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Research Article

The Psychological Impacts and Coping Strategies of People Under 60 Living With Mesothelioma Cancer: A Qualitative Study

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Introduction: Mesothelioma is a life-limiting cancer that results in an array of psychological difficulties. While this cancer is associated with older men exposed to asbestos, it can develop in people under 60, though little research has considered the challenges and ways of supporting this younger demographic.
Methods: Online semistructured interviews were carried out one-to-one with a total of 18 individuals; 6 men and 12 women, aged 26–59 (mean age 45), diagnosed with pleural or peritoneal mesothelioma. Participants could also share and discuss photographs to help further convey their cancer experiences. An interpretative phenomenological approach guided the analysis of transcript and photographic data.
Results: Two themes with discrete subthemes are presented: "dying young of an older person's disease," which explores individuals' experiences of shock at diagnosis and widespread sense of disrupted living, concern for family members, and lack of peer support, and "living young with an older person's disease," which explores psychobehavioral coping via focus on the atypicality of mesothelioma in young groups, return to everyday living, and via activities and exercise to manage anxiety and foster a sense of agency.
Conclusion: Findings demonstrate the need to develop tailored clinical and psychotherapeutic support to address the practical and psychological difficulties younger people encounter.

Keywords: age; cancer; coping; mesothelioma; psycho-oncology; qualitative methods

1. Introduction

Mesothelioma is a rare life-limiting cancer that typically occurs in the mesothelial cells lining, either the lungs or the abdomen. There are around 2700 new mesothelioma cases identified across the United Kingdom each year [1], and 30,870 new cases were reported worldwide in 2022 [2]. Pleural mesothelioma of the lung is the most common form and accounts for around 90% of all cases; peritoneal mesothelioma of the abdomen is the second most common form at around 10% of all cases [3, 4].

Pleural mesothelioma generally affects men aged 75 or older as a result of prior job-related exposure to asbestos, typically several decades before the onset of disease. In contrast, peritoneal mesothelioma affects men and women more equally [5–7], and the median age of individuals at diagnosis is between 50 years [8] and 70 years old [9]. Despite current clinical efforts, pleural and peritoneal mesothelioma remain difficult to treat using conventional methods such as chemotherapy, radiotherapy, and surgery; as a result, the prognosis for both is still poor with 3-year overall survival at 10% for pleural patients and 18% for

peritoneal patients [9], though more recent data indicate a slightly better 5-year overall survival of 20.3% for peritoneal patients [10].

Individuals with mesothelioma thus shoulder the psychological burden of living with a terminal illness. This is made worse by a high symptom burden, which includes the following: fatigue, pain, difficulty breathing, cough, disrupted sleep, and loss of appetite, as well as increased memory problems and trouble concentrating, which greatly impairs daily functioning and lowers quality of life [11–14]. Additional psychosocial concerns have also been reported, which include significantly elevated symptoms of depression, trauma, social dysfunction, and isolation [15–17]. Moreover, a recent systematic review studying the mental health effects of mesothelioma concluded that individuals experience an array of negative emotional and cognitive issues, such as shock, frustration, and fear at the point of diagnosis, and symptoms of traumatic stress relating to intrusive memory flashbacks, nightmares, and irritability [18].

There is therefore an evident need to provide effective support to individuals living with mesothelioma, with research also needed to inform the development of clinical and psychotherapeutic care. That said, mesothelioma is often viewed as a condition that only affects older men because of the pleural variants' link to the past widespread industrial use of asbestos. More recent analyses, however, indicate that 4% of patients in Italy are aged under 50 [19], and 2% of patients in the United States are under 40 [20]. This relatively young patient demographic is distinguished in part by the possible cause of disease with evidence to suggest that mesothelioma in younger people is more likely the result of paraoccupational and environmental asbestos exposure [19, 21] and genetic factors [22–25]. Younger individuals also tend to have better overall survival rates than their older patient counterparts [20, 25–28].

Though rare, mesothelioma can develop in people who are significantly younger than the clinical norm, who may also deviate from the normative disease etiology and prognosis. In addition, younger people may experience a host of other psychosocial issues and coping strategies for living with mesothelioma; for instance, individuals may have novel concerns that relate to their employment, finances and family. Research to date, however, has primarily focused on older people with mesothelioma aged 60–80 years [29], and while this is in keeping with the broader patient demographic, it also risks the concerns and needs of younger individuals going unheard and unaddressed. This study therefore aimed to explore the particular psychological impact and coping strategies of individuals between the ages of 18 and 60 who have been diagnosed with mesothelioma.

2. Methods

2.1. Design. The research design was informed by the principles of "Interpretative Phenomenological Analysis" (IPA), which aims to study how people reflect on and make sense of their lived experiences [30]. IPA is conceptually rooted in the epistemological knowledge of human experience and advocates for a qualitative approach to support the in-depth collection and analysis of individuals' subjective accounts in order to develop a detailed understanding of the ways they experience a particular phenomenon.

2.2. Participant Inclusion Criteria and Recruitment. IPA studies aim to recruit relatively small samples of experiential experts with relevant lived experience and the ability to convey their perspective [30]. Purposive sampling was thus used to recruit individuals in line with the following inclusion criteria:

1. Participants needed to have received a diagnosis of mesothelioma.
2. Participants needed to be aged between 18 and 60 years old.
3. Participants needed to be able to speak and read English.

Conversely, individuals who did not have a mesothelioma diagnosis, or were not aged between 18 and 60, or were unable to speak and read English were ineligible to take part.

The first author approached a number of mesothelioma charities, research centers, and support groups by email to request their help in recruiting participants. Organizations that agreed to support recruitment were given a digital study flyer that they shared via social media on "X" (formerly "Twitter") or "Facebook." The charity, "Mesothelioma UK" also agreed to circulate the study flyer via their social media accounts, and in clinics via their nurse specialist teams who work directly with patients who have mesothelioma. The flyer briefly summarized the study and inclusion criteria except for language, as was presumed since the flyer was written in English. The flyer directed individuals who wished to participate to contact the first author, who gave them a participant information sheet, photography guide, and consent form. Individuals were provided the opportunity to ask questions prior to them giving consent to take part.

2.3. Data Collection. Semistructured interviews were used to afford a research space for the researcher and participant to discuss issues at length and co-produce a detailed experiential account of the subject [31]. Participants were also provided the option to take and share photographs as part of the data collection and interview process, in order to help them reflect on and convey their own thoughts and emotions. Using this visual medium to complement verbal data can be evocative and beneficial to the researchers, as they become more immersed within each individual's own lifeworld [32].

