


ORIGINAL ARTICLE

‘This is not part of my life plan’: A qualitative study on the psychosocial experiences and practical challenges in young adults with cancer age 25 to 39 years at diagnosis

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Abstract

Objective: Adolescents and young adults with cancer face unique psychosocial and practical issues. However, patients across this group encounter different life experiences, cancer diagnoses and treatment settings given the tailored services for patients ages 15 to 24. Here, we qualitatively explore the psychosocial experiences and practical challenges of young adults (YAs) with cancer diagnosed between ages 25 and 39 in the United Kingdom.

Methods: We invited YAs diagnosed with cancer in the 5 years prior to enrolment at participating sites to take part in semi-structured interviews or focus groups. Transcripts were analysed using inductive thematic analysis. Two YA patients reviewed the results to ensure robustness.

Results: Sixty-five YAs with varied diagnoses participated. Participants struggled to balance work, childcare and financial solvency with treatment. The halt in family and work life as well as changes in image and ability threatened participants' identity and

Professor van der Graaf and Dr Husson should be considered joint senior author

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perceived 'normality' as a YA, however, these also stimulated positive changes. YAs experienced social isolation from friends and family, including children. Many struggled to cope with uncertainty around treatment outcomes and disease recurrence.

Conclusion: The disruption of family and work life can lead to age-specific issues in YAs diagnosed with cancer. Age-tailored psychological and practical services must be considered.

KEYWORDS

AYA, neoplasms, qualitative research, social isolation, uncertainty, young adult

1 | INTRODUCTION

Due to the transitional period in life, adolescents and young adults (AYAs) with cancer face specific psychosocial issues compared to paediatric and older adult cancer patients, including loss of independence, frustration with changes in appearance, school or work interruption and fertility impairment (Fidler et al., 2019; Zebrack, 2011; Zebrack et al., 2014). Incident cancer types and tumour biology in AYAs, commonly defined by the oncology community as ages 15 to 39, also differ from older and paediatric patients, while improvements in survival have been slower (Barr et al., 2016; Bleyer et al., 2017).

Past psychosocial research in AYA oncology used traditional task-based developmental theories to describe how cancer impacts the lives of AYAs, such as Erikson's framework, the Stages of Psychosocial Development (Norma M. D'Agostino et al., 2011; Erikson, 1995). These theories infer that psychosocial development is a linear progression and that the interference of cancer on completing prescribed tasks leads to developmental failure.

Recently, however, researchers have encouraged moving away from the notion that all young people share the same stepwise 'life goals' advancing from educational and vocational attainment to establishing romantic relationships and having children (Hammond, 2017; Levin et al., 2019). They reject the assumption that AYAs are a distinct homogenous group and suggest that research should recognise the context in which AYAs exist such as increasing financial precarity, changing timelines and priorities and expanding cultural diversity. This is particularly relevant when considering the potential differences in cancer types and life circumstances between the lower and upper ends of the AYA age spectrum (Close et al., 2019; Sodergren et al., 2018). In addition, in the United Kingdom (UK), there are substantial differences in the healthcare context across AYAs, with teenagers and young adults (TYAs) ages 15 to 24 receiving care in age-specialised services but young adults (YAs) ages 25–39 receiving cancer care in adult settings.

Past research and healthcare interventions in the UK, have focused largely on the TYA group, without distinguishing between TYAs and YAs. The lack of focus specifically on YAs may obscure important differences in experience and priorities. Here, we aim to explore the specific experiences of YAs diagnosed with cancer in the UK context and describe the age-specific psychosocial impact and practical challenges of cancer and its treatment.

2 | METHODS

2.1 | Study design

This was a phenomenological qualitative research study aiming to describe the experiences of YAs diagnosed with cancer in the UK within the last five years. Phenomenological methodologies have been increasingly used in health research to explore the lived experience of illness and recovery (Finlay, 2009). Given the diversity of YAs in the UK, this approach was chosen for its ability to capture the richness and complexity of the direct and subjective experience of time, space, self and relations with others.

