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ORIGINAL ARTICLE

"It sort of hit me like a baseball bat between the eyes": a qualitative study of the psychosocial experiences of mesothelioma patients and carers

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Abstract

Purpose Mesothelioma is an insidious disease with a generally poor prognosis even after invasive treatment. This qualitative study aimed to explore the experiences of patients suffering from mesothelioma and their carers and their perceptions of how their needs may be addressed.

Methods Eligible patients and carers were identified by a lung cancer care coordinator at each participating site, and invited to participate in one-on-one semi-structured telephone interviews ($n = 5$ patients, $n = 3$ carers), or in one of two focus groups ($n = 3$ patients, $n = 3$ carers). Discussions focusing on participants' experiences relating to physical, psychological, social, information and carer domains were audio-recorded, transcribed verbatim and thematically analysed.

Results The five major themes identified were (1) time of diagnosis is a particularly difficult period; (2) the timeliness, accuracy and balance of mesothelioma information is problematic; (3) coping strategies ranged from antagonism to acceptance; (4) the emotional and physical load of caring for the patient is significant and (5) carers need one-on-one support.

Conclusion Mesothelioma patients and their carers face significant challenges, particularly around the time of diagnosis and in the physical, psychological and social/practical domains. There is a clear need for additional information, delivered in a timely and psychologically sensitive manner, as well as for practical and emotional support. Quantitative research may shed greater light on the prevalence and severity of challenges and needs reported by participants, and determine the usefulness of resources such as case workers and dyadic coping interventions in addressing these.

Keywords Mesothelioma · Cancer · Supportive care · Psychological distress · Caregivers · Qualitative

Introduction

Mesothelioma is a complex cancer affecting the pleural lining of the lung that is commonly linked to asbestos exposure [1]. The latency period between asbestos exposure and development of mesothelioma is often longer than 40 years [2]. Therefore, a diagnosis of mesothelioma is often unexpected. Up until the mid-1980s, Australia was a major producer of asbestos and one of the world's highest users per capita of asbestos [3]. Consequently, Australia has one of the highest rates of mesothelioma in the world, with 650 new cases reported in 2015, most of whom were male (78%) and aged over 65 years (82%) [4].

Patients typically experience chest pain, shortness of breath, fatigue, and a wheezing chronic (and sometimes bloody) cough [5]. Patients with early stage mesothelioma generally have multimodal therapy incorporating radical surgery with chemotherapy and/or radiotherapy, whereas those with unresectable disease receive palliative chemotherapy [5]. The prognosis for mesothelioma is generally poor (approximately 1 year) [6] with a 5-year survival rate of less than 10% [7]. Given the severe symptoms,

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invasive treatments and poor prognosis associated with mesothelioma, a greater understanding of its impact on day-to-day life, including the effects on physical, psychological and social wellbeing of patients and their carers is required.

Needs assessment, one of several approaches used to evaluate the impact of cancer, facilitates the identification of people with particular concerns or dissatisfaction with certain aspects of their care [8], and also determines the person's desire for assistance and involvement with services [8, 9]. Cancer patients and carers have reported experiencing supportive care needs across a broad range of domains, including physical (e.g. physical symptoms, treatment side effects), psychological (e.g. depression, anger), social (e.g. family, relationships), emotional (e.g. self-worth, coping), informational (e.g. disease, treatment), spiritual (e.g. meaning of life) and practical (e.g. financial, legal) [10, 11].

Despite a marked increase in assessment of challenges and needs in oncology populations, demonstrating significant psychosocial burden in both cancer patients [12, 13] and carers [14], there is a dearth of literature exploring these issues specifically in people affected by mesothelioma. The limited research in patients highlights their difficulties in completing daily tasks [15], fluctuations in physical capacity [15], fatalistic attitudes toward the disease and its consequences [16] and a desire to share their experiences [15]. Whilst these may all reflect underlying areas of need within the population, further exploration is warranted. Also underresearched are the challenges and needs of carers of mesothelioma patients. Given the significant burden of mesothelioma and the lack of existing literature, the aims of this project were to explore the experiences of patients suffering from mesothelioma and their carers and their perceptions of how their needs may be addressed.

Methods

Study design

Given the lack of literature in this field, a qualitative approach was employed. Qualitative research is particularly useful for understanding how people experience and make sense of events, such as a diagnosis of mesothelioma, without presupposing important variables to assess [17]. The exploratory, idiographic and principally inductive nature of qualitative enquiry gave mesothelioma patients and carers the flexibility to self-identify issues of greatest concern and facilitated in-depth exploration of those issues [18]. Interview and focus group discussions were semi structured, providing a basic scaffold of questions and topics to cover which corresponded to the domains defined in the Supportive Care Framework [10].

Study sample

Patients were eligible to participate if they:

- Were aged 18 years or over;
- Had a confirmed diagnosis of mesothelioma;
- Had received care at any time at a participating hospital;
- Were judged by a cancer care coordinator to be well enough to participate in an interview/focus group;
- Provided informed consent

Carers of corresponding patients, aged 18 years or over, were also eligible, as were recently bereaved (< 12 months) carers, identified from clinic records by a cancer care coordinator. Patients and carers could participate independently of the other.

