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Gender and the experiences of living with mesothelioma: A thematic analysis

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ABSTRACT

Purpose: Mesothelioma is a terminal cancer caused by exposure to asbestos. As a cancer with a higher rate in men than women, women's experiences of living with mesothelioma are often underexplored. Furthermore, men's experiences are often taken for granted and therefore have remained underexplored. This paper considers men's and women's experiences across the mesothelioma pathway.

Methods: This qualitative study incorporated semi-structured interviews with 13 men and 11 women living with mesothelioma. Telephone interviews took place between July and December 2019, and were audio recorded, transcribed and anonymised. Thematic analysis was used to analyse the data.

Results: Three themes were developed in relation to the gendered experience of mesothelioma: familial responsibility and social perceptions; support preferences; and treatment and trials. Analysis suggests that men and women's sense of familial responsibility varied. Differences in priorities and motivations influenced approaches to seeking support, compensation and, making decisions around treatments and clinical trials.

Conclusions: The current study reports on how gender can influence the experience of living with mesothelioma. The findings indicate how the patients' role in their families and society can more broadly influence their experiences, choices and preferences. Nurses caring for mesothelioma patients need high quality research on which to base their practice. Recognition and an understanding of the underlying factors influencing patients' decision-making will enable nurses and other professionals to support their patients better.

1. Introduction

Studies on the care needs of cancer patients are important for maintaining and improving the quality of care that patients and their families are provided with (Carroll et al., 2010; Patel et al., 2017). There has been a call for research which takes account of how certain patient experiences may be specific to gender or cancer type (Carroll et al., 2010; Ussher et al., 2013). With 2700 new cases diagnosed annually, the UK has the highest incidence of mesothelioma in the world (Cancer Research UK, 2020; Royal College of Physicians, 2020). Mesothelioma is an aggressive, rare cancer resulting from exposure to and inhalation of asbestos (Odgerel et al., 2017). Mesothelioma is predominantly a pleural disease (89% in the UK). It also occurs less commonly in the peritoneum (3%), testes and other unspecified sites (8%) (Cancer Research UK, 2020). There is no known cure for mesothelioma. For many, life expectancy is between eight and 15 months (Bibby and Maskell, 2018; Royal College of Physicians, 2020).

Mesothelioma is more common in men (83%) than women (17%) (Health and Safety Executive, 2019). This difference is mainly attributable to occupational patterns. The incidence of mesothelioma is high in certain occupational groups including construction, and other industries with a high risk of asbestos exposure (Rake et al., 2009). These industries traditionally have high rates of male employment. Evidence suggests that those employed in occupations associated with asbestos exposure may have knowledge about the dangers of exposure to asbestos and their rights regarding compensation and benefits (Marinaccio et al., 2020). Little is known about those who work outside of industries with a high risk of asbestos exposure.

In addition to gendered occupations, biological sex may provide an explanation for epidemiological differences in mesothelioma incidence and survival. In cancer epidemiology, sex-differences are widely accepted with men more prone to die from cancer (Kim et al., 2018). This sex-difference is often attributed to regulation at the genetic level and sex hormones such as oestrogen providing protection for women

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(Kim et al., 2018). Occupational exposure to asbestos and physiological differences in biology, mean that sex-differences and gender differences can compound each other.

Gendered differences between men and women's experiences of living with mesothelioma are beginning to be explored in the literature (Barsky et al., 2020; Bonafede et al., 2018; Kirkham et al., 2011). Differences in surgery and chemotherapy utilisation, survival, seeking compensation and psychological distress between men and women have been found (Barsky et al., 2020; Bonafede et al., 2018; Ejegi-Memeh et al., 2021; Marinaccio et al., 2020). However, to our knowledge, the Gendered Experience of Mesothelioma Study (GEMS) is the first study to focus on gendered experiences across the mesothelioma pathway. The present paper explores the differences in gendered experiences across the mesothelioma pathway.

2. Methods

This was a qualitative study using semi-structured interviews. GEMS was approved by the University of Sheffield Research Ethics Committee (reference number: 026353). The inclusion criteria required that each participant:

- Was diagnosed with mesothelioma
- Was not experiencing physical or emotional distress that would be exacerbated by taking part in the interview
- Was able to give informed consent
- Spoke English

2.1. Sample

A convenience sampling method was used. This method allowed recruitment to take place in a timely fashion (Higginbottom, 2004). Invitations to participate were circulated via Mesothelioma UK and Asbestos Support Groups (ASG). When contacted, Mesothelioma UK information line staff or ASG workers discussed the study with potential participants. With agreement of the potential participants they liaised with the research team. Information sheets and consent forms were then provided for consideration, and an interview arranged following consent to participate. One person showed interest in taking part but later withdrew due to becoming too unwell to participate. We recruited 11 women and 13 men. Based on existing literature and previous studies conducted by the research team (Ejegi-Memeh et al., 2021; Taylor et al., 2019; Warnock et al., 2019) this was considered sufficient to ensure data saturation (Baker and Edwards, 2012).

2.2. Data collection

Interviews were undertaken by SEM between July and December 2019, lasted between 31 and 113 min (average length = 56 min) and were conducted over the telephone, enabling people to participate from across England and Scotland. The use of telephone interviews improved cost-effectiveness, permitted the inclusion of participants over a greater geographical area and may have increase the level of comfort for both participants and the interviewer (Musselwhite et al., 2007). None of the participants were known to the researchers prior to interview. The interview topics were generated through exploration of existing literature and previous studies conducted by the research team (Ejegi-Memeh et al., 2021; Warnock et al., 2019) (Supplementary file 1 - Interview schedule). The interview schedule focused on experience of diagnosis, treatment and trials, benefits and legal claims and greatest concerns about living with mesothelioma.