2.2 | Participants

Potential participants were identified in clinic lists or locally held patient databases by the clinical team. In person or by phone, a clinical team member invited patients diagnosed with any cancer type aged 25–39 in the 5 years prior to enrolment. We recruited a convenience sample, aiming to sample a range of tumour types, from participating sites including the Royal Marsden NHS Foundation Trust, Imperial College Healthcare NHS Trust, University Hospital Southampton NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust, and Bart's Health NHS Trust.

The Royal Marsden and Institute of Cancer Research Joint Committee on Clinical Research reviewed and sponsored the study (CCR4648). The Research Ethics Committee and Health Research Authority in the UK approved the study nationally (17/LO/0219). Informed consent was obtained from all individual participants included in the study. The study complies with the standards of the Declaration of Helsinki.

2.3 | Setting

Focus groups were conducted in hospital meeting rooms or local charity centres. A nurse or oncologist was present to address clinical questions. One-to-one interviews were conducted in-person either in hospital or by telephone.

2.4 | Data collection

Data collection took place between November 2017 and July 2018. Each participant provided written informed consent and chose to take part in a focus group or interview. Travel was reimbursed for participants who participated in person. Participants self-reported sociodemographic and clinical information prior to participation.

Semi-structured individual interviews and focus groups were conducted as complementary data collection methods to enhance the richness of the data collected (Lambert & Loisel, 2008). Integrating both methods of collection allowed the interviewers to obtain a description of personal experience in individual interviews and explore agreeing and contrasting opinions and beliefs in focus groups. The facilitator (EL), a non-clinical public health researcher formally trained in qualitative research, followed a semi-structured interview schedule (Table 1). The interview schedule, drafted specifically for this study by the authors, was intentionally broad to elicit the issues most salient to the participant and avoid inference about developmental tasks or timelines. The two YA patients and two healthcare providers with a research focus on young people with cancer reviewed the interview schedule for relevance and comprehensiveness and provided written feedback by email. Based on the comments, we amended the question exploring areas of need to elicit issues perceived to be specifically related to age. Discussions were audio-recorded and transcribed verbatim. Field notes were kept to provide context.

2.5 | Data analysis

Transcripts were analysed using the six phases of inductive thematic analysis described by Braun and Clarke which include the following: (a) familiarisation with the data, (b) generating initial codes, (c) searching for themes, (d) reviewing potential themes, (e) defining and naming themes and (f) writing the report (Braun & Clarke, 2012). Two researchers (EL and CV) openly coded the data independently and reconciled the initial codes in NVivo (Version 12, QSR International). Field notes were consulted during initial coding to provide context to the transcripts and aid interpretation. The researchers used the codes to identify potential themes and

TABLE 1 Semi-structure interview schedule

Questions
1. Could you tell me about your experiences in the time since your cancer diagnosis?
2. Have you faced any challenges or problems?
3. Have you had any particular needs or issues in the following areas as a YA cancer patient?
Psychological or emotional
Risk behaviour
Practical
Social
Spiritual

subthemes. These were refined in an iterative process in discussion with the larger study team including two YA patients (ET and KS). The YA patients provided an expert opinion on interpretation of the data and robustness of the results. The analysis process was fluid rather than linear as we continued to refine the themes while producing the manuscript. We specifically sought to identify commonalities across participants and provide a detailed account of important themes unique to YAs.

3 | RESULTS

Of the 152 patients invited, 65 (42.8%) patients participated, 50 (76.9%) in individual interviews and 15 (23.1%) in five focus groups. Three patients declined due to illness, two felt too distressed, seven were too busy, 45 declined without reason, six did not meet eligibility criteria after review and 24 did not participate after consent. Interviews averaged 43 minutes (range: 20–88 minutes) while focus groups averaged 117 minutes (range: 92–150 minutes).

YAs were 33.6 years old on average at the time of participation (Table 2). The majority of participants were female (N = 39; 60.0%), white (N = 50; 74.6%), married (N = 35; 53.8%), university educated (N = 45; 69.2%) and did not have children (N = 38; 59.4%). YAs varied in living arrangements and employment status but the majority experienced some level of financial difficulty (N = 33; 54.1%).

