

ORIGINAL RESEARCH: EMPIRICAL
RESEARCH - QUALITATIVE

Life Interrupted: Experiences of adolescents, young adults and their family living with malignant melanoma

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Abstract

Aim: Melanoma is one of the most common human malignancies; yet, it is often thought of as a disease of adulthood rather than one affecting adolescents and young adults. This study sought to understand the experiences of adolescents, young adults and their family living with malignant melanoma.

Design: A qualitative study using Interpretive Phenomenological Analysis, through a multi-perspective design.

Methods: Data collection was conducted between January and August 2018 in each participant's Primary Care Centre when they were attending for an outpatient appointment. Each young person and a nominated family member were interviewed (n = 10) either individually (n = 4) or as a dyad (n = 6) according to their personal choice. In-depth semi-structured interviews were conducted and audio-recorded with the participant's consent. Interview data were transcribed verbatim and analysed.

Findings: The metanarrative 'Life Interrupted' was the core conceptual thread woven throughout the findings. It represents the interconnections and interrelationships between the adolescent or young adult and their family. Being able to recognize the disease and seek support was challenging with often limited physical, emotional or social support resulting in feelings of fear and isolation. Four super-ordinate themes were identified: (a) 'Is it Serious', (b) 'Too Much too Young', (c) 'Not the Same' and (d) 'Time to Live'.

Conclusions: With the rising incidence of MM in the adolescents and young adults population globally, there are demands to improve healthcare professionals and nurse's knowledge and understanding of MM. As young people with MM experience their journey outside specialist cancer services, the care delivery for this patient group and their families require stronger links between services.

Impact: This study will inform the improvement of care delivery for MM in order that this patient group is provided with the same access to service delivery as other adolescents and young adults with cancer.

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KEYWORDS

adolescents, experiences, family, interpretative phenomenological analysis, malignant melanoma, narrative, nursing, qualitative, research, young adults

1 | INTRODUCTION

Incidence of melanoma is increasing globally, with 132,000 cases reported annually in the adult population (Ali et al., 2013; Cancer Research United Kingdom, (CRUK) 2020; Ferlay et al., 2015, Melanoma United Kingdom (MUK) 2020; McNally et al., 2014). The risk of developing melanoma increases with age and it is still very rarely diagnosed in children under 10 years old, accounting for only 0.7% of all malignancies in this age group. Rates of melanoma have seen a marked increase in adolescents and young adults (AYAs) living in developed countries (Indini et al., 2018; Purdue et al., 2008). This trend is attributed to variations in racial skin phenotype, as well as differences in sun exposure around the world. In the United States of America (USA), for example, 98.2% of cases are reported amongst white-skinned individuals (Ali et al., 2013) and is the second most common form of cancer for people aged 15–29 years in the USA and is the third most common cancer in this patient group in the United Kingdom (UK) (Ferlay et al., 2018; Indini et al., 2018; Information Services Division (ISD), 2020; Public Health England (PHE) 2021).

Current evidence suggests that early diagnosis of melanoma can help ensure a positive prognosis and a healthy outcome (Melanoma United Kingdom, 2020; Scottish Government, 2016). Yet, if not diagnosed and treated with alacrity, the outcome can be fatal (Cancer Research United Kingdom, 2020). Despite global advances in cancer treatments, clinical management and concerted efforts to increase public awareness of skin cancer risks and prevention strategies (Hubbard et al., 2018, 2020; Kyle et al., 2014), reported incidence continues to rise, especially in the AYA population (Cancer Research United Kingdom, 2020; Hajdarevic et al., 2014; McNally et al., 2014; Melanoma United Kingdom, 2020; Scottish Government, 2019).

Understanding the experiences of AYAs living with cancer is vital to the development of supportive psychological, clinical and educational interventions (Aldiss et al., 2019; Hubbard et al., 2018; Lea et al., 2018; Pearce et al., 2020). Historically, melanoma was seen as intractable and untreatable, whereas today, it is revealing its molecular weaknesses (Levy et al., 2018). Advances in clinical research mean that patients with melanoma can now expect positive outcomes and a good quality of life (Al Omari & Wynaden, 2014; Al Omari et al., 2017; Hajdarevic et al., 2014). Curative treatment, however, is dependent on early diagnosis and the stage of the disease at the time of diagnosis, with the specific treatment dependent on the stage of the disease (Levy et al., 2018; Walter et al., 2010).