2.3. Data analysis

Interviews were audio-recorded, transcribed verbatim and imported

into Quirkos© software for analysis. Field notes were made during each interview. The data were analysed using a six-step thematic analysis (Braun and Clarke, 2006). Thematic analysis was chosen for its ability to provide a structured and rigorous process for qualitative data analysis.

An inductive approach to data analysis was taken. First, an initial familiarisation stage was conducted. This involved iterative reading through transcripts and making notes. The data were then imported into Quirkos©. Codes were developed by the first author SEM, and revised and refined by SR, AT, BT, LD. All transcripts were analysed by two of the five authors. A provisional coding framework was developed and used to code transcripts. Revisions to the coding framework were made following team discussions.

The framework was further revised and applied to transcripts to be tested and verified. Developed codes were then organised into potential themes which were organised in tables and revised following team discussions. It was during this team-led process of theme development, through the latent analysis stage (Braun and Clarke, 2006), that gender comparisons were made facilitated by the required level of critical interpretation of this stage. Though the point at which qualitative comparison analysis takes place can vary, Lindsay (2019) note that half the studies in their scoping review conducted such comparisons after coding was completed. Completing comparisons at this point enabled us to make fewer *a priori* assumptions about similarity and difference. Rigour was supported by data-immersion, iteration, team discussions, reflexive analysis, and audit trial. Furthermore, to ensure that the themes were grounded in the data, they were supplemented by direct quotes from the participants. All participant names are pseudonyms.

3. Results

The final interview sample comprised of 11 women and 13 men. For four of the 24 interviews, family members also participated at the behest of the participants. Only data from the patients' were extracted and analysed. Participants' ages ranged from 31 to 81 (women 31–81 years; men 44–77 years). Three women and two men were living with peritoneal mesothelioma. The remaining participants were living with pleural mesothelioma. Table 1. Participant characteristics.

Twenty-five codes (Fig. 1. Coding framework) and three overarching themes were developed (Table 2. Thematic framework).

There were many similarities in the men's and women's experiences. These included interactions with health care professionals and systems and experiences of distress at diagnosis. Within this paper, we focused primarily on where their accounts indicated differences in the experience of living with mesothelioma. Findings are presented under three themes; familial responsibility and social perceptions; support preferences; and treatment and trials.

3.1. Familial responsibility and social perceptions

The participants were often, understandably, shocked and distressed upon hearing they had a diagnosis of mesothelioma. These feelings quickly translated into action with both men and women describing practical steps they took following diagnosis. However, how this practicality was enacted often depended upon their perceived role within the family. For several of the women interviewed, their role focused on domestic tasks. In part, this reflected the way women thought they could best help their partners after they had passed away. This focus for women on domestic responsibilities continued throughout the participants mesothelioma journey:

"I took down the net curtains, because I said well, men don't wash net curtains. I bought him a new oven, a new freezer. I bought everything new, so that when I was gone there was nothing he had to buy." F1, Amy

In addition to a focus on the management of the household, several

Table 1
Participant characteristics.

Pseudonym	Gender	Age	Occupation	Living circumstances	Location of mesothelioma	Time since diagnosis
F1 Amy	Woman	70–79	Retired. Worked in a lighting company and various other jobs	Lives with husband	Pleura	10 years
F2 Belinda	Woman	80–89	Retired. Worked as a social worker	Lives with husband	Pleura	2 years
F3 Cath	Woman	70–79	Retired. Worked in several secretarial roles	Lives with husband	Pleura	8 months
F4 Donna	Woman	30–39	Secretary	Lives with husband and young daughter	Peritoneum	2 years
F5 Edna	Woman	60–68	Language school teacher	Lives with husband	Pleura	11 months
F6 Fiona	Woman	70–75	Retired. Worked as a cashier/office work in a garage	Lives with husband	Pleura	15 months
F7 Grace	Woman	30–32	Manager – data analyst	Co-habiting with male partner.	Peritoneum	5 months
F8 Hannah	Woman	60–69	Secretary	Single. Lives with daughter	Pleura	2 years
F9 Irene	Woman	50–59	Retired. Worked as an actuary	Lives with husband	Peritoneum	1.5 years
F10 Julia	Woman	60–69	Retired. Worked in various jobs in banks and supermarkets	Lives with husband	Pleura	4 years
F11 Kay	Woman	80–89	Retired. Worked at home with family	Widow. Lives alone	Pleura	1 year
M1 Arthur	Man	70–79	Retired. Worked as a joiner	Lives with wife	Pleura	4 years
M2 Ben	Man	60–69	Actor	Lives with wife	Pleura	1 year
M3 Callum	Man	60–69	Retired. Worked as a Chartered building engineer and development project manager	Lives with wife	Peritoneum	1 year
M4 Derek	Man	60–69	Retired. Worked as a pipe fitter	Lives with wife	Pleura	3 years
M5 Eddie	Man	70–79	Retired. Worked as a carpenter/joiner	Lives with wife	Pleura	10 months
M6 Fred	Man	70–79	Clergyman	Lives with wife	Pleura	2 years
M7 Graham	Man	70–79	Retired. Worked in catering for the railways	Lives with a close male friend.	Peritoneum	1.5 years
M8 Ivan	Man	60–69	Retired. Worked as a mechanical engineer	Lives with wife	Pleura	3 years
M9 Henry	Man	70–79	Retired. Worked as a mechanical engineer. Health and safety advisor	Lives with wife	Pleura	1.5 years
M10 Jude	Man	60–69	Retired. Worked as an electrical supervisor	Lives with wife	Pleura	3 years
M11 Kevin	Man	50–59	Telecoms engineer	Lives with wife	Pleura	4 years
M12 Lenny	Man	40–49	Technology risk management for a bank	Lives with wife	Pleura	6 months
M13 Mike	Man	70–79	Retired. Worked in chemical sales	Lives with wife	Pleura	10 years