Individuals agreeing to take and share photographs as part of the data collection and interview process could refer to the photography guide. This encouraged individuals to share images, which they felt best conveyed their own unique experiences of mesothelioma, with minimal researcher input and framing. Individuals were, however, asked to avoid taking identifying photographs of themselves or third parties. Individuals were asked to email their photographs to the lead researcher prior to the interview so that they could

be securely stored and presented for discussion in the interview.

Eighteen one-to-one interviews were carried out online using "Microsoft Teams" during 2021 and 2022. The first author conducted interviews from his residence to reduce the risk of disruption and produced notes to record nonverbal gestures as well as verbal statements to ask for additional clarification. Participants were likewise at home and unaccompanied for the duration of their respective interviews, with the exception of one participant (Mia), whose young child was also present throughout. Individuals were invited to introduce themselves and were then presented with an open-ended orienting question: "Generally speaking, what is living with mesothelioma like for you?." This gave them the opportunity to convey the more salient aspects of their illness experience that could be explored later in the interview. Subsequent questions proceeded to explore specific psychosocial elements of living with mesothelioma. The interview schedule was utilized as a flexible guide and was supplemented by unscripted follow-up questions to help clarify and expand the individuals' telling of their own stories [33]. Where photographic data had been provided, images were displayed on-screen using the share screen function, and individuals were invited to discuss and refer to these in the interview; including why they chose to take and share particular photographs, their intended meaning, and why it was important for them to visually represent this.

Interviews lasted between 50 min and 2 h 50 min (mean length was 1 h 49 min). The wide range and lengths of interviews reflected a participant-led approach to the interview process and a desire to provide individuals the space to convey their experiences in their own time. Consequently, interview lengths varied according to the brevity or breadth individuals chose in sharing their accounts. That said, steps were taken to respect participant's time, such as allowing them to take comfort breaks, and/or to pause and continue the interview at a later date; however, all interviews were completed in one session.

2.4. Ethics. This study was reviewed and approved by the De Montfort University Faculty of Health and Life Sciences Research Ethics Committee (Reference: 412039).

2.5. Materials. A study flyer, participant information sheet, consent form, photography guide, interview schedule, and debriefing form were used in this study. Questions from the interview schedule are listed in Table 1.

2.6. Data Analysis. The interview recordings were transcribed verbatim, with all respective photographs embedded within each transcript at the point of discussion. Text and photographic data were anonymized via the removal of identifying information; this included the substitution of participants' names with fictional pseudonyms. Data analysis was informed by the six steps of IPA described by Smith et al. [30].

Step 1: Each transcript was read multiple times to help the researcher to immerse themselves within an individual's experiential account and further consider the salient and interesting aspects within it. Step 2: Notes were made line-by-line to help summarize descriptive, linguistic, and conceptual issues relating to the study. Step 3: Notes and data were compared across the transcript in order to assess recurring similar and dissimilar concepts and identify "personal experiential themes," that distil the core idiographic aspects of an individual's account. Step 4: The personal experiential themes were further abstracted to identify possible broader conceptual and interpretive links within an individual's account. Step 5: The prior four steps were applied separately to each transcript to help maintain an idiographic case-by-case understanding of each individual's lived experiences. Step 6: "Group experiential themes" were developed via the cross-case analysis of transcripts to help identify individuals' shared and unique experiences of living with mesothelioma. Verbal and visual data were analytically paired throughout with related text and photographic data analyzed and tabulated together, so as to privilege the participant's sense-making and "voice" when thinking about and discussing their photographs and intended meaning. The analysis of photographs thus centered on the participant's thoughts and reflections on how an image depicted elements of their lived experience.

This analysis sought to balance the interpretation of similar and dissimilar experiences between cases. "Member-checking" was also used to provide individuals the opportunity to comment on whether they felt that personal experiential themes reflected their views and experiences [34]. This was performed separately, with each participant being able to provide feedback on the analysis of their own interview, as an individual case study, to help maintain an idiographic approach to analytical validation and rigor [30]. Six individuals did not provide feedback. All other individuals did provide feedback to say that the themes generally reflected their perspectives shared at the interview.

Several themes were identified in the analysis that do not relate to the experience of people under 60 as such, but rather reflect the particular psychological impacts of living with peritoneal mesothelioma. These peritoneal mesothelioma themes are reported in full in our sibling publication [35].

3. Results

3.1. Participants. Eighteen individuals took part in the study, 6 men and 12 women, aged between 26 and 59 years old, with a mean age of 45 at the time of study. Eight people had been diagnosed with pleural mesothelioma and 10 with peritoneal mesothelioma. Individuals were between 1 month and 9 years since their initial diagnosis, and all participants were White-British, heterosexual, and married. Eleven people were posttreatment and "cancer-free" at the time of interview; five people were still in-treatment; and two were pretreatment, either awaiting surgery or undergoing medical surveillance (Table 2).

Table 1: Interview schedule questions.

Q1. Can you tell me a little bit about yourself?
Q2. Generally speaking, what is living with mesothelioma like for you?
Q3. When did you first become concerned about your health, and how did you pursue a diagnosis?
Q4. What was your response to being diagnosed with mesothelioma?
Q5. How would you describe the support you receive as someone living with mesothelioma?
Q6. How have other people around you responded to you having mesothelioma?
Q7. How might the support you receive be improved?
Q8. Thinking more generally, how has your life changed since being diagnosed with mesothelioma?
Q9. What are the unique challenges that you face as a younger person living with mesothelioma?
Q10. How do you manage these challenges in living with mesothelioma?
Q11. What emotional challenges do you face in living with mesothelioma?
Q12. What do you do to help improve your well-being in living with mesothelioma?
Q13. As someone living with mesothelioma, how have you experienced the coronavirus pandemic?
Q14. Moving forward, how do you see the future?
Q15. What advice would you give to a younger person recently diagnosed with mesothelioma?
Q16. Is there anything else related to mesothelioma you feel we should discuss?

3.2. Analytical Findings. Two themes each with four subthemes are presented as follows: (1) "Dying Young of an Older Person's Disease" and (2) "Living Young with an Older Person's Disease." The theme labels are intended to reflect the words and views expressed by participants who often described mesothelioma as an "older person's disease," and presented their own experiences in reference to this idea. Both themes and subthemes are further conceptualized to provide a summary of the salient concerns and coping strategies reported by people under 60 living with mesothelioma, and this is illustrated via an interpretative map (Figure 1).

3.2.1. Theme 1: Dying Young of an Older Person's Disease. This theme explores individuals' feelings of shock upon first learning of their mesothelioma diagnosis and distress at the thought of dying prematurely. It also explores younger peoples' concerns for family, and the difficulty to engage with conventional peer support. Four subthemes are presented as follows:

- Subtheme 1.1: The shock of diagnosis.
- Subtheme 1.2: Disrupted living.
- Subtheme 1.3: Shared impact on younger families.
- Subtheme 1.4: Limited peer support for younger people.