2 | BACKGROUND

Melanoma diagnosed in people aged 15 to 24 years may be preventable by avoiding UV light exposure and burns from the sunlight

(Public Health England, 2021). There is little evidence or guidance on the treatment and management of AYAs with this specific disease and if suspicious lesions are detected, these are initially referred for further assessment by their General Practitioner (GP) or local dermatologist (Murray & Edgar, 2012). In the UK, AYAs do not always have access to specialist cancer services due to the treatment journey for melanoma being different from other forms of cancer. Most of the management is provided through outpatient appointments, depending on the stage of the disease. For all cases, treatment is usually a wide excision of the primary tumour with clear margins around the mole with no cancer cells evident. However, the definition of what represents a suitable clear margin and whether regional lymph nodes are affected and removed during surgical treatment is subject to extensive debate in the medical profession (Cancer Research United Kingdom, 2020). Adjuvant therapy such as immunotherapy may be used as an additional treatment to supplement the primary excision for high-risk patients, but there is no standard practice in this area of care (Indini et al., 2018; Levy et al., 2018). Medical oncologists are trialling immunotherapy, which is expected to help substantial numbers of patients, but the best timing for this type of intervention has not been determined (O'Reilly et al., 2020). Systemic treatment is used in palliative and end-of-life care along with radiotherapy, especially for patients with metastatic disease (Levy et al., 2018). Some AYAs experience disease recurrence, undergo multiple surgeries and attend clinics for many years (Ali et al., 2013).

In addition, the successful management of melanoma depends on the approach to care delivery. Recognition of early symptoms to ensure prompt diagnosis and treatment is crucial (Zebrack et al., 2014). Delivery depends on regular reviews of services and the identification of relevant treatment protocols and pathways in combination with a trained workforce to meet demand. This is a fundamental requirement so that AYAs and their family can be supported and prepared for their future.

Cancer during adolescence shapes and reshapes young people's lives and relationships at a crucial life stage when they are in the process of developing their adult (sense of) self, gaining greater independence and making life plans (Cable & Kelly, 2019; Davies et al., 2018, McNally & Cruickshank, Pearce et al., 2020, Weston et al., 2018). However, a narrative review of 18 qualitative research studies showed that experiences of AYAs living with melanoma are poorly understood, with no studies in the age group of 12–26 years and that the experiences of family are omitted (McNally et al., 2021). Only two previous studies have used Interpretative Phenomenological Analysis (IPA) to examine AYAs' experiences (Al Omari & Wynaden, 2014; Al Omari et al., 2017), and no previous papers have used IPA to understand the experiences of AYAs alongside their families.

3 | THE STUDY

3.1 | Aim

The aim of the study was to gain an understanding and find meaning from the lived experience of AYAs and their family. Understanding the impact on the individual sense of self and that of their family is critical if nurses and other healthcare professionals are to deliver more appropriate care and support for AYAs with this disease. Specifically, we addressed the following research questions:

1. What are the experiences of AYAs and their family living with MM?
2. What are AYAs and their families' experiences of the support and care they require or need?
3. What further support or improvements in care do AYAs and their family identify?

3.2 | Design

A qualitative study using IPA was conducted in Scotland. Influenced predominantly by Heidegger's interpretative phenomenology (examining the lived experience), hermeneutics (interpretation of the lived experience) and idiography (attention to particulars of individual stories) (Larkin et al., 2019), this approach examines what experience means to individuals through a process of in-depth reflective inquiry (Smith et al., 2009). IPA is an interpretative process between the researcher and the researched. This means acknowledging the challenge of the main author's preconceptions drawn from 25 years of experience as a cancer nurse for children and AYAs. Regular supervision was vital throughout the whole process to reduce subjectivity and guard against the possibility of coercion and bias (Polit & Beck, 2010).

IPA multi-perspective designs where relationships between participants are explored are gaining increasing prominence among researchers who recognize that an experience such as living with a long-term disease 'is not solely located within the accounts of those with the diagnosis' (Larkin et al., 2019 p.182). For this reason, this study viewed the family as integral to the experiences of AYAs living with MM and their journey together in supporting one another through this experience. However, it did not impose this theoretical lens on participants themselves by, for example, only adopting a

dyadic interview approach, but instead gave AYAs the choice about how and with whom they would share their experiences.

3.3 | Sample/participants

Adolescents and young adults were recruited through their Clinical Nurse Specialist (CNS) who was the supportive link for the AYAs and their family members throughout their treatment and follow-up care. CNSs approached the AYAs who met the study inclusion criteria (Table 1) and provided them with an information sheet about the study and an invitation to contact the lead researcher if they were interested in taking part. Seven young participants, 16–26 years, were purposively sampled across three Scottish National Health Service (NHS) Boards to gain variation in care environments, professionals and pathways. Children in Scotland below 16 years of age will typically be treated in children and young people's services, whereas AYAs aged over 16 years will be seen in an adult service (Scottish Government, 2016). These three NHS Boards were adult primary treatment centres (PTCs). Most participants were male with two female participants initially expressing an interest but withdrew on the actual day of the interview. Each young person was asked to nominate a significant other who was important in their cancer journey. According to their personal choice, five AYAs, four family members and one significant other (partner) were recruited to the study. The term family includes the significant other (partner) throughout. Table 2 summarizes the sample characteristics and Table 3 provides a biographical narrative for each participant. Most of the young participants lived at home with their parents who were still part of their lives, which may not be typical of young people in this age group who may rely on their peers more (Kumar & Schapira, 2013; Stegenga & Ward-Smith, 2009; Woodgate, 2006).