women's accounts showed evidence of a sense of responsibility for the emotions of their families, of their male family members. Examples included participants' husbands, partners and sons:

"I'm going to try and convince [my boyfriend] to come for the second week when I'm looking a bit better rather than the rest week. Because I think him seeing me on a ventilator isn't really going to help his anxiety very much" F7, Grace

While this focus on domestic and emotion management was not evident in men's accounts, ensuring that their families would be financially secure was very important to several of the men interviewed. The men appeared to consider financial provision for the family to be a core responsibility:

"I did [return to work]. Because pay out on death at work is a lot of money [...] Say if you're still working and you die at work, your partner's pay out is quite significant as opposed to just retiring." M11, Kevin

"My main worries were my kids and my wife, they're my priority. If it happened to me tomorrow what would happen to them? Can they survive financially?" M12, Lenny.

The men's strong sense of financial obligation to family was often given as a motive for seeking compensation:

"I deserve that [compensation] and I should have that and I want as much as possible. And the reason I want that is, not for me to spend because I've got enough myself, but for when I'm not here that the family is well catered for." M8 Ivan.

This feeling that compensation was deserved, twinned with a desire to ensure that the family was catered for financially, was seen in several of the men's accounts. In contrast, in most women's accounts, discussion about financial obligation to the family or sense of financial compensation entitlement was largely absent. This difference in men and women's accounts may have been due to gendered family roles and dynamics. It also may be due to social expectations that men are the financial caregivers for the family and women are not financially

motivated. The following quote also highlights that women may be more influenced by societal judgement:

"I didn't want to come across as being greedy." F4 Donna

However, it is important to note that participants who had worked in an asbestos related industry appeared to pursue a claim more willingly; they were more familiar with the right to compensation and this possibly generated a feeling that compensation was deserved. No women interviewed had worked in asbestos industries. For both women and men, working in non-asbestos related industries, the advice of ASGs and health professionals was key to informing them of their rights to compensation and benefits:

"... the lady that set up [ASG] she came, and she left a sheet with the solicitor's names on it [...] And, gave us the information and filled in the forms regarding the industrial benefit and that sort of thing." F5, Edna

"... so my clinical [specialist] nurse and several consultants that I saw said you really ought to consider seeking compensation." M2, Ben.

The perceived confrontational nature of seeking compensation also acted as a deterrent for some women:

"I just feel it [seeking civil compensation] could have been quite acrimonious and unpleasant ..." F9, Irene.

These different ways of practical and emotional care for their families influenced how men and women navigated their personal relationships and interactions with professionals. This included their relationships with loved ones, their employers, health care systems and legal systems. The importance attributed to these different aspects of their lives also influenced how the participants wished to be supported after their diagnosis.

3.2. Support preferences

Participants valued support from spouses, friends, the community

- Help-seeking and Diagnosis
 - Help-seeking
 - Misdiagnoses
 - Coping and support at point of diagnosis
 - Feelings around diagnosis
- Support, caring and coping
 - Sources of support
 - Types of support (emotional, practical, benefits, legal)
 - Caring for the carer
- Treatment
 - Access
 - Decision-making/control (including language used)
 - Experiences
 - Symptoms and side effects
 - Managing
- Compensation
 - Was it spoken about? When?
 - Sources of information
 - Feelings around seeking compensation
 - Motivations
- Identity
 - Roles, duties and responsibilities
 - Gendered identity talk (what participants say about others gender)
 - Altered identity since being diagnosed
 - Embodied identity (including body image)
- Asbestos exposure
 - Asked about asbestos (whether, how, who by, when?)
 - Type:
 - Occupational exposure
 - Workplace environment
 - Wider environment
 - Para-occupational
 - Unknown
 - Perception of risk
 - Knowledge about exposure (including not knowing, how and why did they know)
 - Feelings about exposure (including not knowing)

Fig. 1. Coding framework.

and professionals. Both men and women in established relationships (married or co-habiting) praised the support received from them. For the men, valued support was often practical in nature. This included medication management, appointment management, encouraging exercise and generally ensuring that the patients maintained a healthy lifestyle:

“... she’s [my wife] chipping me on now. I’m more active again now. We’ve just got electric bikes to get exercising.” M3, Callum

“I have an incredibly supportive wife who is absolutely diligent in ensuring that I do everything properly ... she’s absolutely on the ball up to the second of the requirements and nags me in a nice way to do everything I’m supposed to do [...] I don’t know how I would be if I hadn’t had her” M6, Fred

In the women’s accounts, emotional support appeared to be most valued. In contrast to most of the men interviewed, women often expressed their emotional support needs directly:

“[My best friend] was there for moral support.” F8, Hannah

Table 2
Thematic framework.

