

Transcript

The research study and its findings

Wendy McInally:

Hello, we're here today to talk about the young lives interrupted by melanoma, exploring the experiences within relational context. So, hello and welcome to these two short podcasts. The second research podcast will be on my own findings about the young lives of teenagers and young people, who have had a diagnosis of skin cancer, which is melanoma.

So, my name is Dr Wendy McInally. And I'm the associate head of research, scholarship, and knowledge exchange here at The Open University. Combining knowledge, skills, insight, and experience and expertise developed over 30 years in clinical and educational delivery environments across the UK and internationally, I have built a comprehensive research and education portfolio around children and young people with cancer. I am a widely recognised cancer nurse specialist and have played a leading role in developing many best practice initiatives.

In November 2022, I was awarded one of the teenage and young adult cancer research grants of which I am immensely proud. The team consisted of Professor Susanne Cruickshank, Emma Hainsworth, who was our research assistant, who is also a nurse, and Jack Brodie, a young man who was our consultant. But more importantly, Jack was a young man who at the age of 16 developed melanoma.

So now, we'll go to Susanne for the very first of our podcasts, which is challenges in ethical approval for vulnerable groups and multicentre. So just to set the scene, melanoma in young people. So, during the 1970s, melanoma in teenagers and young adults in the United Kingdom was rare. But over the intervening decades, there has been a marked increase in the reported incidence of melanoma in young people around the globe.

Amongst the young age 15 to 24 years at diagnosis, other than renal hepatic and Gynaecological, malignant melanoma accounted for at least 30% of registrations from 1997 to 2016. These figures reveal that this is the third most common cancer in the age group that I am interested in, which is TYA, teenagers and young adults within the UK. Incidence is also increasing globally with approximately 1,000, 3,000, 2,000 cases reported annually in the adult population.

So, despite improvements in survival rates, prognosis is known to be poor if the diagnosis is delayed. So, treatment for this disease is predominantly based on the adult paradigm. And this is something that this study was particularly also interested in.

There is also a higher percentage of this disease within the female TYA population compared to male and TYA children, which we call paediatric or even adult melanoma population. The cause is uncertain. But there is evidence to say that the UVC light can cause skin cancer.

But there's also research to show that endogenous estrogen exposure or behavioural, such as the UVC light can contribute to this disease. As mentioned previously, there are different models of care throughout the globe. But here in the UK, we have children, young people's services. We also have teenagers and young adults. And we also have adult services.

And we know that teenagers and young adults are a hard-to-reach group, as they're getting on with their lives. There's a depth of evidence and surveillance and treatment around the physical, emotional, and the social. So, we need more evidence around that.

And this was the main reason for undertaking this study and to explore melanoma within a different demographic group, as opposed to my old PhD journey in 2020 that was specifically around teenagers and young people living with this disease but in Scotland where I live. So, this study aimed to explore the experience of young people 16 to 24 years at time of diagnosis. And that's important to hear, at time of diagnosis, living with and beyond melanoma within whatever context that was, whether they were living with a significant other, their partner, friends or maybe alone.

So, our main objectives were to describe the context in which young people and their significant other are treated for malignant melanoma, to explore their experiences, not just about during but after the treatment, and to identify the enablers and barriers at each of the critical point of their cancer journey. So, we actually looked at it across the cancer trajectory from the minute they suspected this abnormal mole or lesion on their skin right till after their treatment for this disease. And it was also part of our objectives to work in partnership with participants to translate the findings into interventions, specifically for young people and their significant other.

And this is an important part of all research that we do. What is the impact from our research, especially for and practice? So, the methodology. Well, as you said, it was a quality piece of research and aiming to explore the experiences.

And we knew this would be a small sample because we also wanted to use something called interpretative phenomenological analysis, which in short is called IPA. Now, IPA looks to explore in depth the experiences of people that are living with x, y, or z. In this case, it was melanoma.

So, IPA is a branch of phenomenology seeking to capture the experience of participants and to understand and identify key themes through an interpretive phenomenological analysis process. It is concerned with capturing people's accounts and reflections to explore the meanings attached to and the sense that is made of them. IPA was initially developed in the discipline of health psychology but has more recently been utilised in the wider health and social sciences discipline, such as nursing.

And due to the very nature of the study, the research design utilised, eliminates, illuminates, and steers this research to gain an understanding of young people's experiences through their cancer journey and that of their significant other. The qualitative data addressed objectives one to four through singles, semi-structured interviews. But for objective four, which was to work in partnership.

And to make sense of the interpretations and the narratives that we found, we did hold a stakeholder event and to make sure that we addressed objective four. The interviews with the young people as Sue said and their significant other were offered individually and either through face-to-face or through teams. And all of them chose to have the interview through teams. This seemed to be the most convenient way of collecting the data for them but also for us to gather their stories. So, we had 10 young people. And we had five significant others. And in the end, we only recruited from one primary treatment centre in England. And this was the main site that we used.