4 | DATA COLLECTION

In line with a multi-perspective approach, the study set out to interview AYAs and their nominated family member separately. However, as young people were often accompanied by their family member to the outpatient appointment before or after which the interview would take place, AYAs requested a shared interview. Four individual (n = 4) and three dyad interviews (n = 6) therefore

TABLE 1 Inclusion and exclusion criteria

Inclusion Criteria:	Exclusion Criteria:
<ul style="list-style-type: none"> • Aged 16–26 years. • Family members aged 16–80 years. • Male or female. • Malignant melanoma, stages 1–4. • Live within Scotland. • English speaking. 	<ul style="list-style-type: none"> • <16 years and >26 years. • AYA with severe cognitive impairment. • All other cancers. • Non-resident in Scotland. • Non-English speaking.

TABLE 2 Research sample population characteristics

Participant (1=single 2 = dyad)	Age at Diagnosis (Years)	Age at Interview (Years)	Stage of Disease	Occupation at Interview	Family / Significant Other	Age at Interview (Years)
John Male	16	19	2B	University Student	Eve Mother	52 ¹
Paul Male	21	23	3A	Health Administrator	Anna Mother	52 ¹
George Male	21	23	3A	Mechanic	Richard Father	72 ²
Patrick Male	11	16	3B	Starting College	Terry Father	38 ²
Helen Female	25	26	3B	Hotel Manager	Stuart Partner	26 ²

TABLE 3 Research population biographical narrative

Participant	Research population biographical narrative
John Dyad: No	John was 16 years of age when he was diagnosed with stage 2 MM on his neck. The mole and part of the lymph were surgically removed, and no further treatment given aside from routine follow-up check-ups. The surgery left scarring. They are a close family with support from extended family and friends.
Eve Dyad: No	Eve, John's mother, is a registered nurse. Both mother and son secure a close bond. Since the diagnosis, Eve had been blaming herself for the disease.
Paul Dyad: No	Paul was 21 when he was first diagnosed with stage 1 MM. The mole was surgically removed, but the MM reoccurred six months later as a stage 3 MM. Further surgery was required, followed with regular check-ups. Paul has widespread scarring on his neck.
Anna Dyad: No	Paul's mother, Anna, works in an insurance company. Anna was separated from Paul's father and has one son, Paul. Although mother and father were separated, they remain a close family.
George Dyad: Yes	George was first diagnosed with stage 3 MM at the age of 21. The surgery left a scar on his neck and head. Recurrence detected at a follow-up appointment. George lived at home with his family.
Richard Dyad: Yes	George's father, Richard, is not his biological father but has cared for George and his twin since birth. They are a close family unit.
Patrick Dyad: Yes	Patrick was a young child of 11 when he was first diagnosed with stage 3 MM in his leg. Disease did spread and this was his third relapse. He lived at home with his father and younger brother. He had missed a lot of school from being in hospital.
Terry Dyad: Yes	Patrick's father, Terry, cared for his two sons. Patrick's mother did not live with them.
Helen Dyad: Yes	Helen, a young woman, lived with her partner, Stuart. At the age of 25, she was diagnosed with stage 3 MM on her abdomen. The mole was removed, followed by surgery to remove those lymph nodes that were affected. The surgery resulted in extensive scarring to Helen's arms and abdomen and following a follow-up appointment further spread of the disease was detected and she was waiting to receive immunotherapy at a Specialist Centre.
Stuart Dyad: Yes	Stuart and Helen had been in a relationship for two years and lived together. Stuart had family close to where they lived.

took place. Although the use of individual and joint interviews had implications for data collection and analysis, this study illustrates the strengths from using a multi-perspective design in IPA to capture this shared experience. Data collection was conducted between January and August 2018 in the participant's PTC. In-depth semi-structured interviews were conducted with the lead researcher and the participants interviewed in a private room identified through the PTC prior to the date of interview. Interviews lasted between 90 and 120 min and a sample of the questions is

given in Table 4. The sample size exceeded that recommended by Smith et al., (2009) and generated rich data for analysis and interpretation.

4.1 | DATA ANALYSIS

Interviews were transcribed verbatim and analysed using a systematic inductive interpretative approach (Smith et al., 2009) following

the recognized six key steps approach as shown in Table 5 (Smith et al., 2009). Each transcript was analysed separately both for the AYAs and for the family whether as an individual or dyad to explore the experience from these different (albeit related) standpoints. Analysing the data individually allowed the narrative to ‘open up’ and reveal the experiences of the participant’s as various ‘individual parts’ and then as a ‘whole’ as seen in Table 6 (Peat et al., 2019; Smith et al., 2009). The lead researcher is also a member of the Scottish IPA group and this was supportive in ensuring the methodology was following IPA methodology.