Themes	Sub-themes	Women's quotes	Men's quotes	Brief description of theme/sub-theme
Theme 1: Family responsibility and social perception		<p>“My response to my diagnosis was to come home and to chuck everything out, and I took down the net curtains, because I said well, men don't wash net curtains. I bought him a new oven, a new freezer. I bought everything new, so that when I was gone there was nothing he had to buy.” F1, Amy</p> <p>“I'm not looking forward to having the operation and obviously I'm scared. But I'm not at the point where it affects my everyday life like it does [my boyfriend]” F7, Grace</p> <p>“I'm going to try and convince [my boyfriend] to come for the second week when I'm looking a bit better rather than the rest week. Because I think him seeing me on a ventilator isn't really going to help his anxiety very much” F7, Grace</p> <p>“I decided to have the surgery which was ... I don't know really; I think I was worried about what would happen to my husband if I wasn't there to organise him” F9, Irene</p>		<p>In the face of the terminal diagnosis of mesothelioma, both men and women reported practical reactions. However, how the practicality was enacted often depended upon their perceived role within the family.</p>
		<p>“Interviewer: why do you think you wouldn't discuss that with the family, the side effects and things like that?”</p>	<p>“... what I did was decided to put all my [financial] affairs in order, and I mean all my affairs, rather than not do anything about it, and then all of a sudden you die and then you leave a heap of stuff to do for [wife] and the kids, et cetera” M8, Ivan</p>	<p>Participants often discussed the impact of their diagnosis and treatment on their male family members. Some women described that they were careful about how much they disclosed to their male family members. This was done in an attempt to protect their emotions. This act of protecting the emotions was not evident in men's accounts.</p>
		<p>“I think they've [her husband and sons] been through enough. And I just keep going on my own way. I used to say to them I'm going back into a trial, don't worry about me. I fought it before and I'll fight it again” F1 Amy</p> <p>“... [blood] was just like seeping through the stitches and it was normal but I decided not to tell him because I think that if I told him that I had blood all over my bedding because it had been seeping through the stitches [...] ... he'd have been a nervous wreck” F7 Grace</p>	<p>“I deserve that and I should have that and I want as much as possible. And the reason I want that is, not for me to spend because I've got enough myself, but for when I'm not here that the family is well catered for.” M8 Ivan</p> <p>“I'm more concerned about making sure my wife ... and I think most people are like this, you know, you make sure that if you're not going to be around your partner is ... you know, you will get the best out what's there” M3 Callum</p>	<p>Men's accounts showed protection of the family in instrumental ways. Men often described roles such as, ensuring that finances were in order and ensuring that their partners would have enough money once they passed away. Derek's quote showed that he felt that there may be generational differences in how the distribution of labour within households. The accounts from our youngest participants suggested that generational differences may not be as stark as he might think. This was evidenced by both women interviewed who were in their thirties (F4 and F7) discussing their role within the household. These roles were focused on emotional care-giving, caring for children and domestic chores:</p>
	<p>“I'm going to have to teach my husband how to use the washing machine because he's never used it before.” F4 Donna</p>	<p>“we're a traditional 50s/60s, if you like, family, as much as she is the housewife, the cook and the mother, and I do all the bills, I do everything in the house as far as the running of it, if you like. So I've got to try to start getting her to do all the banking, all the money, all the bills, that part of it that maybe your granddad used to do or whatever, I do, and she does the lady role of it, which now ... I mean, I don't know how old you are, Stephanie, but it's a different world now, isn't it? Women get on and do all that sort of stuff, but not when we were young. So that's a bit of a worry” M4 Derek</p>	<p>Social expectations for women not to be ambitious/money focused and wanting to avoid confrontation acted as deterrents for seeking compensation.</p>	
	<p>Preparing the family for the future</p>	<p>“I didn't want to come across as being greedy.” F4 Donna</p>	<p>“My main worries were my kids and my wife, they're my priority. If it happened to me tomorrow what would</p>	<p>All participants who had had prolonged and extensive occupational exposure to asbestos were men. These men were</p>

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Table 2 (continued)