A range of tumour types were included, most commonly sarcomas (N = 13; 20.0%), breast cancer (N = 12; 18.5%) and central nervous system (CNS) tumours (N = 12; 18.5%) (Table 3). YAs were an average of 31.7 years old at diagnosis and a mean of 1.9 years from diagnosis. The majority were in follow-up (N = 37; 56.9%), treated with curative intent (N = 40; 66.7%) and had received chemotherapy (N = 46; 71.9%) or surgery (N = 38; 59.4%).

We identified four main themes. The themes and subthemes along with codes and exemplary excerpts are presented in Table 4. Numbers in parentheses denote the in-text reference for the excerpt in the table.

3.1 | Theme 1: Competing responsibilities

3.1.1 | Subtheme 1: Balancing treatment and work or childcare

YAs encountered difficulty balancing responsibilities while undergoing treatment or in recovery due to hospital appointments and immobilising side-effects. Some participants could not or did not want to stop working for extended periods of time. Patients felt the challenge of navigating treatments and appointments among work commitments were not always appreciated by the healthcare team (1.1.1). Particularly for single parents, the unpredictability of wait times and hospital admissions made childcare challenging. Some patients felt there was little support around caring for children while on treatment (1.1.2).

TABLE 2 Patient-reported demographic information

	Mean (Range) 33.6 (25–42) years Number (%) (Total = 65)
Age at participation	
Gender	
Female	39 (60.0)
Male	26 (40.0)
Ethnicity	
White	50 (74.6)
Asian/Asian British	11 (16.4)
Black/African/Caribbean/Black British	2 (3.0)
Mixed/Multiple ethnic groups	2 (3.0)
Relationship status	
Married	35 (53.8)
In a relationship	16 (24.6)
Single	13 (20.0)
Divorced	1 (1.5)
Children under 18 (N = 64)	
No	38 (59.4)
Yes	26 (40.6)
Current living situation	
Live with spouse/partner	24 (36.9)
Live with spouse/partner and children	20 (30.8)
Live with parents	6 (9.2)
Live with housemate(s)	6 (9.2)
Live alone	6 (9.2)
Live with spouse/partner and parents	2 (3.1)
Live with children	1 (1.5)
Highest level of education	
University or degree	45 (69.2)
College or diploma	11 (16.9)
Secondary School	7 (10.8)
Vocational qualification	2 (3.1)
Current employment status (N = 64)	
Full-time employed	30 (46.9)
On sick-leave	15 (23.4)
Part-time employed	7 (10.9)
Self-employed	5 (7.8)
Unemployed	3 (4.7)
Homemaker and/or caretaker for children	2 (3.1)
Other	2 (3.1)
Experienced financial difficulties (N = 61)	
Not at all	28 (45.9)
A little	20 (32.8)
Quite a bit	9 (14.8)
Very much	4 (6.6)
Decrease in income	27 (81.8)
Travel costs	8 (24.2)
Childcare	2 (6.1)

TABLE 3 Patient-reported clinical information

	Mean (Range)
Age at diagnosis	31.7 (25–39) years
Years since diagnosis	1.9 (0–5) years
	Number (%) (Total=65)
Diagnosis	
Sarcoma	13 (20.0)
Breast cancer	12 (18.5)
Central nervous system tumour	12 (18.5)
Gastrointestinal cancer	7 (10.8)
Urological cancer	6 (9.2)
Gynaecological cancer	5 (7.7)
Haematological cancer	5 (7.7)
Lung cancer	3 (4.6)
Melanoma	2 (3.1)
Current treatment status	
In follow-up	37 (56.9)
On treatment	28 (43.1)
Treatments received (N = 64)	
Chemotherapy	46 (71.9)
Surgery	38 (59.4)
Radiotherapy	28 (43.8)
Clinical trial	13 (20.3)
Hormone therapy	7 (10.9)
Immunotherapy	7 (10.9)
No treatment	5 (7.8)
Targeted therapy	5 (7.8)
Bone marrow or stem cell transplant	1 (1.6)
Brachytherapy	1 (1.6)
Treatment intent (N = 60)	
Curative	40 (66.7)
Unknown	12 (20.0)
Palliative	8 (13.3)
Disease recurrence (N = 61)	
No	41 (67.2)
Yes	10 (16.4)
Not applicable	10 (16.4)
Number of comorbidities (N = 61)	
None	45 (73.8)
1	12 (19.7)
2	1 (1.6)
3	3 (4.9)