3.2.1.1. Subtheme 1.1: The Shock of Diagnosis. Individuals reported a long and often complex diagnostic journey that started for many with seemingly benign symptoms, relating to abdominal, back, or shoulder pain; bloating; or disrupted menstruation. As a result, some did not seek medical support until their symptoms worsened. Other people, however, had no symptoms, and instead their tumors were inadvertently detected by routine scans and tests. Regardless, during subsequent investigations, individuals recalled little discussion about mesothelioma, and clinicians voiced skepticism if it was ever discussed.

> *I always remember the professor saying, "I'm 95% certain; you've never worked with asbestos, you're not the right age. I'm 95% certain it's not meso that would be your worst-case scenario."* (Liam)

> *(Oncologist) said, "it looks like, if you'd have been a lot older, it looks like mesothelioma" she said. And then she said, "You haven't been in contact with asbestos when you were younger, have you? You haven't worked in asbestos?" She didn't even wanna listen to my reply. She said, "No, you haven't got that kind of thing."* (Natalie)

Liam and Natalie's extracts echo the accounts of others when discussing the prospect of mesothelioma, as clinicians voiced doubt on the basis of diagnostic markers that include age and working background. Natalie's comment that the oncologist "*didn't even wanna listen*" suggests a terse and even dismissive consideration of mesothelioma. Symptoms were commonly attributed to other cancers or conditions, for example, gallstones or appendicitis. Accordingly, when the mesothelioma diagnosis was confirmed, individuals recalled vivid feelings of shock and dismay.

> *It is just a massive shock. I must have been 34, I mean, Jesus Christ! I'm only 34, where did that come from? You know I'm thinking again like, the questions of asbestos, where did that come from?* (Owen)

> *I had heard of mesothelioma because my grandfather died of it many years ago. (. . .) being told (diagnosed) was like, that's a disease for old men. How can I have a disease that an old man gets? You know, it just seemed. . . it seemed quite cruel.* (Abigail)

Being diagnosed with mesothelioma was both profoundly shocking and upsetting for every individual, and this was likely intensified by clinicians saying it will not be mesothelioma. Owen's exclamation of, "Jesus Christ!," and Abigail's questioning, "*How can I have a disease that an old man gets?*" both underline this depth of feeling and surprise to be diagnosed with a condition often associated with older people. Moreover, Abigail saying, "*it seemed quite cruel,*" further conveys a sense of unfairness in her diagnosis, feeling it was wrong she had mesothelioma given her age and sex.

Table 2: Participant demographic and participation information.

Participant pseudonym and sex	Age	Diagnosis	Time since diagnosis	Treatment status	Relationship and parental status	Interview length	Provided photographs	Provided analysis feedback
Owen (male)	43	Pleural mesothelioma	9 Years 2 Months	Posttreatment	Married 1 Child	02 h 06 min.	Yes	Yes
Emily (female)	39	Pleural mesothelioma	4 Months	In-treatment	Married 2 Children	01 h 51 min.	Yes	Yes
Hannah (female)	34	Peritoneal mesothelioma	2 Years 6 Months	Posttreatment	Married 0 Children	01 h 58 min.	Yes	No
Evelyn (female)	51	Peritoneal mesothelioma	2 Years 4 Months	Posttreatment	Married 2 Children	01 h 21 min.	Yes	Yes
Danielle (female)	49	Pleural mesothelioma	6 Months	Pretreatment	Married 2 Children	01 h 10 min.	Yes	Yes
Sofia (female)	32	Peritoneal mesothelioma	1 Year 5 Months	Posttreatment	Married 0 Children	02 h 35 min.	Yes	Yes
Faye (female)	55	Peritoneal mesothelioma	4 Years 6 Months	Posttreatment	Married 2 Children	01 h 08 min.	No	No
Liam (male)	46	Pleural mesothelioma	6 Years 6 Months	Posttreatment	Married 2 Children	01 h 35 min.	Yes	Yes
Gladys (female)	57	Peritoneal mesothelioma	1 Year 11 Months	Posttreatment	Married 2 Children	02 h 33 min.	Yes	Yes
Abigail (female)	57	Pleural mesothelioma	1 Year 10 Months	In-treatment	Married 1 Child	02 h 31 min.	Yes	Yes
Jeanne (female)	58	Pleural mesothelioma	10 Months	In-treatment	Married 1 Child	01 h 49 min.	No	No
Clara (female)	39	Peritoneal mesothelioma	1 Month	In-treatment	Married 0 Children	02 h 50 min.	Yes	Yes
Tom (male)	30	Peritoneal mesothelioma	3 Years 4 Months	Posttreatment	Married Expecting first child	01 h 54 min.	Yes	Yes
Mia (female)	26	Peritoneal mesothelioma	2 Months	Pretreatment	Married 3 Children	00 h 50 min.	No	Yes
Natalie (female)	46	Peritoneal mesothelioma	3 Months	In-treatment	Married 0 Children	01 h 46 min.	Yes	No
Brian (male)	59	Peritoneal mesothelioma	2 Years 5 Months	Posttreatment	Married 2 Children	01 h 17 min.	No	Yes
Joel (male)	56	Pleural mesothelioma	2 Years 9 Months	Posttreatment	Married 3 Children	02 h 22 min.	Yes	No
Alex (male)	35	Pleural mesothelioma	5 Years 7 Months	Posttreatment	Married 3 Children	00 h 57 min.	No	No