Themes	Sub-themes	Women's quotes	Men's quotes	Brief description of theme/sub-theme
			happen to them, can they survive financially, and it's kind of made me realise that financially [inaudible 0:42:30] it would with these insurances that I've got [...]" M12 Lenny	keen to pursue compensation. The language that the men interviewed used around seeking compensation was often around deserving or being entitled to compensation. However, the motive for seeking compensation was closely linked with familial responsibility. Most women in intimate relationships did not appear to consider the financial well-being of their intimate partners in the same way that the men did. In women's accounts, the lack of discussion around financial obligation to the family may have been due to partnership dynamics. It also may be due to social expectations where men are expected to be the financial care-givers for the family.
	Protecting the family	"I just feel it could have been quite acrimonious and unpleasant in the circumstances." F9 Irene	"... we've started making a file of stuff but partly financial, like bank account details, direct debits, who my accountant is, stuff ... so she doesn't have to look it up, or she knows where everything is." M2 Ben	Often men's accounts revealed a strong sense of financial obligation to family. This was often a motive for seeking compensation, continuing to work and securing life insurance.
	Compensation and finances	"I've paid for my funeral a couple of weeks ago so that's all dealt with. I'm updating my will so, because I had a will before but I updated that ... So that's all in order." F8 Hannah	"I did [return to work]. Because pay out on death at work is a lot of money [...] Say if you're still working and you die at work, your partner's pay out is quite significant as opposed to just retiring." M11 Kevin	However, one participant who was a single-mother did discuss financial arrangements. This was in order to protect her children. This reflects that women who are single parents and living with mesothelioma may have different priorities to those women with children in intimate relationships.
Theme 2 Support needs and coping	Articulation of support needs Valued support	"[best friend's name] was there for moral support" F8, Hannah	"I think my feeling - I'm trying to analyse what I was feeling - I would rather tell the wife first rather than him [a friend]." M6, Fred	
		"... even before we got home, I think, I was on the phone [to her son and daughter]. Because you just do, don't you. You just have to sort of get it off your chest really" F10, Julia	"I think it's going to be some people with the same as what I've got, I suppose, so maybe, you know, you feel a bit more sympathetic towards people and they more towards you. I don't know. I'm not quite sure how it goes as we've not met up with anybody" M5 Eddie	
		"if I was accessing a group I would want it to be a small mesothelioma group or cancer group" F2 Belinda	"... you've got certain friends that will come up and they are incredibly supportive and understanding and empathetic without even saying anything. And there's one particular friend, who I love to bits, but all she would do is gawp and touch you on the arm and go, oh, you alright? Well, I don't need that; I don't want that." M8 Ivan	The women interviewed were more expressive about their emotional support needs at the point of diagnosis. Most women articulated the reasons why they chose to tell certain people about their diagnosis and who they chose to support them. The men interviewed tended to struggle to articulate why they chose to be accompanied by or discuss their diagnosis with certain people.
		"I just feel that I want to be looked after at the moment" F3 Cath	"... she's chipping me on now. I'm more active again now. We've just got electric bikes to get exercising." M3, Callum	Women often expressed their emotional support needs very clearly. They had clear ideas about what was and was not conducive for their individual support environment. Most men expressed their support needs less clearly.
		"[My husband is] caring, looking after me, supporting me and he was absolutely brilliant after my surgery. So just in a caring way because when I get tired obviously, he has to do stuff and also just emotional support as well." F9, Irene	"I have an incredibly supportive wife who is absolutely diligent in ensuring that I do everything properly ... she's absolutely on the ball up to the second of the requirements and nags me in a nice way to do everything I'm supposed to do [...] I don't know how I would be if I hadn't had her" M6 Fred	Men discussed non-verbal emotional support though friends and family members being present but not necessarily discussing health related issues.
		"[best friend's name] was there for moral support, and I told the children" F8, Hannah	"... [support group] meetings are very good, excellent. You know, you seem to learn something at each meeting you go to. It's all different speakers, so different subjects." M9, Henry	Both men and women with intimate partners praised the support received from their partners. For the men interviewed, the support that was discussed included medication management, appointment management, encouraging exercise and generally ensuring that the patients

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Table 2 (continued)

Themes	Sub-themes	Women’s quotes	Men’s quotes	Brief description of theme/sub-theme
Theme 3: Treatment and trial choices		“... it’s nice to know that I’ve got people there [at the support group] that understand it [living with mesothelioma]. And the people that run it understand it and I can talk to them about it if I want to.” F6 Fiona	“I’ve gone to mindfulness classes which are both male and female. They’re good also but maybe it would be harder for women and men to speak about different cancers in front of each other so I find the men’s group fine [...]”	maintained a healthy lifestyle (instrumental support?). In the women’s accounts, emotional support was brought up more often than the health management aspects seen in the men’s accounts. There was evidence that women attended support groups primarily for discussions around experiences, both their own and those of others. There was evidence that information and learning new things was important to men.
		“... I just go with the flow as to who happens to be sitting next to me at the time and we just have a chat and things like that, you know.” F8 Hannah	I was quite a private person and kept my worries to myself but going to this men’s [cancer support] group on a Friday afternoon it encouraged me to speak more about my fears and my problems [...] it gets quite tearful at times when you’re speaking about different things” M10 Jude	Jude was the only male participant to explicitly discuss the emotional benefit that he received from attending a support group. He was also the only participant who attended a men only support group. Link to literature on men’s only support group. This may suggest that some men may find it easier to speak openly about their emotions in a single-sex group.
			“I don’t know if I’m very strong or what, but there were people there every day, every time I went in a really bad way with the chemotherapy, it really affected them, and it just didn’t affect me at all” M7 Graham “Ivan: ... it’s not a walk in the park having your ribcage opened up. Interviewer: Was it tough, the operation? Ivan: Not really. Eight or 9 h on the operating table and then recovery, which I was fine with it really, to be honest. The tough bit was being in the hospital and not being able to get out and enjoy the sunshine.” M8 Ivan “I feel okay, yeah, I’m just breathless. I mean, I’m in a fair bit of pain” M13 Mike	
	Expression of physical strength	“I know I had ... I think ... Whether it was that first time ... I wasn’t sure whether I wanted to go ahead and have chemotherapy, which was suggested. I wanted time to think about it.” F3, Cath “I don’t discuss it with my family [...] I used to say to them I’m going back into a trial, don’t worry about me.” F1, Amy	“My quality of life is more important. So I’ll be telling them to stick their chemo where the sun doesn’t shine” M8, Ivan “In all honesty, I didn’t realise just how big an operation it was [...] I’m not sure I’d do it again”. M13, Mike	Several men focused on their physical strength, or weakness, when discussing their experiences of living with mesothelioma, treatment and trials. The men interviewed were sometimes reluctant to admit suffering or pain experienced/tried to downplay the severity of their experiences but at the same time wanted their suffering to be known? Or wanted it known that they had been able to bear the suffering?
Motivations around treatment and trials	“I’m happier sort of being told what to do. I’m not very good at making decisions.” F3, Cath			