3.1.2 | Subtheme 2: Financial insecurity

A number of participants experienced financial difficulties after receiving a cancer diagnosis. This was often due to a loss of income

TABLE 4 Coding hierarchy

Theme	Subtheme	Code	In-text reference	Example excerpts
1. Competing responsibilities	1.1 Balancing treatment and work or childcare	Work and treatment or recovery	1.1.1	I was, like, so stressed trying to finish loads of work off... It was almost like, well don't burden yourself with thinking about all those other things; let's just get through the treatment... I can't not burden myself with these things. I have to; they're there. – female breast cancer patient on treatment
		Childcare and treatment or recovery	1.1.2	The logistics between having two young children that aren't at school. Husband having to go back at work. Fatigue and just generally trying to find childcare for them when I'm in the hospital, in and out of hospital. – female haematological cancer patient on treatment
	1.2 Financial insecurity	Financial strain	1.2.1	It did affect financially. So the house that we lived in, we had to rent out. And we had to move in with our parents; my wife and kids. So yes, so financially it was meaning that we couldn't pay our mortgage. – male CNS tumour patient on treatment
		Returning to work pre-maturely	1.2.2	I certainly couldn't afford to take time off when I was going through treatment. I knew I had to work through treatment financially. – female breast cancer patient in follow-up I tried to get right back to work in October. Partly that was because I think I was going to be going down to half pay... I think the realisation of what I had gone through plus the fact that I was really struggling at work. I kind of then went off with severe depression. – female CNS tumour patient in follow-up
		'Get on with it'	2.1.1	It was maybe also a bit of a coping mechanism ... when I went up to the hospital I was a patient the duration of the appointment. And then once the appointment was over, that was it... kind of a way, I guess, of telling myself that the illness wasn't the most important thing in my life. – male sarcoma patient on treatment
		Self-conscious	2.1.2	They gave me a zimmer frame. I actually looked at it and said, no, I'm not using that... I'm 37 years old. I'm not 78 years old. I didn't want to do it. I'm very proud and private and I didn't want to be seen as old and frail... I want to be me and I haven't been able to be me since being diagnosed and I will never be me again. – male urological cancer patient on treatment
2. Retaining normality and identity	2.2 Work life a component of YA identity	Retaining a sense of normality	2.2.1	I'm really pleased to be back, and, like you say, because obviously I'm young and my career was my focus in life before my diagnosis, having that stripped away, yes, it was a huge, huge deal. – female breast cancer patient in follow-up
		Difficulty returning to work	2.2.2	I just don't know if I can put myself back into a situation where people feel they knew me, like I was second in charge of my department, like doing all this stuff, like aiming for head of department, and now I am just not there. – female gynaecological cancer patient on treatment
		Changes in ability	2.2.3	I am so embarrassed, I am still young, I want to be strong and I want to be the top performer again. – male CNS tumour patient in follow-up
	2.3 Positive change in outlook and priorities	Personal growth	2.3.1	It really allowed me to understand better who I am. I have made some pretty important decisions, and if there is anything good that has come out of this disease it's that really, I think I have matured enormously. – male urological cancer patient in follow-up
		Prioritising family and well-being	2.3.2	I do miss [teaching] incredibly. I miss the kids, I miss the colleagues I worked with, but ultimately, now, I'm just like it's not important for me anymore. My family is important, my friends are important, my health is important, my life is important. – female CNS tumour patient on treatment
		Improving relationships	2.3.3	I think also, because like I say my relationship was relatively young, we were relatively early in our relationship. My partner has been incredibly supportive; it has made us stronger I think. – female breast cancer patient in follow-up

(Continues)

TABLE 4 (Continued)