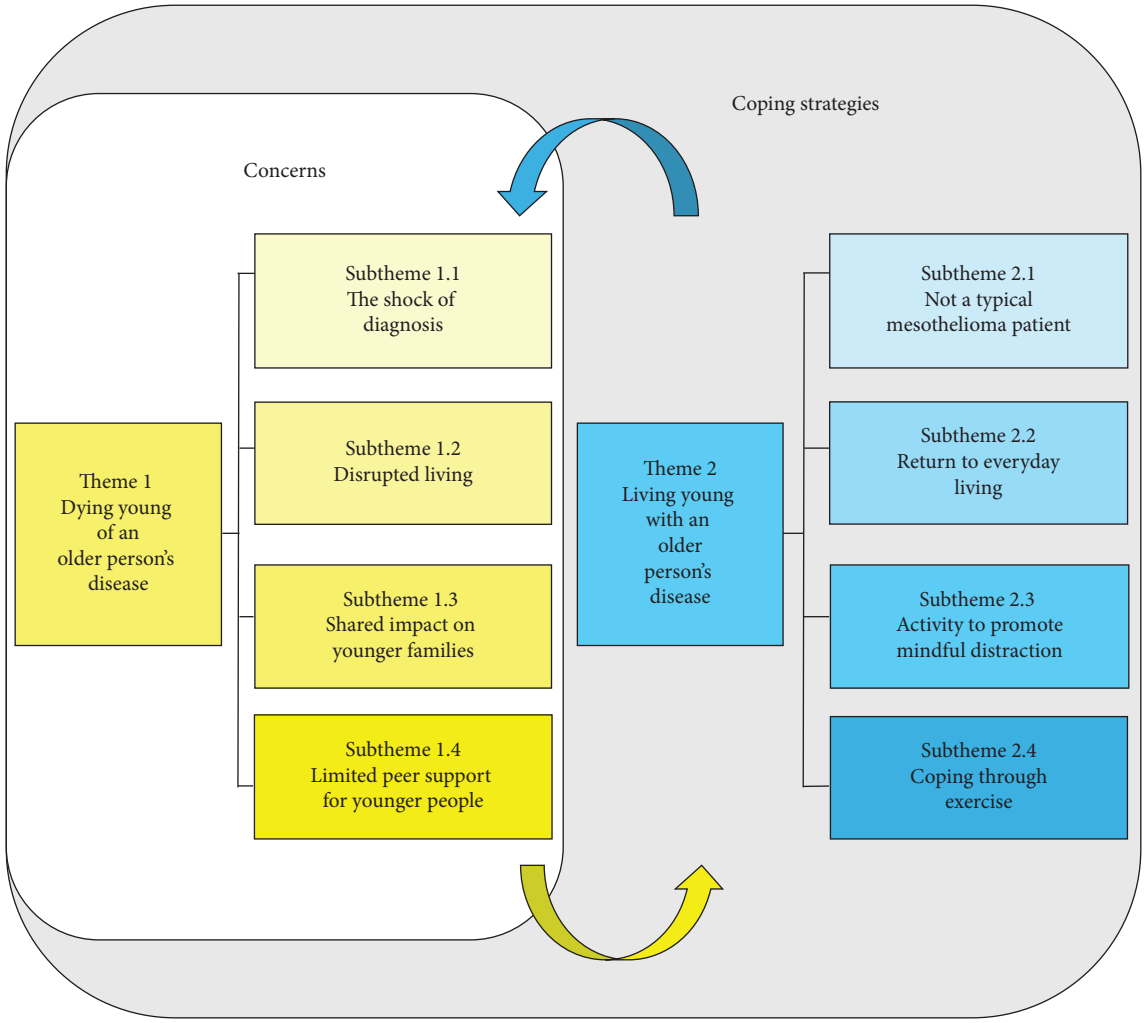

Figure 1: Interpretative map illustrating the concerns and coping strategies reported by people under 60 years old living with mesothelioma.

This sentiment was shared by others, and the notion of unfairness is explored more in the next subtheme.

3.2.1.2. Subtheme 1.2: Disrupted Living. After recalling the shock of diagnosis, individuals often described acute feelings of anxiety and distress. Moreover, individuals voiced a deep and widespread sense of disruption to their daily lives and futures, and this was perhaps most apparent when discussing their own mortality.

> *For a young person, it's being robbed of those experiences, whether it's good or bad. You know, it could be getting married, having children, or it could be a bad experience (. . .) And I think it's being robbed of those experiences is where a young person like me would struggle.* (Alex)

> *It's that adjustment of being a younger person's mind in what is now essentially an old person's body. (. . .) If you, if you look at the lifespan of a body, my body is, it's, no if or buts, it's very much very close to the end of its lifespan. And so, in a way, you're kind of trapped in that.* (Abigail)

> *I think that's the difference because the older generation is, you know, they've lived their life. You know, we're all going to die at some point in our eighties, so if I get meso in me eighties, well like, yeah, take me type of thing. You know, we're going to pass away of something.* (Liam)

Repeated thoughts of death and dying naturally elicited strong feelings of anxiety amongst individuals, and several people further lamented the thought of dying prematurely. Indeed, Alex, Abigail, and Liam describe themselves as being "*robbed*" or "*trapped*" by the disease, in contrast to older people who have "*lived their life.*" This exemplifies the deeply distressing fears of premature death some individuals had and the underlying sense of unfairness. In addition, some individuals reflected on the disruptive impact of mesothelioma on their careers and related finances.

> *I wanted to work until I was 57 which would give me 40 years' service. I felt that was my duty; my duty was 40 years' service. (. . .) I wanted to come out of there with that badge of honor of I've done my 40 years' service. And the fact I won't get to that really, really is upsetting.* (Emily)

I've worked continuously. I haven't taken time out. I've been back and done postgrad studies and so on, but I've always been a nine-to-fiver. And that was, again, suddenly switched off in December. So it left me, I suppose, mentally slightly destabilized. (Joel)

We were first time buyers that we just bought a house, you know we didn't have some financial stability (. . .) So, I felt it was a challenge to kind of keep up to like, pay the mortgage and keeping things afloat. (Tom)

Emily and Joel reflect on the loss of their careers and how this negatively impacted their mental health, due to the associated loss of who they were, their sense of "*duty*" and achievement in their professions, while Tom describes the negative impact on his finances and situation as a new first-time homeowner. These experiences were shared by others and further exemplify the disruptive, and even disorienting, effect mesothelioma had on the lives of younger individuals in disrupting their imagined futures, both existentially, in terms of their life expectancy and ontological security, and materially, in terms of their jobs, finances, and homeownership. Together, these extracts convey the sense of upheaval people felt in living with mesothelioma, which persisted for several months or years, as some individuals struggled to accept their diagnosis.

3.2.1.3. Subtheme 1.3: Shared Impact on Younger Families. When thinking about the deeply disruptive elements of living with mesothelioma, almost every person discussed the negative impact on their family members, which prompted additional feelings of distress. Some voiced concern for their still dependent and often very young children.

It is also bad for me because I think now, I've got them (children) to think of. So, it's quite hard because you can't just, I can't just go in and think about myself and just, focus on my recovery, because I'm constantly going to be like, right where's the kids? (Mia)

He (son) did struggle a bit because obviously, if I got ill, he thought I was going to pass away. He still says it now. He still says that every time he hears the phone ring at school, he thinks it's mummy telling me I've gone. You know we've had to reassure him; he has had therapy, and he's had counselling, but it plays on his mind. (Owen)

Unlike their older peers living with mesothelioma, several people in this study still had young children at the time of their diagnosis and through their treatment. This could present a further cause for worry, particularly for those such as Mia, who struggled to manage the combined burdens of illness and childcare, and Owen, who recalls the psychological impact on his son. Likewise, several individuals also expressed concern for their children's futures.