“[My husband is] caring, looking after me, supporting me and he was absolutely brilliant after my surgery. So just in a caring way because when I get tired obviously, he has to do stuff and also just emotional support as well.” F9, Irene

No gender differences were identified in regards to the relationship with health care professionals and systems (both good and bad experiences were recounted). In terms of information provision, emotional support and making social connections, many participants found support groups to be beneficial. However, gendered differences were identified regarding motives for attending support groups.

There was evidence that women attended support groups primarily for discussions about experiences, both their own and those of others. Some women stated that talking with others living with mesothelioma and feeling understood was something they appreciated and enjoyed about attending support groups. For several women, being in a smaller group where they were listened to and were able to express their

feelings, was particularly important and perceived as being conducive to a supportive environment:

“... [large city hospital] have a very large social group with about 25 or 30 people in. And, I felt that was really inappropriate, ... you can’t talk about your feelings when you’ve just been diagnosed or even later, to a very large group [...] if I was accessing a group I would want it to be a small mesothelioma group ...” F2, Belinda

One woman was involved in the organisation of online mesothelioma support groups. She expressed that women did want informational support and often sought this support through social media. It is possible that women felt more able to ask for, and provide information for others, online:

“They’re [women] the ones that come on to social media. Men don’t believe in Facebook, do they? They don’t believe in it. But women do

... And we've kind of said, it's information. That women might be seeking answers." F1 Amy

Obtaining information and learning new things motivated several of the men interviewed to attend support groups. However, this prioritisation of the value of information over emotional support may have been due to group dynamics. From the interviews, it appeared that most groups were attended by both men and women. Nevertheless, some men may find it difficult to speak openly about their emotions in a mixed-sex group. The participant below was the only one to explicitly discuss the emotional benefit that he received from attending a support group. He was also the only participant who attended a men-only support group:

"I've gone to mindfulness classes which are both male and female. They're good also but maybe it would be harder for women and men to speak about different cancers in front of each other so I find the men's group fine [...]"

I was quite a private person and kept my worries to myself but going to this men's [prostate cancer support] group on a Friday afternoon it encouraged me to speak more about my fears and my problems [...]"

it gets quite tearful at times when you're speaking about different things" M10 Jude.

When considering the types of support that they found useful, some men discussed the importance of non-verbal support. This included friends and family members being present but not necessarily discussing health related issues:

"I remember when I was in hospital [after an operation] and just seeing people at the end of the bed, you might just be sitting there talking amongst yourselves but I know that you're there for me [...]" So just people being there, just knowing that people are supporting you is a massive boost." M12 Lenny

"... you've got certain friends that will come up and they are incredibly supportive and understanding and empathetic without even saying anything." M8 Ivan

This theme focused on the different support preferences that men and women had. Their instrumental and emotional needs influenced the support that they sought and valued. For men this often included informational and non-verbal support. For women, it more often included emotional support. However, there was also evidence that the context in which different types of support are offered may influence how acceptable these options are to patients. This included men being more open to sharing their emotions in single-sex groups and women perhaps being interested in emotional support in small groups and information when it was presented online. The importance of providing various choices to patients is further explored in the next theme relating to treatment and trials.

3.3. Treatment and trial choices

Gendered differences in language and decision making, particularly in relation to treatment choices, impact on family and maintaining a sense of control, are discussed here.

When recounting their experiences of deciding which treatment to accept or decline, men's accounts often appeared more concrete, using more decisive language, while women's accounts indicated a more tentative approach to treatment decisions:

"My quality of life is more important. So I'll be telling them to stick their chemo where the sun doesn't shine." M8, Ivan

"I know I had ... I think ... Whether it was that first time ... I wasn't sure whether I wanted to go ahead and have chemotherapy, which was suggested. I wanted time to think about it." F3, Cath

Both these participants were unsure whether to pursue chemotherapy (both subsequently did pursue it) but the expression of the decision-making process differed. For Ivan, the initial (strongly expressed) decision not to have chemotherapy was reversed after further time for reflection and consideration of possible outcomes. This seems to have generated a less reactive approach to future decision making as he goes on to explain:

[when asked if he would partake in another trial] "I'm not saying I'd jump to it automatically because of what the benefits or the risks are, but I would look at it. I wouldn't knock it on the head straightaway or go, yes, I'll have that, but I'd really look at it." M8, Ivan.

Other men also made rapid decisions that, on reflection, they wish they had considered more carefully:

"In all honesty, I didn't realise just how big an operation it was [...] I'm not sure I'd do it again". M13, Mike

The gendered expectation then that men should take quick and conclusive action when facing threatening situations is expressed through the use of decisive language. However, as we see in Ivan's quotes, such verbal certainty is not always indicative of subsequent actions. While Cath was quite able to articulate her need for "*time to think about it*", it may be that men feel less able to articulate this even though it is no less important for them. This has implications in relation to how practitioners might help legitimate men having time to reflect.