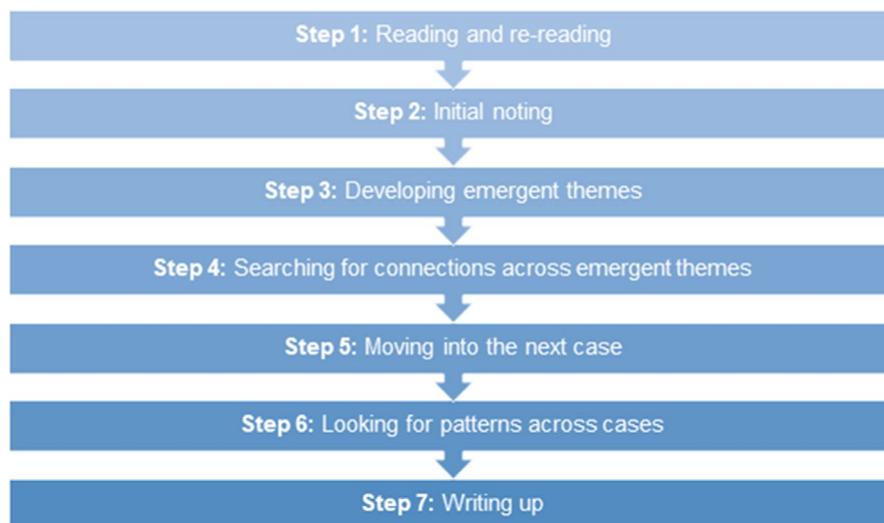
4.2 | Rigour

There are many frameworks available for assessing the quality and rigour of qualitative research (Elliott et al., 1999; Yardley, 2000). The lead author primarily conducted data analysis with discussion

TABLE 4 Interview questions

AYA
To begin with, I would like to learn a bit about your journey to being diagnosed with malignant melanoma.
What things stick in your mind about the time leading up to diagnosis?
What stands out for you from your experience through this journey from diagnosis, to treatment or after treatment? (Probes: diagnosis, treatment, after treatment)
Family
What is your experience of caring for your family member with melanoma? How has it been for you?
Has your life changed/been affected in any way and how? (In a positive/negative way)?
What are the challenges you have been faced with during this time as a family member?
What has gone well and what has not gone so well during this experience? (Probes: care, treatment, support) Could you give me an example?

TABLE 5 Key steps



from the research team to ensure rigour and credibility in the analysis (Yardley, 2000). Rolfe (2006) suggests that there should be no rigid generic framework to establish rigour, as this has the potential to thwart the authenticity and creativity of the individual study. Yardley (2000) presents four broad principles for assessing the quality of qualitative research and in particular in IPA; (a) sensitivity to context; (b) commitment and rigour; (c) transparency and coherence (d) impact and importance. These were the four principles followed in this study to ensure credibility and rigour.

5 | ETHICAL CONSIDERATIONS

Ethical approval was received from both the lead researcher’s academic institution (FHLSS/1787 Version no.2) and NHS (2016/0319). Subsequent to NHS approving the research, a formal Research Passport was required to obtain multicentre approval from three NHS Boards across central Scotland. All participants were given a pseudonym to maintain anonymity. Participants were assured that the information they provided would be treated as confidential and that they reserved the right to refuse to participate in the study.

6 | FINDINGS

The findings were meticulously drawn on from the three philosophical perspectives: as discussed under design (Larkin et al., 2019). Four super-ordinate themes were identified comprising 12 sub-themes (a) ‘Is it Serious’ capturing the experience of finding a mole and feelings of bewilderment and confusion; (b) ‘Too Much too Young’ being young and life on hold; (c) ‘Not the Same’ being different from other experiencing different cancers and (d) ‘Time to Live’ not being defined by the disease and living their lives. The metanarrative ‘Life Interrupted’ was the core conceptual thread woven throughout the findings. It represents the interconnections and interrelationships

TABLE 6 Step 3 – Developing emergent themes

Participant transcript: George		
<p>Yes. Well I've got quite a lot of moles all over and never really paid attention to them because I knew they were there. So, I was off getting my haircut, and my hairdresser went 'that mole doesn't look right'. So, I made a doctor's appointment just to get checked, and they weren't happy with it, they weren't sure about it because it only just a little local doctor.</p> <p>Well we made the initial appointment for him and we saw a local man, who's from the same part of the country as myself, highlands understanding. He said 'aye' just send him up and we'll take it off.</p>		
Interpretation Review:		
Description / Content:	Language Use:	Interrogative coding:
Tell me about when you first noticed a change in your mole?	'never really paid much attention', 'off getting haircut'	No real signs or symptoms that there was something wrong with his mole, has may all over his body, never bothered him before, why now? Going about his daily routine Slightly worried but really not sure

This colour coding allowed for the individual voices to be heard throughout the detailed analysis, which is a critical component of the IPA approach.

between the four identified super-ordinate themes and 12 sub-themes as seen in Figure 1.

6.1 | Metanarrative: Life interrupted

The metanarrative provides an overarching interpretation of the participants' experiences of living with MM and is concerned with describing the whole story, specifically one which integrates with the other narratives. In living with MM, the young participants and their family experienced interruptions and setbacks in their customarily familiar or anticipated lifeworld (Eatough & Shaw, 2019). During the AYAs' lives, the MM experience arrived at a time when they were in the process of developing their early adult life plans and were at a fundamental crossroad in their lives. Despite the varying individual personalities and personal circumstances, the in-depth research acknowledged that these participants were experiencing a significant interruption in their typical 'day-to-day' routine and plans. School and career plans along with life and prospects for adulthood were affected by the disease and its treatment. This paper will now present the findings from both the AYAs and the family to illustrate the shared experience.