I think the unique difference is, you know, we're worried about our kids; we're worried about, how are they going to cope if daddy's not around? (Liam)

That trainline: it's what's down the track, it was going to be a sort of, I was trying to sum up whether to do a picture of the kids going with a rucksack on their back going back to Uni. And it's not knowing what's ahead really for me and them. (Evelyn)

In this way, feelings of uncertainty and apprehension for the future were discussed by multiple people, both in regard to their own futures and in respect to the future health and well-being of their families; Evelyn depicts this ambiguity in Figure 2 via the trainline stretching toward a more distant and unseen future. Indeed, many were keen to emphasize the shared impact of mesothelioma as something that affects themselves and their loved ones, including their children, partners, and in some instances, their parents. This could engender a sense of guilt and fear of becoming a burden to others.

My family would be really upset if they heard me saying this but it's true, I don't want to bother them because then they'll, you know, seeing them worry in some ways would maybe make me worry more. (Faye)

There was like certain things I couldn't say to him (partner) because I just didn't want him to be like upset. (Sofia)

I'm hoping that the boys just have a full understanding of what I have had done and they just see me as like a healthy person who's like functioning as normal and I'm not spoiling their lives. (Gladys)

Faye, Sofia, and Gladys voiced concern for their relatives and tried to lessen the impact on their families. Faye and Sofia talk about concealing issues from family members in order to protect them and avoid "*spoiling their lives*," as Gladys suggests. Others were similarly selective in choosing what they disclosed, especially to young children, as they sought to adopt a more stoic facade to shield their families either by not discussing or downplaying practical and/or emotional issues. However, this could risk individuals shouldering various concerns with little or no psychosocial support from their family members.

3.2.1.4. Subtheme 1.4: Limited Peer Support for Younger People. Further to the shock of diagnosis and the deeply disruptive impact on them and their family members' lives, individuals reflected on the healthcare and social care support they had received. While many praised their medical care, some individuals reported problems trying to engage with peer support.

The support groups available locally a lot of the people are older (. . .) I feel like to compare me to a 70-year-old lady who has been diagnosed, it is probably very different because I've still got young children, I've still got my mortgage, you know, so the financial implications will be different for me than they will be for somebody of that age. (Emily)

I actually go to, belonging to another support group, which is just for people who've had cancer in their 20s, 30s, and

Figure 2: By Evelyn.

40s, and they all report the same. That (. . .) the majority are in their 60s. You get someone in there who is in their 20s and, you know, they feel a bit isolated. (Hannah)

Like Emily and Hannah, some people felt that peer support groups for mesothelioma served the needs of older attendees better, which Emily contrasts to her having young children, a mortgage, and different financial concerns. Indeed, Emily and Hannah, both in their 30s, allude to feelings of isolation in living with mesothelioma as young people, who have distinct psychosocial, family-based, and financial needs that are unlikely to be shared and/or discussed by their older peers. Consequently, some people chose to avoid peer support.

Being a younger person, most of the people on these support groups are obviously a lot older. (. . .) Because a lot of them obviously, I think they got it through, actually people used to work with asbestos, didn't they? (. . .) I won't really go into these meetings and stuff like that, because obviously they are a lot older, and there are people who will just look at me. (Mia)

My most terrifying thought was going to sit in a room in a hospice in a chair with another 20 or 30 people in their 80s or 90s, gradually deteriorating (. . .) That's what I didn't want to do. And I suspect for me at the moment, I don't think it would necessarily be helpful for me. (Joel)

Like others, Mia voiced age as a barrier to her accessing peer support. Moreover, her belief that people "*will just look at me*" suggests she would feel otherized and generally out of place in a social group for mesothelioma patients. Joel also cited age as the reason for his avoiding peer support groups, though his reasoning is different: in perceiving peer group discussions among older people with mesothelioma as intrinsically more negative (even "*terrifying*") and something which he did not think would help him.

Combined, these extracts highlight younger individuals' difficulties to attend and engage in conventional forms of peer support due to age disparities. This may limit opportunities for meaningful and relatable conversation with others in a similar situation to them, both in terms of their living with mesothelioma and navigating the same kinds of psychosocial and financial issues. That said, some people did not seek peer support regardless of the age of other attendees, as they chose to prioritize time with their families as part of a broader effort to engender a sense of normality (Subtheme 2.2: return to everyday living).

3.2.2. Theme 2: Living Young With an Older Person's Disease. Having outlined the disruptive, familial, and support-related concerns reported by younger individuals, this theme proceeds to explore the coping strategies they used to help manage life with mesothelioma, either by stressing how they are different from the typical (older) mesothelioma patient demographic, developing a new sense of normalcy, or by focusing on everyday hobbies and health-related activities. Four subthemes are presented as follows:

- Subtheme 2.1: Not a typical mesothelioma patient.
- Subtheme 2.2: Return to everyday living.
- Subtheme 2.3: Activity to promote mindful distraction.
- Subtheme 2.4: Coping through exercise.

3.2.2.1. Subtheme 2.1: Not a Typical Mesothelioma Patient. When asked how they managed living with mesothelioma, and what advice they would give to others, most individuals made a point to emphasize the uniqueness of having mesothelioma at a younger age. This emphasis seemed to reflect a kind of coping process, as individuals separated themselves from the older patient demographic and disease statistics.

I would say don't believe all the data because it is based on men that are 20, 30 years older than you are (. . .) especially if you're female and you're younger then, for me, I think the odds are probably in your favor. (Danielle)

Don't Google anything for God's sake because that's what frightened me is Googling something. You Google mesothelioma and you're effectively dead within a year. But that- I'm not a normal mesothelioma patient. Neither is anybody else that's young. (Alex)

Like Danielle and Alex, many pointed to their respective age, sex, or peritoneal mesothelioma diagnosis in order to distinguish themselves from the archetypal older patient living with pleural mesothelioma. This served to differentiate them from the clinical norm and fostered a sense of psychological distance, and coping, by subsequently disputing the relevance of mortality figures derived from older patients. In addition, some individuals highlighted the case studies of younger people who had lived with the cancer for several years, adding that younger people may be able to better manage treatment and recovery, as a result of them

having generally better health, and fewer preexisting conditions, relative to their older patient counterparts.