There were other gender differences noted in the approach to treatment and trials. Women often discussed the emotional impact that trial participation would have on their families. At times, this anticipated impact deterred women from trial participation. In other cases, it discouraged women from discussing treatment and trial participation with their families:

"I don't discuss it with my family [...].I used to say to them I'm going back into a trial, don't worry about me." F1, Amy

As noted earlier, many of the women who participated expressed a sense of responsibility for the emotional well-being of their family. Linked to this, considerations around the type of support required after trial intervention were also influenced by the needs of family members.

Women's focus on reducing the emotional impact on family suggested that they prioritised their families' emotional well-being when deciding whether to take part in a treatment or trial. This echoed the sense of responsibility for the emotional well-being seen in the earlier theme "Familial responsibility and social perceptions".

In contrast, the men interviewed did not directly discuss the emotional impact of their treatment and trials on their family members. Instead, they gave more consideration to the financial impact of mesothelioma on their loved ones:

"I worry for my wife, what's going to happen when I go, because she relies on me quite a lot [...] I do all the bills, I do everything in the house as far as the running of it, if you like. So I've got to try to start getting her to do all the banking, all the money, all the bills, that part of it." M4, Derek

For several men, their experience of trial participation included some loss of control due to the process of randomisation and potentially receiving a placebo. Control was then reasserted in specific ways, for example seeking non-NHS funded or off-trial treatment to ensure getting the desired treatment:

"... the option was to go on the trial, but you were taking a chance, so we paid for it" M4, Derek

This same link between clinical trials and control was not found in the women's accounts. They were often more willing to be guided by the health professionals:

"I'm happier sort of being told what to do. I'm not very good at making decisions." F3, Cath.

This theme provided insight into how decisions around treatments and trials may differ by gender. Men's initial tone suggested that they were more certain of their decisions than they actually were. Similarly, women's tentative approach suggested that they were unsure. Additional time and explanation may be needed for both men and women to help make difficult treatment and trial decisions.

The results have shown that several aspects of living with mesothelioma may be gendered. Understanding these factors may be useful for those supporting patients living with mesothelioma. The impact of mesothelioma on the patients' role in the family, their support needs and a sense of control all influence men and women's experiences of living with mesothelioma.

4. Discussion

This paper explored the gendered experiences for people living with mesothelioma. For both men and women, social constructions and a sense of familial responsibility may influence their priorities, desired support and decisions around treatment, support and seeking compensation.

Traditionally, women have been responsible for juggling multiple roles which involve housework, childcare and emotional care-giving for the family (Erickson, 2005; McCaughan et al., 2012). Our findings show that the traditional distribution of labour may continue to exist for many families living with mesothelioma. When professionals are caring for women, they should be aware that their priorities may include the emotional well-being of their family and that this may influence their decisions around seeking compensation, treatment, and support. Men are also influenced by traditional role norms. Work on men's experiences of chronic ill-health and of prostate cancer shows that paid work and financial provision for the family are major themes (Chapple and Ziebland, 2002; Flurey et al., 2018). Our findings reinforce this showing that, for men, securing the financial well-being of their family is highly important to their well-being and their on-going sense of male identity. Financial compensation can alleviate some of the financial burden of living with mesothelioma or caring for a person living with mesothelioma. It can also alleviate concerns for the financial well-being of family members after the death of the patient. Given the high number of mesothelioma diagnoses in men, awareness of this may help professionals working with families to identify their patients' focus. For people living with mesothelioma, particularly those unsure of where they were exposed, the decision to seek compensation may be complex.

People living with mesothelioma in most industrialised countries (including the UK) are entitled to government, and often civil, compensation. Occupational exposures are currently responsible for the vast majority of asbestos induced cancers in industrialised countries (Goldberg et al., 2006). Evidence shows that women are less likely to seek compensation than men (Chamming et al., 2013; Kirkham et al., 2011; Senek et al., 2020; Tod et al., 2020). Our findings suggest three possible explanations for this. First, there may be a gendered cultural expectation for women not to be financially driven. Second, women may not have the same sense of financial responsibility to the family. Third, a lack of knowledge of a clear occupational link has also been suggested as a deterrent to women seeking compensation (Kirkham et al., 2011). There is evidence to suggest that many working in schools, hospitals and support roles in industrial settings underestimate their risk of exposure to asbestos. This is due to mesothelioma being historically considered an occupational disease, associated with heavy industrial exposure (Kirkham et al., 2011). Nevertheless, there is little research to understand the motives for and against seeking compensation for mesothelioma and asbestos related diseases (Payne and Pichora, 2009). Our findings show that professionals (health, ASG and legal) can play an important role in educating patients of a potential entitlement to compensation and

benefits, and supporting patients through the process of seeking compensation and benefits. For women in particular, professionals may play an important role in counterbalancing powerful social and cultural norms that suggest women are not financially literate and/or should not be interested in money (Anthes and Bruce, 2000).