6.1.1 | Is it Serious?

'Is it Serious?' captured both AYAs' and the family members' experience of finding a mole and the associated feelings of bewilderment and confusion. Although some AYAs discovered a suspicious mole through personal vigilance (e.g., Helen) or routine day-to-day activity, such as shaving (e.g., Paul), for many this was the moment that drew others into their experience. For example, George was initially alerted by his hairdresser:

"I was off getting my haircut, and my hairdresser went 'that mole doesn't look right'. So, I made a Doctor's

appointment just to get checked, but it had got bigger, it had gone black and was all horrible" (George).

Knowing that others had noticed a change in their mole was enough for the young person to seek further advice on the mole. Many of the participants were uncertain and unsure what this change in the mole meant, including the general practitioner (GP). As George's father, Richard expressed:

"The GP kicked it off, remarking at the time , we're no touching that, not sure what it is and then it was downhill all the way after that "(Richard).

Unlike experiences of other cancers, none of the participants had painful symptoms; however, all experienced changes in the colour and size of the mole. These experiences emphasize the need for greater public awareness and knowledge about skin cancer. All the participants in this study confirmed that their understanding of the risks of skin cancer was minimal. This lack of awareness combined with the belief that 'it will never happen to me' (Paul) can lead to significant delays in AYAs being diagnosed with MM. Recognizing these early symptoms was crucial, but for most, the next part of the journey resulted in a long and anxious waiting game. Throughout, all participants referred to the cancerous mole as 'it', even when the diagnosis was given. This first part of the journey was a fraught and difficult experience, although it was not always clear whether the participants had taken 'it' seriously, especially when the initial diagnosis was reached.

6.1.2 | Too Much too Young

Confirmation of a diagnosis of melanoma brought an overwhelming sense of the unknown into their lives. For many, the stark reality of their MM diagnosis had still to be entirely accepted and internalized, even though for some, this was their second or third

Participant transcript: Paul

I was **absolutely shattered and in a lot of pain**. I had to sit up in bed which was painful, I was **out of breath constantly** so it was a **horrible night, horrible night**, then of course, **depression came back that night, so I was not suicidal but it would have been easier if I never woke up. I had strong painkillers but made me constipated**. It was just the one night, **mostly on my own**, didn't want to wake my mum, I was a total shambles.

Interpretation Review:

Description / Content:

What was it like for you when you went home, after discharging yourself early?

Language Use:

'absolutely shattered and in a lot of pain'
 'out of breath constantly, horrible, horrible night'

Interrogative coding:

Worry setting in, reality of the surgery and what had happened to him.
 Anxiety causing breathlessness in addition to the surgery.
 Community care from hospital discharge to home.