Theme	Subtheme	Code	In-text reference	Example excerpts	
3. Facing isolation	3.1 Distancing from friends	Friends can't relate or don't understand	3.1.1	Relationships I had deteriorated, kind of disappeared... So it's difficult. It was very isolating in some ways. And yes, you do feel ashamed for kind of the situation that you're in. Well, I certainly have anyway. In the end, you find out who your friends are and the world becomes much, much smaller. – female gastrointestinal cancer patient on treatment	
			3.1.2	I feel like I'm always dropping a bombshell, that this happened. Like, like, even with, like, things like, I don't know, dating someone new and things like that, I don't quite know. I haven't sort of really, like, broached that sort of bit yet and I don't know how I will. – female breast cancer patient in follow-up	
		Wanting to protect loved ones	3.1.3	I was trying to protect people, to some extent, because I remember certain people being really affected and emotional or freaked out and even distancing themselves because they didn't know what to say or how to be around me. – female gastrointestinal cancer patient in follow-up I think sometimes you don't realize as well, how much you are holding in... the hardest part is seeing how it affects other people. For me, it was seeing the way my father reacted when I told him... he just totally broke down and flopped his arms on the table in front of me. – male gastrointestinal cancer patient on treatment	
	3.2 Feeling younger than other cancer patients	Can't relate to older patients	3.2.1	The people who were in there with cancer had generally retired, so there was very little in common when it came to my wife taking time off work, working hours, what type of job you did, those type of things weren't on their agenda. – male haematological cancer patient in follow-up	
		Feeling out of place in hospital	3.2.2	I don't enjoy sitting in the waiting room mainly because I do feel everyone there is so much older than me... I walk through and people are, What's that person doing there? What's she doing there? She's too young to be here. – female melanoma patient in follow-up	
		Miss children due to treatments	3.3.1	There wasn't really a good place to take him while we were [in hospital], so that was quite difficult and we stopped bringing him up... It was quite hard. Especially, I'd see such a change in him when I'd go in and then come home afterwards. It was quite tough. – male sarcoma patient in follow-up	
	3.3 Missing out	Miss social life	3.3.2	There are certain activities I can't take part in any more, like big nights out drinking... I can't do big physical activities, like going for runs... there's a longing in me sometimes, I wish I could train for this and take part. So there are things I do miss out on now. – male CNS tumour patient in follow-up	
		4.1 Uncertain life circumstances	Unexpected illness	4.1.1	I was well, I was running, just fit and healthy. There was no symptoms of the lung cancer and obviously I'm not really in the demographic... it's a lot more shocking I think for a young adult. – female lung cancer patient on treatment
			Transitional period	4.1.2	I was 31 and I was not expecting it. I'd resigned from my job as well. It was loads going on. I had to go back and tell my employer that it's come up and that I couldn't start the new job, and then it was all a bit of a blur... we were actually going to start IVF. It was a tough, tough time. – female breast cancer patient in follow-up
4. Coping with uncertainty	4.2 Uncertain clinical outcomes	Life on hold	4.2.1	It's not knowing what to do next. If I can find a job... Anything feels permanent I can't put my foot into it, because I don't know when I'll have to take my foot out of it... I feel like I'm floating through my life. – female sarcoma patient in follow-up It's the fear of always waiting for the next blood test, always waiting to see are the markers going to go down. It's the fear of the unknown. Fear of... not knowing if you're going to be alive any more or not in the near future. It's very hard, it's extremely hard. – male urological cancer patient in follow-up	
		Coping with uncertainty	4.2.2	When I sit down and have two minutes to myself and I think of what's happened and what's going to happen for the future. Yes it can be a bit worrying if it ever comes back and how am I going to tackle that and what is going to happen. As I said, all I can do is take one day at a time. It happens. – male CNS tumour patient on treatment	
	Fear of recurrence	4.2.3	I think that, when you first finish treatment as a cancer patient, I think you literally live with a fear all of the time that something is going to return. So, every headache you get, every time your arm hurts, everything... You feel that's it, it's coming back. – female breast patient in follow-up		

Abbreviation: CNS Central nervous system

with extended sick leave but also to concurrent events such as moving house or reduced income during maternity leave (1.2.1). YAs often relied on parents for childcare and in some cases received financial support or moved back in, which was perceived as a relief. Some YAs worryingly described financial difficulty as a major factor in returning to work before full recovery, leading to mental health challenges (1.2.2).