If you're ill and you're younger, regardless of what you get, you tend to get over things better. (. . .) the younger you are, the chances are you got over it better because it just didn't have the same effect as somebody that was older, that maybe had other pre-existing background illnesses. (Jeanne)

When you think of it from a really practical point of view, people have got like underlining conditions and different ages and backgrounds and everything. There's so many things to take into consideration. (Clara)

Other people provided similar explanations in trying to convey and highlight the protective role of age. Indeed, this suggests that individuals felt more secure and comforted by the knowledge that they were not a typical mesothelioma patient, whether because of their age, sex, and/or (peritoneal) diagnosis, since in effect, this gave them a justification to distance themselves from hard-hitting disease statistics, allowing younger people to think that negative mesothelioma facts and figures need not apply to them, particularly if based on an older patient demographic. This is to acknowledge the psychological benefit individuals articulated in seeing themselves as different from older groups, which seemed to engender a sense of optimism.

I have always felt that I am that outlier; I am in that little box. And I suppose that's my religion. That's my belief: that I am the outlier on the graph. (Joel)

I'm hoping for a miracle that I'm going to keep the doctors on their toes by beating it for a lot longer than (. . .) If you're an older person, you're gonna have other underlying conditions. (Natalie)

Joel and Natalie voice hope in view of their age relative to most other people living with mesothelioma. Joel feels positive about his "*outlier*" status as a younger person, while Natalie hopes to live longer than expected in view of her not being an "*older person*" with "*underlying conditions*." These sentiments were shared by others, and the use of religious terms and phrases: *"that's my religion. That's my belief*', and *I'm hoping for a miracle*" evokes a powerful sense of salvation sustained by the belief that they are not a typical mesothelioma patient and are unlikely to follow the typical disease trajectory.

3.2.2.2. Subtheme 2.2: Return to Everyday Living. Another thing that individuals discussed when reflecting on their coping and living with mesothelioma was the intrinsic value of reclaiming and shaping their lives, and returning to a kind of everyday living, informed by their general sense of living a "*normal*" life.

I think you probably don't realize how important getting back to normality is because you don't feel like you're ever going to get there in the beginning because you think, "Oh God, this is what my life's like now." (Emily)

Try to keep life as normal as you possibly can. Try not to, you know, don't give up on things unless you really physically have to. (Jeanne)

Many described a "*whirlwind*" of negativity after diagnosis, as they became fixated by thoughts of dying, which is illustrated by Emily, who recalls thinking her entire life would be consumed by mesothelioma. In contrast, the return to everyday living seemed to reflect a shift in peoples' thinking away from death toward thinking about life, and the continuation of "*normal*" routines, such as spending time with their family members.

It's children, it's taking them from school, it's going to watch sport, and family life has just continued on as normal for me, and so that's, but that normality has been really positive. (Joel)

The support I need really is more my daughter asking me to learn with her. That's support. That's normal; that's normal living. That's what you do on a daily basis. (Alex)

Spending time with their family and friends was often central to peoples' everyday lives and well-being, and it provided the opportunity to focus their attention outward to other people and "*make memories*"; in effect, affording people the mental space to focus on loved ones and not think about their ill-health. For Hannah, her return to work after treatment provided a similar focus and distraction.

When I did go back to work, work was like my escape from the anxiety really. It was the time where I wasn't thinking about things like that because I had to focus on my job. So actually, I think the best thing I did was go back to work. It certainly helped anyway. (Hannah)

Likewise, others chose to focus on upcoming events and holidays.

We've been doing exercises about thinking about the future [. . .] And I'm just focusing on the new house and then booking holidays and just enjoy life really. (Sofia)

[We] had always planned to do a lot more travel especially, you know, thinking ahead to retirement that we would have this campervan and go around Europe. And yeah, we're just trying to do a bit more of it now. (Evelyn)

Together, these extracts and images in Figures 3 and 4 show some of the ways people ground their thinking within the everyday of family, work, and leisure, as participants often chose to maintain busy and active lifestyles in order to make the most of now, and live a life that was not entirely defined by them having cancer. In this sense, the return to everyday living reflects a shift in people' s thinking away from a fixation with death toward thinking about life, and the overall desire to reclaim and rebuild their futures as their health improved.

3.2.2.3. Subtheme 2.3: Activity to Promote Mindful Distraction. Further to maintaining a busy schedule to foster a sense of normal everyday living with mesothelioma, a number of

Figure 3: By Sofia.

Figure 4: By Evelyn.

individuals discussed the benefit of specific activities and hobbies they used to supplement their well-being, such as through gardening, expressive writing, forest bathing, and arts and crafts.

> *The one with the cat is a paint by numbers (. . .) It was very intricate, but I found that when I was doing it I was so concentrating on staying in the lines that I won't then be thinking about my anxiety (. . .) And I felt that the picture itself actually was something that represented like the strength of, you know, the kitten looks in the pool of water and in its reflection, it sees a tiger. And I thought that it sort of represented what we'd both been through.* (Hannah)

> *(The lathe) is a release valve. And obviously you can build stuff up, you can build emotions up and, you can talk to people, but sometimes you just need to go away, and you need to think to yourself and go through it in your head. (. . .) For me, this is somewhere to go and to reorganize myself to sort things out.* (Owen)

Hannah began painting after being diagnosed with cancer and found that this helped to focus her thoughts and feel less anxious. In addition, Hannah interprets the kitten seeing a tiger in Figure 5 as a representation of her living with mesothelioma, by visualizing her inner strength to overcome physical and mental adversity. Hannah thus recognizes her art as a therapeutic practice and outlet for negative thoughts and feelings and as a medium that enables

Figure 5: By Hannah.

her to creatively process, and make sense of, her own lived experiences. Owen likewise recognizes his lathe work in Figure 6 as a coping strategy (or "*release valve*") that is conducive to his engaging in positive self-talk to help "*reorganize*" and manage the build-up of negative emotions.

These sentiments were shared by other participants who similarly reflected on the therapeutic benefit of various pastimes, which not only stirred their interests but also provided constructive and meaningful outlets to refocus their aims and reorient their thinking.

> *Having an aim, having something to look forward to. You know, living life as much as you can, (. . .) We all have distractions, don't we? You know we all have other things on that distract from them low feelings.* (Liam)

> *I've switched my mindset from those type of thoughts now to focusing on stuff we're doing, like the garden, meeting friends. (. . .) because it does you no good focusing on stuff like that. So it's about focusing your mind. Initially it's very difficult, but it does come with time.* (Natalie)

Like others, Liam and Natalie found benefit in purposeful daily activity, such as gardening, whether as a means to help "*distract from their low feelings*," or switch their "*mindset from those types of thoughts*." In this way, individuals appeared to utilize various activities and hobbies to regulate their mental state, using techniques of mindful distraction to direct their attention towards positive and meaningful tasks, in order to abate negative thoughts and feelings.