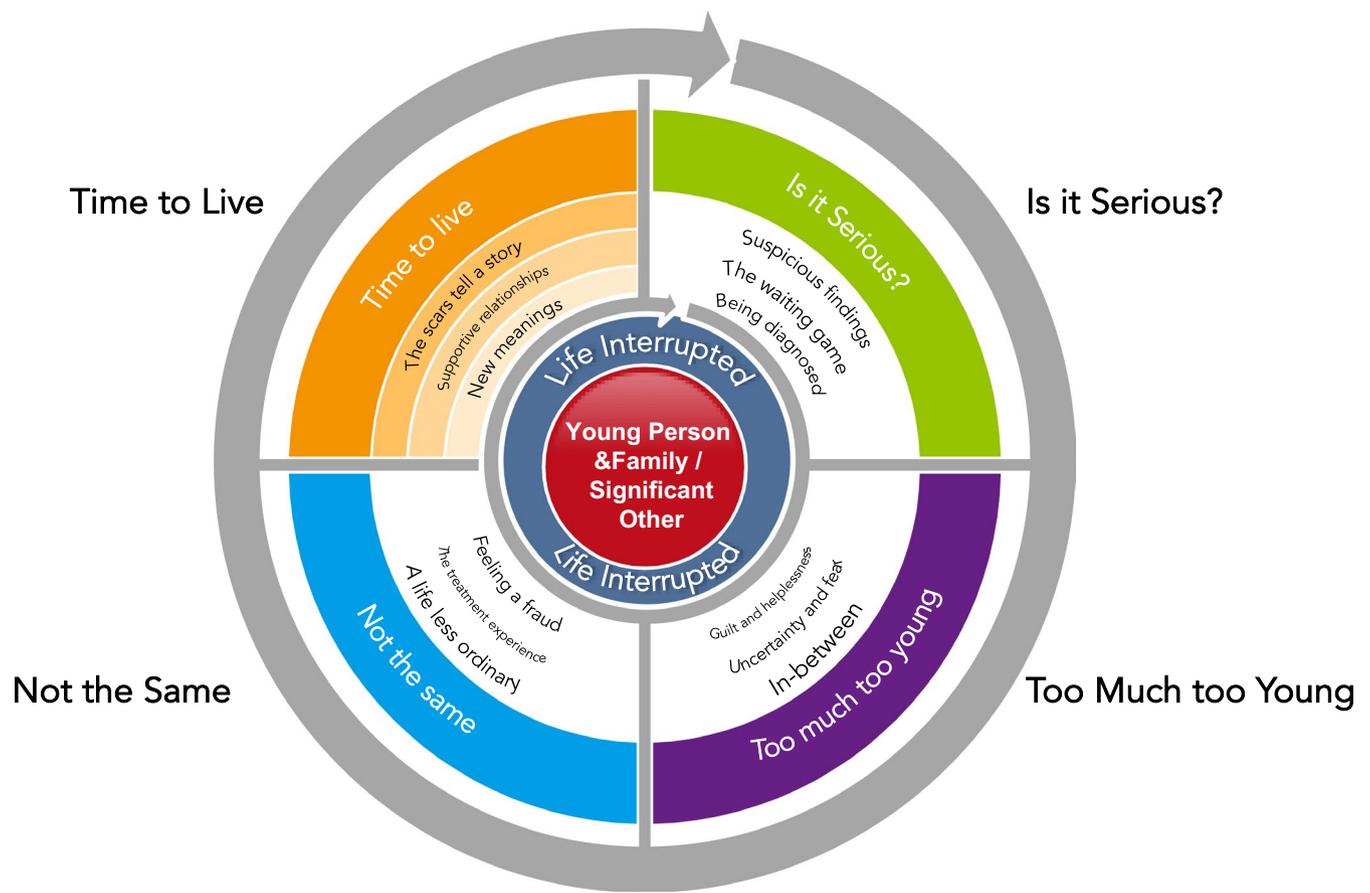


FIGURE 1 A visual representation

recurrence. Earlier life plans and ambitions had to be rearranged and postponed, replaced with the immediate priority of dealing with the physical, emotional and social impact of the disease. For example, as described by John.

“who wrote this into my life plan? I was diagnosed when I was 16, so that was the start of my sixth [final] year at school. I was just about to sit my exams when it all kicked off “ (John).

The pervading feelings of uncertainty and fear arrived at a fundamental crossroad in the lives of the AYAs when they and their loved ones were in the process of developing and supporting early adult life plans. This was the point where the participants now realized the seriousness of this disease and what this could mean for their lives. As John's mother, Eve, described:

“At 16 they are making choices about subjects and University. I had hopes and dreams of what he would

go off to do at University and study, and suddenly your life is sort of on hold "(Eve).

Some family members blamed themselves for the disease and sought reassurance from other sources such as friends, the CNS to understand why their child/loved one had to 'suffer in this way' (Eve). For many of the participants, this was when the 'it' was given a name, and the term 'skin cancer' was used. This came pre-loaded with social stigma and was commonly seen as synonymous with death.

6.1.3 | Not the Same

The MM diagnosis and associated treatment journey caused all the participants to re-evaluate their lives and consider what was important to them. Prolonged periods of hospitalization for this disease were rare at the beginning of their journey and they did not recognize that they were unwell or living with cancer, unlike other forms of cancer affecting AYAs or other people they knew. All were treated and nursed in general surgical wards for the surgery, apart from John who was cared for in a breast cancer unit for women.

"he ended up actually in the breast clinic, for his surgery, which in a way was lovely, because it was all women, and all the nurses were fawning over him and looking after him because he was the only guy in there" (Eve).

Even with most experiencing a hospital episode and recurrence, they still felt different from other AYAs experiencing cancer. As Anna, Paul's mother explained:

"Actually, he said he felt a bit of a fraud because he had no illness whatsoever I suppose he just felt lucky, not lucky to have it, but it can be operated on and not having to have the chemotherapy or the radiotherapy. Because my friend's daughter, who had Leukaemia, she'll have problems all her life and she'll probably never be able to have kids "(Anna).

Paul reiterates this experience through his thoughts about what typically having 'cancer' involves and why this did not resonate with him. Most participants reflected on their own experiences of having a friend or relative who had been diagnosed with other cancers. Paul described this:

"After the first one it felt like I've had cancer, but I've not had cancer and then this one, it feels like it's getting there, but I've not had chemo or radiotherapy, so it was like, I feel like a fraud, in some way " (Paul).

Part of this experience was compounded by the fact that none of the AYAs were treated in an age-appropriate specialist cancer

environment, such as a Teenage Cancer Trust (TCT) Unit, which is designed specifically for teenagers and young adults in the UK and some parts of the United States of America (USA). Consequently, some felt that the healthcare system was not designed to meet their particular requirements and contributed to the feeling that they were not the same as others who experience cancer: As Patrick explained:

"When I first woke up, I looked around, and I was with older folk because I was in intensive care, and there weren't any kids in intensive care. And then I got moved into a sort of children's hospital, and I think I was the oldest in the ward" (Patrick).