3.2 | Theme 2: Retaining normality and identity as a YA

3.2.1 | Subtheme 1: Avoid cancer identity

YAs wanted to 'get on with it' and avoid cancer becoming the focus of daily life. For YAs, this often meant continuing to work or spending time with friends and family, often avoiding cancer-related activities as much as possible (2.1.1). Changes in physical appearance such as hair loss or weight gain were often distressing as they belied their illness and attracted attention, particularly as YAs compared themselves to healthy peers (2.1.2). Hair had particular cultural importance for some YAs from minority backgrounds who faced a lack of inclusive wig services, where the hair offered was more appropriate for Caucasian women. Changes in physical ability, including sexual function, lowered confidence and made YAs feel 'less capable'.

3.2.2 | Subtheme 2: Work life a component of YA identity

Working life was a central component to YA's sense of normality in terms of goals and daily routine (2.2.1). Returning to work was an important part of returning to 'normal.' However, many YAs found returning to work difficult or daunting due changes in cognition, energy levels, physical ability and time passed (2.2.2). Many YAs viewed their ability at work as a part of their identity and self-worth. Some participants were frustrated if they were unable to return to the same level of performance or the same role as before the cancer diagnosis (2.2.3). A number of YAs described a great amount of pride in their careers and experienced immense feelings of loss if unable to return.

3.2.3 | Subtheme 3: Positive change in outlook and priorities

Despite the adversities described, many YAs felt the unexpected cancer diagnosis was a catalyst for personal growth in various ways, including gaining fearlessness or confidence and learning to accept a lack of control (2.3.1). Some participants felt they learned to prioritise family and personal experiences over work, appreciating time spent with loved ones (2.3.2). Experiencing cancer also helped improve relationships with partners, parents and friends when confronted with emotional distress and potential early mortality (2.3.3).

3.3 | Theme 3: Facing isolation

3.3.1 | Subtheme 1: Distancing from friends

Although some relationships improved, YAs found that other friendships were weakened by the cancer diagnosis. YAs found that friends without personal experience of cancer or severe illness did not understand what they were going through, making it difficult to relate and leading to discomfort (3.1.1). YAs worried about forming new relationships as they were unsure how or whether to disclose their diagnosis, particularly with potential romantic partners (3.1.2). Participants experienced a range of cancer-related worries including fear of disease progression or recurrence. Despite these concerns, many YAs downplayed their emotions or declined to disclose full details about the diagnosis in order to protect loved ones, sometimes contributing to perceived emotional distance (3.1.3).

3.3.2 | Subtheme 2: Feeling younger than other cancer patients

Not only did YAs find it difficult to relate to peers, but they often found it difficult to relate with other oncology patients due to the common age difference (3.2.1). YAs felt their psychosocial concerns, healthcare needs and social interests were very different from those of older patients. Being visibly younger also made participants feel uncomfortable and out of place in the hospital as it attracted unwanted attention from patients and hospital staff (3.2.2).

3.3.3 | Subtheme 3: Missing out

Many patients felt isolated from friends and family due to side-effects like fatigue, fear of infection or extended hospital admissions. For YAs with young children, this was particularly distressing as they felt they missed out on important developmental changes (3.3.1). Hospital settings, designed for older adults, made it difficult to bring children to visit. YAs usually felt extremely busy before the cancer diagnosis, making the isolation due to treatment and side-effects more difficult to cope with. Participants felt that they missed out on social activities with friends and family as well as the social aspects of work (3.3.2). Only a few YAs discussed missing religious gatherings as a source of frustration, but this was particularly important for some.

3.4 | Theme 4: Coping with Uncertainty

3.4.1 | Subtheme 1: Uncertain life circumstances

Challenges faced by YAs were compounded by the transitional nature of YA life and future uncertainty. All participants were extremely shocked by their diagnosis as cancer is rare and unexpected

among YAs who are usually otherwise healthy (4.1.1). At the time of diagnosis, many participants described moving house, changing jobs, building new relationships or having children. The uncertainty in life circumstances made managing treatments and appointments more difficult (4.1.2). While not all YAs were interested in having children or growing their family, the need for timely treatment required YAs to make decisions about fertility treatment they felt unprepared for. The diagnosis and treatment were particularly disruptive as it forced YAs to face possible mortality at a time full of plans for the future.