We found it was a challenge to find these young people across the different sites. And that is something that needs to be explored further when we go on to do more research in this area. With the respondents' consent, interview data was transcribed, anonymised, and then analysed using an interpretive inductive approach.

Emerging subthemes were selectively coded and refined into a smaller number of themes, which I'll tell you about in a little minute. And we followed the seven-step approach by Smith et Al, Jonathan Smith 2022. Each sentence and section of the transcript was subsequently examined to expose meaning and to identify the experiences of each participant.

Regular meetings was part of the process. And this was held with the research team, which was Sue, Jack, Emma, and myself to discuss the data that was been collected analysed and reviewed. This ensured that the interpretive processes involved was insightful, collaborative, and corroborated. During my PhD journey, I stumbled across the following song by Sir Paul Weller. The sole true meanings aspects is fitting for IPA and how we try to make sense of our life and our world. Please follow the link below, which will take you directly to the song.

I would suggest that you listen to this because it will help you to follow how I and the team made sense of the data that was collected and the things that emerged. We are now going to talk about the findings. We had four superordinate themes which were identified and 12 subthemes.

So the first theme was, is something wrong? This theme captures the feeling that something wasn't right. I'm not really sure. It's very sore. It's in my mouth. And I don't know what it can be.

Back and forward, got a gut feeling something's not right. And I'm back and forth, back and forth, not just to one health care professional who is often my GP but could be someone else, like physiotherapist or dentist. So that was the first theme.

And the underlying subthemes were having a gut feeling that something wasn't right, not really being heard. Goodness me, is anyone ever going to listen to me? And knowing I might be at risk.

If someone's not looking at this, what's going to happen? So, getting really concerned. The second theme is, well, suddenly, it's serious. Receiving the news that this is melanoma, but not really taking it in. What do they mean, melanoma? I've never heard this word before.

Then realizing its cancer. Being in complete shock around what the treatment means and to their lives. Many seeking new knowledge to try and find out more about the actual disease. And then going back to the healthcare professional to find out more about what this disease actually means.

So, the subthemes here were around the giving of bad news, how it was actually communicated to not just the young person but to the significant other. Often, the young person was there on their own when the news was given. And seeing a diagnosis of, well, you've got melanoma, one young person thought, oh, that's easy, it's just melanoma. I don't really know the seriousness of it.

Until his friend said to him at school, you know that's cancer. So, we have to think about that subtheme, the giving of bad news and then the reality setting in. That was the second thing. Oh, my goodness, what happens now? And then try to seek new knowledge on how to move forward.

The third scene is around feeling. I've named this theme, out on a limb. So, for those few people who required wider surgery or immunotherapy, they were overwhelmed and tired and preventing them from going on with their study or working. And they felt so isolated and felt so different from their peers.

Some were also cared for within an idle environment. Was only 3 of the 10 younger people actually having access to a teenage cancer trust unit. So that's the TYA services that I was referring to earlier on in the podcast.

And they were also very concerned on the journey ahead in the future. So, the subthemes here were treatment was all consuming. Just feeling out of place didn't really fit in because they were in an environment where there was a lot of old people that were out. And here, they were only 20, 21, 22. They were all-- some people were left in an environment where they had already been and had experience of because they had lost a loved one to cancer through visiting the hospital. Then there was the second subtheme about feeling out of place. And then the third one about what? None.

So, the final theme was finding our place. So, for these young people and the significant other, this was the final theme which encapsulates being lost and alone at times and the fear for their futures. One young person and their partner described it as leaving the army and not knowing where to turn to next once the treatment had finished.

Trying to find their place back in society and with their family, friends, job, social life, et cetera was a challenge. So, the subthemes for this was people don't get it. Who really understands? And last but not least, the fear of recurrence.

So just to end here, the lives of teenagers and young people's matter. Their experience matters. Their futures matter. And their significant others matter. The aim of the study was to explore the experiences of TYA and their significant other living with melanoma and to develop an understanding of the lived experience.

And I think we did capture that from one group who were being cared for within one specialist area in London. The interpretive approach allowed the participants to reflect on the lived experience and co-construct narratives around that of their experience. And with the incidence of melanoma increasing in the TYA population, not just within the UK but globally, there is a pressing demand to improve healthcare services and in particular, nurse's knowledge and understanding of this disease.

As young people with this disease may experience the journey outside specialist cancer services. The care delivery for this patient group requires stronger links between services working better together than apart. And further research is required to answer whether young people diagnosed with skin cancer are supported across the cancer trajectory, specifically in our United Kingdom.

So, thank you for listening. We are hoping to publish our work in the future and disseminate our findings. And we can keep in touch to let you know. And we hope that this has given you an understanding of interpretative phenomenological analysis, but also about young people and their families or significant other living with melanoma. Thank you.

Speaker:

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