It was not clear why he was in the adult Intensive Care Unit (ICU) and not in an age-appropriate environment, and Patrick was quite confused by this. Patrick was aware that no 'kids' were present, and when he did get moved, he was the oldest (at this time, 15). Terry, Patrick's father, who stayed with his son whilst in hospital and had lost his job through his son being ill, explained the uncertainties of place and care:

"He got caught between adult, yeah. Because they are stuck between a rock and a hard place. There are maybe other kids his age, but they have to decide whether they are adult or child, one way or another, they shouldn't be passing them about "(Terry).

The treatment experience was unique for each participant with most feeling that the healthcare system was not designed to meet their particular requirements. They often felt isolated and alone as there was no one with the same diagnosis, same age, same experiences and that their journey was not linked to other AYA cancers apart from the CNS (although not always a TYA CNS, but, a Skin Cancer CNS), who offered some support.

6.1.4 | Time to live Live (capital L)

Most participants adopted a range of emotional coping strategies early in the journey and had accepted the need to live with their cancer diagnosis. This positive thinking allowed them to redefine their goals and focus on the meaningful aspects of their lives. For the family, this was described as 'we'll all just beat it again' (Terry) alongside the uncertain futures and having to live with MM through recurrent times. Common to many AYAs experiences was the sense that they have moved through the disease and were mainly positive and optimistic about the future. George explained:

"We've all worked really hard together, to pull each other up. And it's been really supportive, it actually brought us closer, the whole experience, we've all said that as a family it brought us closer than we could ever be"(George).

Yet, for many YP, the MM experience had left physical and emotional scars that were a constant reminder of their experience. For example, Richard explained:

“Some days it’s like he’s been in a bar fight with Chuck Norris. If he takes his beanie off, then you’ll see it, he says it doesn’t bother him, but he has that hat on all the time” (Richard).

Nevertheless, supportive relationships were critical to the MM journey, and all described this as a shared experience. As most of the AYA lived at home with their family/significant other, it was their parents/loved one who became their primary carer, supporter, adviser, advocate and friend along this journey. In addition to the immediate family member, others were also affected, for example, siblings. Eve, John’s mother, similar to other parents, had assumed a new role as a result:

“I am the ‘mole mapper’ of the whole family. I’ve become more anxious because of it. I’ve changed, I know I’ve changed” (Eve).

Although on a new path, with new meanings for most, there was still the worry and fear that the MM could return at any point in their life, but for now they would get through this together.

7 | DISCUSSION

Life Interrupted echoes previous studies involving AYA living with other cancers (Davies et al., 2015, 2018, 2019; Grinyer, 2007; Soanes & Gibson, 2018; Woodgate, 2006; Zebrack et al., 2014). However, our study’s multi-perspective focus on the specific experiences of AYA and their families living with MM raised three important considerations: public awareness and education, being an AYA and age-appropriate care and future research.

Firstly, MM is not a disease that is often associated with children and AYAs, and generally is un-noticeable by the general population and indeed often to themselves (Bird et al., 2015; Ferrari et al., 2021; McNally, 2018; McNally et al., 2014). There are several factors known to contribute to this disease, such as lack of awareness around the dangers of UV exposure especially in childhood, light skin colour, blonde or red hair, number of moles and family history (Bader et al., 1985; Basta et al., 2011; McNally et al., 2014). Most of the AYAs, from what they could recall, had not participated in any form of unprotected UV light exposure. The families also reported that they had always tried to protect their child’s skin from overexposure to the sun. Most of the AYAs in this study were bewildered and surprised with their changing mole, and although had sought medical advice straight away delay in diagnosis was evident and not always fully recognized or accepted by the GP. It is still relatively rare for an individual GP to experience a young person with cancer such as MM (Miedema et al., 2006; Scottish Government, 2019); however,

continuing symptoms meant that despite these initial reassurances, they found themselves going ‘back and forth’ to consult with their GP multiple times. Their worries and concerns were only taken seriously once the mole had been eventually biopsied or excised. Several studies have shown the importance of education around the signs and symptoms of cancer and emphasize the importance of seeking appropriate medical guidance and support without delay (Albritton & Bleyer, 2003; Kyle et al., 2014; Smith et al., 2016). This study reinforces the need for greater public awareness, knowledge and understanding about skin cancer, especially for AYAs. Education must continue in schools, colleges and the media to increase awareness of skin cancer and prevention (Hubbard et al., 2020; Lea et al., 2018; Teenage Cancer Trust (TCT), 2020). Given the findings of our study, any changes to the delivery of education must not dilute the importance of sharing the experiences of young people (Lea et al., 2018). Indeed, including learning from this study in future educational resources may overcome some of the bewilderment and confusion experienced by future AYAs on the discovery of a mole and provide assurance that they can seek physical, emotional and social support and prompt medical attention at the appropriate time.