3.2.2.4. Subtheme 2.4: Coping Through Exercise. Exercise was also discussed by many as a means to support their physical and psychological well-being. Some people had already lived physically fit and active lives before diagnosis, and for these individuals, the reuptake of physical exercise was often seen to be part of their return to "normal" everyday living, as they tried to reclaim and shape their lives and futures (see Subtheme 2.2: return to everyday living). In

Figure 6: By Owen.

addition, many individuals found exercise to be a useful coping strategy to help them deal with the psychological toll of mesothelioma.

> *After work when I'm exhausted, I will force myself to go gym, or for a long walk if I'm absolutely exhausted. I do try and do a couple of runs a week and go gym once a week. I think that's how I cope really.* (Faye)

> *I think the gym really helps kind of get stress out and kind of just get your mind away from everything, because you're focusing on yourself and your routine and what you're doing, and it's nice to just kind of switch off from everything.* (Tom)

> *Doing the exercise you're mentally just doing the exercise, and you're not thinking about anything that's worrying you. And then the feel good after afterwards. It's a win, win all-round.* (Natalie)

As with other activities in the prior subtheme, several people found that doing physical exercise helped them to "switch off'" and avoid intrusive thoughts through an activity which focused their full attention, thus, enabling those such as Tom and Natalie to focus on "*yourself and your routine and what you're doing,*" and not think "*about anything that's worrying you.*" In this regard, exercise was not only another useful practice for mindful distraction but was also used by some participants to seek reassurance about their health.

> *(Exercise) now is as much a monitor and a gauge and to make sure that I still can. Because if I go to the gym three or four times on the trot and I just don't feel like doing anything, I'd start to be worried.* (Brian)

> *I've always thought, well, if I feel if I feel crap; if I start feeling like I can't, I can't go play football anymore, I can't come walk the dogs anymore, I can't walk upstairs, then I'll worry about it. Until then, I know there's no need for me to worry about it.* (Alex)

While most individuals were "cancer-free" at the time of study, and were receiving regular cancer screenings, there remained an acute and chronic fear that the mesothelioma could potentially return in the future. In response, Brian and Alex as well as others used exercise, such as going to the gym or playing football, as a kind of pseudocheck for cancer by construing their physical abilities to perform tasks and exercise as a "*gauge*" to self-monitor for tumor growth, wherein their ability to lift weights or run long distance engendered a sense of reassurance that they remained in good health, and by implication cancer-free. Some also used exercise to improve their health in anticipation of mesothelioma possibly returning.

> *I want to be fit and strong and if the cancer does come back to where I've got to have surgery or treatment then I'll be as strong as I was the first-time round.* (Gladys)

> *I'm just mindful of being fit and healthy. And, or if I have to have any other treatment in the future you know, you're always gonna be in a better position if you're like fitter and stronger, to sort of tackle these things. So yeah, always kind of looking after myself.* (Tom)

Gladys and Tom exercised to become "*fitter and stronger*" to help themselves better manage the possible reoccurrence of mesothelioma and the impacts of treatment, and this is illustrated by Gladys in Figure 7. Moreover, Gladys and Tom's use of language and focus on training are reminiscent of discourses around fighting cancer and convey a sense that they used exercise to feel more secure and in control of their health and ability to overcome mesothelioma. This was echoed by other people who described using exercise to proactively "handle the situation" to improve their health and perceived ability to fight cancer in the future.

4. Discussion

This paper offers a unique phenomenological exploration of people under 60 living with mesothelioma, and their experiences of adversity and coping, which have previously gone unheard and unrepresented by studies that focused on the accounts of older individuals.

In terms of diagnosis, younger individuals in this study were shocked to learn they had mesothelioma; some participants had never heard of the condition, while others perceived it as a "disease for old men." This contrasts with older groups who may feel an anticipatory anxiety several decades before diagnosis because they are aware of their increased risk of developing mesothelioma after working with asbestos [18]. Indeed, none of the people that we spoke to had experienced any such anxiety, and many had previously believed the lay misconception that mesothelioma only affects older people. Correspondingly, some doctors also reportedly ruled out a diagnosis for mesothelioma prematurely, explaining that patients were too young or had not worked with asbestos to merit further investigation. This comports with the accounts of other rarely affected demographic groups, whose diagnoses likewise challenge common cancer stereotypes, such as for men living with breast cancer [36], and women living with bladder cancer

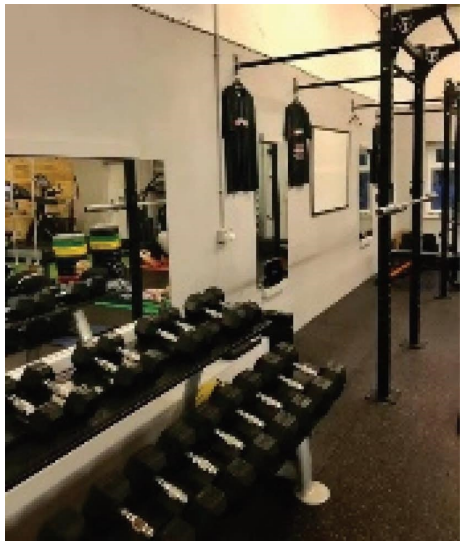

Figure 7: By Gladys.

[37], and further speaks to the diagnostic barriers young people may face seeking a diagnosis for typically age-associated cancers, such as prostate cancer [38] or colorectal cancer [39].

In terms of long-term psychological impact, individuals reported acute feelings of anxiety amid fears of future suffering, cancer reoccurrence, and death. This reiterates the significant psychological burden of living with mesothelioma [15, 16] and is consistent with the research showing elevated levels of anxiety in populations living with cancer more generally [40]. However, young people further conveyed a sense of acute disturbance to their current and future lives, as they grieved the loss of their professions, and perceived opportunity to experience major life events. This reflects other qualitative research, highlighting the emotional impacts and identity changes felt by young people living with other forms of cancer and their struggles adapting to the psychosocial changes to both their professional identities and family-based roles [41, 42]. This resonates with Bury's [43] concept of biographical disruption and suggests that younger groups may experience the onset of disease as an abrupt shattering of their envisioned lives; moreover, several individuals had recalled feelings of surreal disbelief and great difficulty in piecing their lives back together. In addition, while older people may reflect positively on having had a more full and complete life [44], younger individuals felt robbed of their potential and lives they had not yet lived, as they further anticipated the prospect of a premature death and how this may impact their family. These concerns, among others, were further compounded by difficulties in accessing peer–based support, particularly with people of a similar age. This in turn limited participants' opportunities to "trade notes" and mutually explore the emotional, practical, and existential nuances of their living with mesothelioma [45, 46] and contributed to feelings of isolation.

