. Others described their family's involvement as a burden as they experienced cultural clashes in ways of processing emotions and diverging views of cancer treatment with their community, which resulted in frustration and stress.

"The culture is very family oriented. So having my family involved… that adds to the pressure…it only makes me more indecisive of what I wanna do."

Feeling othered and lonely: Many described struggles of finding people whom they could relate to culturally in support groups, which left them feeling lonely. Loneliness was exacerbated for those whose family were abroad as they were left to navigate their cancer journey on their own.

"I've gone to support groups out there…but 9 times out of 10, I'm probably the only Black person in the room."

Cultural influences: Participants commented on the intersection between religion and their culture and shared narratives of cancer as a challenge from god. Some found it helpful in coping with their illness, whilst others rejected these views as they felt it only served to reassure their families, and young people wished for their feelings to be validated. Other cultural considerations, such as the importance of fertility and scarce minoritised stem cell donors, also impacted on treatment options.

“I always used to hear “God puts his strongest soldiers through the hardest battles”. But sometimes you just want your feelings to be validated and understand that you're going through a hard time.’’

Facilitators and Barriers to Cancer Care Themes

Participants described their overall experience of cancer care as positive, though some were disappointed at the prolonged journey of diagnosis. Some felt that the lack of cultural sensitivity and *“*not being taken seriously*’’* led to delayed diagnosis that impacted on their prognosis. Some expressed feeling overlooked as they shared stories of upsetting clinician interactions, service mistakes and communication gaps that left them frustrated, invalidated and uninformed.

Personalised and accessible care that tailored to young people’s needs were valued. Many highlighted the importance of emotional support and peer support that shared similar experience and cultural background fostered connection, hope and reduced feelings of isolation. Findings underscored the importance of cultural sensitivity and visibility in services that helped young people feel seen and promoted a sense of comfort and reassurance.

Kind Regards,

Lynette Chan
Trainee Clinical Psychologist

Appendix R: Author Submission Guidelines for Psycho-Oncology

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