Secondly, all participants in the study would have valued contact with other patients with the same disease, care that was similar to other AYAs who are experiencing cancer (Cable & Kelly, 2019). The young participants were undergoing many forms of developmental transitions such as developing from a child to a teenager or teenager to young adult and being conscious of their sense of identity and increasing independence, autonomy and responsibility. Identity has not been researched from a clinical perspective; however, in an ever changing and often traumatogenic world, it becomes key in recovery. Bury (1982) and Soanes and Gibson (2018) highlight that being diagnosed with a chronic illness, such as cancer, often leads to loss of self and identity as AYAs struggle to keep their independence and hopes for their futures alive. Although most of the AYAs did not regard MM as ‘chronic’ or indeed that they were unwell, they did experience altered life plans but managed to continue with their lives. All of the young people participating in this study were adamant that they did not want their lives to be defined by the MM as it was generally seen as a ‘mere bump in the road’ (Paul). Managing psychosocial and developmental issues should be part of the formal curriculum in nursing and all professional training for those who encounter young people with a cancer diagnosis such as MM.

As patients with melanoma are diagnosed through a different route and do not always have access to the specialist cancer services for AYA, such as the TCT units, they experience a different journey (Cancer Research United Kingdom, 2020; Lea et al., 2018). This may have contributed to their overall perception of having no specialist support, apart from the CNS. Although most of the participants would have welcomed support from others who were ‘in the same boat’ (Kelly et al., 2004 p847), support did come from various other places including family and close friends. The MM lived experience involved the whole family and the relationships provided a positive impact on living with the disease.

Thirdly, research into AYAs with cancer has focused on the more common forms of cancers, such as leukaemia, hodgkin's lymphoma and bone cancer with MM being understudied (Davies et al., 2018, 2019; Fern et al., 2013; Lavender et al., 2019; Pearce et al., 2020; Taylor et al., 2013; Zebrack et al., 2014). Research by Lavender et al. (2019), through a narrative inquiry with health professionals, explored one specific cancer and how AYAs were prepared for inclusion in clinical trials. Once again, this study highlighted the importance of well-educated and well-trained healthcare professionals caring for the AYA cancer population, irrespective of the cancer they may have.

Our study highlights that the MM journey was a shared experience and one that they ventured on together. The ebb and flow of familial relationships can, in some situations, magnify the impact of the physical disease, with the emotional turmoil often rivalling the physical manifestation of the disease. Conversely, relationships did help the AYAs and the family cope with the disease in a more positive and supportive way.

Obtaining an early diagnosis is crucial to identifying the stage of this disease and enabling swift treatment to help prevent metastases (Ali et al., 2013; National Institute for Health and Care Excellence [NICE], 2005). Melanoma can be difficult for GPs to diagnose, but patients should be referred to appropriate specialist services if the lesions are suspicious (Marsden et al., 2010; Melanoma United Kingdom, 2020; Scottish Government, 2019; TCT, 2020). Early detection and diagnosis, clearly defined referral pathways and equitable access to specialist services, minimize unnecessary delays and enable treatment to start as promptly as possible (Murray & Edgar, 2012).

Following diagnosis, AYAs in our study experienced further challenges in accessing specialist services. As AYAs with this disease begin their journey outside specialist cancer services, the care delivery for this patient group and their family, require close and clear links to be established between services. For example, stronger connections between treatment centres, health and social care professionals and skin cancer services would have provided AYAs and their families with assurances around the suitability of the place of care and access to supportive nursing services. Being able to cope with cancer is challenging, and mechanisms need to be in place to support AYAs and their families psychologically including, for example, support groups and online spaces that recognize the different and isolating experience of MM for AYA and the family.

8 | LIMITATIONS

Our study has two main limitations. Firstly, the findings of this study have been drawn from ten ($n = 10$) participants who live in Scotland. This offers a unique perspective from a Scottish context and as such the findings are not intended to be generalizable beyond this setting although will have relevance to the care for AYA and their family living with MM. Secondly, although the sample size of ten ($n = 10$) was appropriate for an IPA approach, only one young female and one significant other (male partner) participated in the study. With

the reported incidence of MM in young women greater than among young men, future research should focus on young women's experiences and that of a significant other.

9 | CONCLUSIONS

The lives of AYAs matter; their experiences matter; their futures matter and their families matter. The aim of this study was to explore the experiences of AYAs and their family living with MM and to develop an understanding of the lived experience. The interpretive approach allowed the participants to reflect on their lived experience and construct narratives around that experience. With the incidence of MM increasing in the AYA population globally, there is a pressing demand to improve healthcare services and in particular nurse's knowledge and understanding of MM. As young people with this disease may experience their journey outside specialist cancer services, the care delivery for this patient group require stronger links between services, working better together than apart. This study has addressed the gap in the existing literature around the experience of AYA living with MM utilizing IPA methodology. In addition, this study included the critical role played by the family in supporting the AYAs in their MM journey and the interconnection and interrelationships that exist as they shared the experience of living with MM, and this is illuminated through the metanarrative of Life Interrupted. As a direct progression from this study, further research would expand the understanding of this specific participant group living with MM.

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AUTHOR CONTRIBUTION

WMcl, RGK, CGB, ZC: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; WMcl, RGK, CGB, ZC: Involved in drafting the manuscript or revising it critically for important intellectual content; WMcl, RGK, CGB, ZC: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; WMcl, RGK, CGB, ZC: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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