3.4.2 | Subtheme 2: Uncertain clinical outcomes

Uncertainty about short-term treatment outcomes and long-term life expectancy weighed heavily on the minds of many participants, particularly for patients with rare or advanced cancers. YAs had to defer plans for relationships, moving home and furthering careers. Several patients felt the uncertainty made them feel like life was 'on hold' (4.2.1). Other patients described coping with the uncertainty by 'living one day at a time' or actively deciding not to focus on prognosis and staying positive about future life expectancy (4.2.2). After treatment, anxiety around cancer recurrence was heightened by reduced monitoring and less frequent contact with the healthcare team (4.2.3).

4 | DISCUSSION

The psychosocial experiences and practical issues identified here are centred on the active day-to-day routine of YAs with early careers and young families and the sudden disruption of their activity following a cancer diagnosis. This interruption may threaten YAs' sense of identity as a young person, in contrast to older adults who may find cancer less disruptive to personal identity in the context of ageing and declining health (Hannum et al., 2016).

Family, important to people of any age, plays a unique role for YAs. While social isolation is experienced acutely across the AYA age range, YAs have the added complexity of missing out on the lives and development of young children (Barakat et al., 2016). At present, YAs do not benefit from tailored measures to reduce social isolation in wards and clinics that exist in TYA treatment centres (Bibby et al., 2017). While psychosocial support for TYAs focuses on access to peers, services for YAs need to also provide family support. Although not specifically asked about, YAs did not describe feeling frustrated about becoming dependent on parents again or perceive relying on parents for childcare or housing as a regression in development as previous theories infer. Notably, these feelings are often observed in TYAs (Belpame et al., 2016; Hokkanen et al., 2004). In contrast, YAs actively protected parents and friends from the emotional burden of the condition (Norma Mammone D'Agostino & Edelstein, 2013).

Work plays an important role for YAs as a financial necessity but also in providing a sense of normality, a source of social interaction and, for some, a contributor to identity and self-worth. Interventions to support attaining educational and vocational goals have been

developed for TYAs to facilitate reintegration after treatment (D'Agostino et al., 2011). YAs need similar support to return to work and 'normal life,' navigating the myriad of legal, social, material and health-related issues they face (Hauken et al., 2013). This is particularly important given the difficulty YAs in this study described in returning to work. Previous research has shown YAs experience higher perceived physical and cognitive deficits compared to older adults that may limit their ability to return to work (Champion et al., 2014; Stone et al., 2017). Financial toxicity, reported extensively in North America, is also experienced by YAs in the UK due to loss of income and travel costs (Finkelstein et al., 2009; Guy et al., 2014). This needs to be addressed to ensure YAs return to work at an appropriate time.

Coping with uncertainty was a strong theme among YAs. While uncertainty and fear of recurrence may occur among cancer patients of any age, it may be particularly pronounced in young patients (Simard et al., 2013). Additional social uncertainty for YAs due to the transitional period in life, as highlighted by the patients here, may contribute to the concerns. Higher illness uncertainty is linked to lower social support and lower quality of life, making the YA experiences of social isolation a cause for concern (Sammarco, 2001). Despite worries about short-term treatment outcomes and recurrence, many YAs shared stories of personal growth and strengthening in relationships. This suggests the current discourse around young people experiencing either post-traumatic growth or post-traumatic stress may simplify the human condition as patients can experience both simultaneously.

Participants in this study shared experiences of job and financial insecurity, also reflected in the responses to the background questionnaire. These findings support the new frameworks suggested by Levin and Hammond that take the changing economic context for young people with cancer into account (Hammond, 2017; Levin et al., 2019). Our findings also support the idea that life goals and priorities vary between individuals, as a number of YAs did not plan to have children and were happy to live with family members. However, the contribution of work to identity and the focus on family life and children fits with previous theories taking developmental life course perspectives (Docherty et al., 2015). The lack of culturally appropriate supportive care services reflects the scarcity of research and support tailored to meet the needs of the diverse UK population. The specific issues faced by growing minority groups of YAs should be explored in-depth in future research.