Reflecting on their coping processes, individuals sought to separate themselves from their older peers and create a sense of psychological distance by focusing on the rarity and distinctiveness of mesothelioma in young patients and a higher rate of survival [20, 25, 27]. In addition, participants discussed the importance of reclaiming a sense of normal everyday living, which is evocative of the notion of biographical repair, wherein individuals seek to reinstate a sense of control, normality, and meaning, following the onset of a serious illness [47, 48]. Moreover, participants attempted to steer their lives toward a normal rooted in family, work, and leisure, as they tried to reclaim aspects of their life and future that seemed forever lost at the time of diagnosis. In this sense, individuals appeared to cope in part by emphasizing the atypical nature of mesothelioma in young groups in order to foster hope and by trying to rebuild their lives comforted by the belief that they were not a typical (older) patient.

Furthermore, individuals still engaged in everyday hobbies and activities to help regulate negative thoughts and feelings. This is in line with a growing body of psycho-oncological research and practice that shows mindfulness-based interventions can help to alleviate anxiety, depression, and fear of cancer recurrence [49] and is in line with the accounts of other young people with other forms of cancer, who likewise cope in part by focusing their attention on immediate tasks to alleviate negative thoughts [50]. Indeed, while none of the hobbies or activities were part of a formal intervention, several participants reflected on them as a form of self-care and are in keeping with other cancer patients using techniques of self-distraction, relaxation, and positive self-talk in order to enhance their well-being [51, 52]. Some individuals also found value in exercise to maintain a sense of control over their health and ability to "fight" mesothelioma or as a means to disrupt intrusive thoughts and allow for the perceived self-monitoring of tumor growth.

4.1. Implications for Practice. There is a need to counter the common misconception that mesothelioma solely affects older individuals and provide a more complete picture of the cancer that recognizes its prevalence in younger groups; see, for example, the "Never Too Young" campaign by Bowel Cancer UK [53]. Clinicians should similarly understand that mesothelioma can affect younger people who have not worked directly with asbestos and tailor their interactions accordingly via the recognition that age is a confounding factor that outlies them from the conventional disease statistics [20, 25, 27]. This diagnostic uncertainty can be well received by patients who do not expect clinicians to have all the answers and prefer transparency about this [54]; indeed, our analysis suggests that more nuanced discussion of the acute difficulties of mesothelioma alongside its atypicality in younger groups may help individuals to navigate the often-traumatizing experience of diagnosis.

While there is nascent research describing psychological interventions for people with mesothelioma, there is as yet limited evidence to evaluate their efficacy [18, 55]. That said, participants benefited via everyday hobbies, activities, and exercise as a way to enhance their sense of normal living and reduce anxiety, and the inclusion of similar structured

activities as part of a broader cognitive behavioral approach may prove valuable for helping individuals to tailor their coping in both clinical and community settings. Moreover to this point, "Acceptance and Commitment Therapy" is a third-wave cognitive behavioral intervention, which has demonstrated acceptability and feasibility to reduce levels of distress and anxiety in people with advanced progressive disease [56], and may be adapted for younger groups more generally with mesothelioma.

4.2. Strengths and Limitations. This study benefits via the combined use of in-depth interviews and participant-authored photographs, as this enabled individuals to visually direct and expand on their narratives at the point of data collection, which is in line with the idiographic sensibilities of good phenomenological practice [30], and helped to foster experientially rich accounts for the analysis and reporting [32]. In doing so, this study provides an intimate look at the experiences and needs of a demographic group who have been largely overlooked within the context of the mesothelioma literature [29]. Likewise, the unexpected over recruitment of 12 women and 10 people with peritoneal mesothelioma to this study has allowed for a more diverse representation of experiences beyond the more commonly represented experiences of men, and those living with pleural mesothelioma [18], and working with a mesothelioma nurse specialist based at a peritoneal care service largely helped to facilitate this recruitment. That said, however, the larger recruitment of women and peritoneal cases means that the current analysis is likely to disproportionately reflect the experiences of these individuals as opposed to the experiences of younger people more broadly.

In addition, phenomenological studies generally aim to recruit homogenous samples of people to help ensure findings speak to the particularities of a defined group [30]. In the current study, while all participants were White-British, heterosexual and married, there remained notable differences in terms of their treatment status, type of mesothelioma diagnosis, time since diagnosis, and even age; accordingly, though the sample was homogeneous in some ways, it was also less homogenous in others. However, the homogeneity of a sample is informed by both interpretive and pragmatic considerations [57], and it is thus worth acknowledging the interpretive similarities reported in the current manuscript and reiterating the rarity of the condition in young groups, which dissuaded the authors trying to refine the research topic and subsequent recruitment of participants any further.

The first author (a cisgender man in his early 30s) also conducted the interviews and was several years younger and the opposite sex to most participants. This could have affected the data collection process; for example, individuals may have been more self-conscious and less willing to talk about certain topics with someone they viewed as less relatable or understanding. That said, the length of most interviews as well as the depth and frank nature of verbal and visual data suggest that this was not generally the case. Online interviewing can also present technical issues and limit a researcher's ability to establish rapport. However, no such technical problems were encountered by the interviewer or reported by participants. The interviewer used clarifying questions, nonverbal gestures, and made encouraging remarks to help convey sincere interest and reassure individuals that their voices were being heard [58].

4.3. Future Research. As per our implications for practice, research is needed to tailor and pilot psychological therapies such as Acceptance and Commitment Therapy to help people redress the anxieties of living with mesothelioma. Because participants in this study described using everyday hobbies and activities as a form of self-care to this exact effect, it is advisable that psychotherapeutic initiatives include similar structured activities as part of these research efforts to act as a therapeutic outlet for both intrusive thoughts and feelings.

In addition, while this study presents several moving accounts of participants at different points in their mesothelioma journeys, some early diagnosis or in-treatment and others several years posttreatment, longitudinal in-depth research is needed to help elucidate the ways in which people's needs and coping processes evolve over time. To this end, diary-based research may prove particularly useful as this can allow individuals to track and record their experiences over time and in reference to contextual factors [59].

5. Conclusion

Via the use of interviews and participant-authored photographs, this study reports the rich and textured accounts of people under 60 living with mesothelioma, including their experiences of diagnostic shock, disrupted living, concern for family members, and lack of peer support, in response to which individuals focused on the atypicality of younger groups alongside efforts to reclaim their lives and reduce anxiety. Together, these findings highlight the need for tailored clinical and psychotherapeutic initiatives to help younger patients navigate diagnosis and to help them further deal with longer-term feelings of distress. Future research should similarly aim to pilot and test the efficacy of these cognitive behavioral efforts and employ longitudinal methods to study individuals' evolving needs and coping strategies.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

The authors declare no conflicts of interest.

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