As well as gendered social roles impacting on family responsibility, in this study traditional roles were shown to influence support seeking needs and experiences. Although little is known about the motivation that people living with mesothelioma have for attending support groups, our findings show that support groups are likely an important source of information exchange and emotional support. In the UK, charities, professionals, patients and carers run mesothelioma support groups. The findings in this paper can be used to consider the different types of support available and the advantages of adding different formats of support for the group attendees. GEMS shows that men often had a preference for information and women for emotional support. This finding, aligns with those from previous studies of men living with prostate cancer and women living with breast cancer (Blank et al., 2010; Carter et al., 2014). However, our findings are not intended to suggest that men do not value emotional support and women informational support. We argue that while there may be a gendered preference for a type of support, how different types of support are offered i.e. in a single sex support group, in a smaller group or online, can also influence acceptance of support. Exploration of women's preference for online informational support may warrant further investigation. It is also likely that motivations for attending support groups might change throughout patients' (and family members) mesothelioma journey (Bell et al., 2010). There was also evidence of different formats of groups being conducive to providing different types of support. Therefore, further consideration around the format of delivery may be beneficial for patients. This information may be useful for those planning support groups.

The way men and women engage with support groups is partly about gendered forms of communication. Findings here show how this was also present in the language used when expressing treatment and trial choices and decisions. Hedegaard et al. (2014) reflect on how mutual constructions of gender, by both patients and healthcare professionals, can lead to gender stereotypical communication. Evidence also suggests that men may express their emotions in ways that are often unclear and can be difficult to interpret (Martopullo et al., 2020). In practice, the expression of a decision, or lack thereof, perhaps requires further exploration. Specialist nurses play an important role in supporting patient decision-making in the context of lung cancer (Tod et al., 2015) and we see here that this may also apply to those living with mesothelioma. Specialist nurses often have the opportunity to support patients over time, permitting further, perhaps more nuanced, exploration of patients' initially expressed decisions.

Traditional masculinity norms emphasise strength and control, both physical and mental (Hilton et al., 2009). Given this, it seems likely that when some men are faced with a decision to make regarding their treatment, they use language and verbalise decisions which can be perceived as assertive and strong. However these initial expressions may not reflect the full decision making process. This highlights the importance of understanding underlying factors that may influence patient's expressed versus actual priorities when making treatment and trial participation decisions. Additionally, there is evidence to suggest that understanding trial information can be challenging for patients living with mesothelioma (Warnock et al., 2019). This further emphasises that importance of ensuring that patients are given information in a various formats, and time to assimilate this information, before accepting their initial decision in regards to treatment and trials.

The findings presented in this paper have important implications for practice. They outline the contribution that both health care and non-healthcare professionals can make to improve the experiences of men and women living with mesothelioma. ASGs and legal professionals play an important role in ensuring access to information about compensation.

Professionals, who may be in regular contact with patients living with mesothelioma, should make patients and their families aware of sources of information, support and financial compensation.

4.1. Limitations

GEMS is the first study to provide in-depth insight into the gendered experiences of mesothelioma. The main limitation of the study is that the sample is small, but it is comparable with similar qualitative experience based studies (Baker and Edwards, 2012) and was sufficient to generate new insight into the gendered experiences of mesothelioma. The second limitation is that the perspectives of family carers were not included. Given the important role that family members had in the lives of participants and studies showing that patient and carers may have differing emotional responses (Clayson et al., 2005), their perspective would have made an additional contribution to the findings presented here. However, the timescale of the study did not allow for further interviews and analysis to take place. A study of carers' experiences of mesothelioma would help to illustrate these additional perspectives and provide depth to what is known about the experiences of living with mesothelioma. Finally, the sample was diverse in regards to the age, geographical location within the UK, living circumstances (partnered or single) and mesothelioma site. However, increased diversity in terms of participants' gender of partner and ethnic origin would have been advantageous. Given the challenges in recruiting participants to a study of a rare condition, in a restricted timeframe, the sample diversity was considered acceptable.

As this was a gender focussed study, it is appropriate to reflect on gender interactions within interviews. Interviews were conducted by a female researcher [SEM]. The researcher felt comfortable and felt that rapport was built during the interviews with both men and women. The researcher was experienced in interviewing both men and women. Rapport between women researchers and interviewees has been explored in the literature (Brooks, 2007; Cotterill, 1992; Oakley, 1981). There is evidence to suggest that some men may feel more comfortable discussing their emotions and experiences with women researchers (Broom et al., 2009). Research on women interviewing men suggests that women may yield different, but equally valid, data to interviews conducted by men with men (Smith and Braunack-Mayer, 2014). This suggests that gender disparity between the interviewer and male interviewees may be a strength of this study rather than a limitation.

5. Conclusion

This paper articulates the experiences of men and women living with mesothelioma. The findings related to these gendered experiences and, in doing so, it generates evidence to identify the implications of these experiences for health, social care and legal practices. GEMS indicates that gendered differences may exist in the mesothelioma patient experience and provides evidence that cultural constructions of gender remain. These differences highlight the importance of supporting patients to make informed decisions regarding access to support, compensation, treatments and trials. Knowledge of the roles that men and women may play within their families, and society, can provide professionals with insight into how best to support patients and their families.

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CRediT authorship contribution statement

Stephanie Ejegi-Memeh: Investigation, Formal analysis, Writing – original draft, Visualization, Writing – review & editing, Project administration. **Steve Robertson:** Conceptualization, Methodology,

Formal analysis, Writing – original draft, Writing – review & editing, Visualization, Supervision, Funding acquisition. **Bethany Taylor:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Visualization, Supervision, Project administration. **Liz Darlison:** Conceptualization, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Angela Tod:** Conceptualization, Methodology, Formal analysis, Validation, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition.

Declaration of competing interest

No conflict of interest to declare.

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