4.1 | Clinical implications

YA experiences suggest that there may be a need for more awareness of YA-specific issues by healthcare providers and improved age-specific practical, emotional and social support during cancer treatment and recovery. The National Institute for Health and Care Excellence guidelines for providing cancer care to children and young people provide excellent recommendations for age-specific multi-disciplinary care (National Institute for Health & Care Excellence, 2014). Patients and providers should review these guidelines to determine whether they should extend to YAs and if current adult

supportive care services should be supplemented with YA-specific support (Gupta et al., 2016).

Scalable interventions should be explored, particularly those that can be delivered remotely (Penn & Kuperberg, 2018; Viola et al., 2020). A paper-based discussion aid called 'Snapshot' providing prompts for psychosocial issues and a mobile phone app supporting symptom tracking have shown to facilitate conversations around personal or sensitive topics in AYAs (Erickson et al., 2018; Poort et al., 2018). Individual psychological support focusing on AYA-related issues including social, family and romantic relationships and a similar intervention using cognitive behavioural therapy have shown to improve quality of life (Aubin et al., 2019; Rosenberg et al., 2015). Consulting with a fertility specialist and undertaking fertility preservation has the biggest impact on reducing decisional regret and improving quality of life, however, web-based decision aids in conjunction with specialist consultation have also shown to reduce decisional conflict (Ehrbar et al., 2019; Letourneau et al., 2012; Wang et al., 2019). Multidisciplinary interventions including physical, psychological information and/or vocational facets can improve return-to-work rates and quality of life in people of working age with cancer (de Boer et al., 2015).

4.2 | Study limitations

While this study included a large number of YAs, the conclusions are limited by its geographic focus in South East England, with a majority of patients treated in London. The study did benefit from representation of ethnicities that roughly match the population distribution in South East England (Office for National Statistics, 2018). Future work should focus specifically on the needs of growing minority groups in order to provide culturally appropriate care. The large number of patients from London may also have influenced the results with the emphasis on careers. However, this perspective is important for treating YAs from a metropolitan area.

A high number of patients in this study had rare cancer types and advanced disease that may also have impacted the main themes identified such as the focus on uncertainty. However, this is also an important group of patients that is often excluded from studies. This study had a broad, exploratory focus allowing participants more autonomy in directing the interviews and focus groups but reducing the possibility for in-depth analysis of the topics identified. Asking patient in follow-up to reflect on their experience since diagnosis also limited our ability to attribute certain issues to treatment status. The large sample enabled the identification of patterns across a variety of tumour types, even though the amount of data also limited in-depth analyses. Future work will conduct sub-group analysis to further explore the diversity in experiences.

5 | CONCLUSIONS

With an unexpected cancer diagnosis, YAs face a number of specific psychosocial experiences and practical challenges with the sudden

halt of family and work lives. Current healthcare services designed to treat much older adults may not fully address these issues and provide adequate support to YA patients. Further research should identify age-specific requirements in supportive care services.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

AUTHOR CONTRIBUTIONS

Guarantor of integrity of the entire study: WTAG, OH, Study concept and design: NST, JL, SS, MNo, SB, ZS, ASD, MG, BS, WTAG, OH, Literature research: EL, OH, Data collection: EL, EY, PE, MNa, NH, NSa, DF, AD, NST, JL, SS, MNo, SB, ZS, ASD, MG, BS, WTAG, OH, Experimental studies / data analysis: EL, CV, KS, EY, PE, MNa, OH, WTAG. Statistical analysis: N/A, Manuscript preparation: EL, CV, KS, ET, ASD, OH, WTAG, Manuscript editing: EL, CV, KS, ET, EY, PE, MNa, NH, NSa, DF, AD, NST, JL, SS, MNo, SB, ZS, ASD, MG, BS, WTAG, OH.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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