Participant recruitment

Eligible participants were recruited from three tertiary hospitals in Sydney, New South Wales (NSW), Australia, throughout 2010. Cancer care coordinators at each site identified eligible participants from their clinic records and mailed them a study information package. Invitations to participate were directed to the patient/carer (including bereaved carers) and interested participants returned their consent form via a reply-paid envelope, indicating their preference for a telephone interview or focus group. The Hunter New England Human Research Ethics Committee approved the study (10/07/21/5.06).

Data collection

Four trained interviewers conducted the one-on-one telephone interviews ($n = 5$ patients, $n = 3$ carers); and the senior author (AG) cofacilitated the patient ($n = 3$), and carer ($n = 3$) focus groups with a second author (AW, SL). Participants were asked questions broadly relating to the domains in Table 1.

Data analysis

Data was analysed using thematic analysis, which is "a method for systematically identifying, organising, and offering insights into patterns of meaning (themes) across a dataset" [19, p57]. Thematic analysis was used within a critical realist framework, which assumes that whilst interview data offers insight into participants' experiences, some degree of interpretation is required to understand the reality of their experience [20]. One team member (SG) independently coded all

Table 1 Example interview/focus group questions

Domains covered in interviews/focus groups	Example interview question
Physical	What physical symptoms have been most troubling to you during your illness?
Psychological	What types of services or support, if any, did you seek or were offered to help you cope with the experience of caring for someone with mesothelioma? Which of these were most helpful and why?
Information	What information did you receive about mesothelioma at the time of the diagnosis? Was this information sufficient?
Social/practical	How has the experience of dealing with mesothelioma affected your life socially? Are there things that you no longer do because of your illness? If yes, please describe these.
Carer/family	What types of services or support, if any, did you seek or were offered to help you and your family cope with these issues? Which of these were most helpful and why?

All interviews/focus groups were audio-recorded and transcribed verbatim by a professional transcription service. Transcripts were validated by comparison with recordings.

transcripts and generated a list of codes, the underlying meanings embedded within the data set which represent the basic unit in the thematic hierarchy. Individual nodes (groups of codes) were then arranged into thematic subgroups and these were further grouped into higher order themes. A constant comparative method (i.e. moving back and forth between the entire data set, the coded extracts of data and the themes generated) [17] was used to ensure the developed thematic hierarchy accurately reflected the interview data. Memos were utilised throughout coding and data analysis to track progress of evolving ideas and themes. To ensure the integrity of the analysis, another team member (ABS) coded two of the interviews early in the analysis process, with subsequent side-by-side comparison of codes and resolution of disagreements through face-to-face discussions.

Results

Eight patients (six males, two females) and six carers (all females) participated in the study, of whom four pairs were patient-carer dyads. At the time of participating in this study, the mean age of patients was 64 years (SD = 8.3), consistent with the Australian mesothelioma population generally [7], and carers' mean age was 64.2 years (SD = 8.6). The demographics of each participating mesothelioma patient and carer are listed in Table 2. Time since diagnosis ranged between 11 weeks and 3.5 years (mean 1.5 years, SD = 1.4). Interviews ranged from 35 to 72 min; and patient and carer focus groups lasted 123 and 119 min, respectively. Pseudonyms are used in the text.

The five major themes identified were (1) time of diagnosis is a particularly difficult period; (2) the timeliness, accuracy and balance of mesothelioma information is problematic; (3) coping strategies ranged from antagonism to acceptance; (4) the emotional and physical load of caring for the patient is significant and (5) carers need one-on-one support.

Theme 1: time of diagnosis is a particularly difficult period

The shock of a mesothelioma diagnosis was consistently reported by both patients and carers. The unexpected nature of a mesothelioma diagnosis and the poor prognosis created a degree of fragility in participants, often leaving them unable to bridle negative feelings. Emotions such as anger and stress were common:

> … it sort of hit me like a baseball bat between the eyes. I didn't expect to hear what I heard. (P5)

Table 2 Demographics of participating mesothelioma patients and carers

Interviewee		Age (years)	Time since patient diagnosis
One-on-one interview	C1	59	3 years
	P1	61	3 years
	C2	76	2 years and 3 months
	P2	78	2 years and 3 months
	C3	63	6 months
	P3	65	6 months
	P4	62	6 months
	P5	61	3 months
Patient focus group	P6	59	11 weeks
	P7	74	3 years and 6 months
	P8	52	5 months
Carer focus group	C4	73	4 years
	C5	54	11 weeks
	C6	60	3 months

A carer also reflected her angry reaction to the news and her difficulty accepting that there was little that could have been done to alter the situation:

> I was angry. Really angry. But did I blame the doctors? I did ask the question – why? When he's had problems for the last couple of years, why wasn't this picked up earlier? And they just explained that it's just a really challenging cancer to diagnose. (C1)

Theme 2: the timeliness, accuracy and balance of mesothelioma information is problematic

Timing of information is important (informational)

Patients and carers reported varying levels of receptiveness to mesothelioma-related information depending on the timing of information relative to diagnosis and whether it was provided by the healthcare team or anecdotally from other sources. Receiving large amounts of information whilst dealing with the shock of diagnosis was seen as inappropriate. Patients wanted information they could refer back to when appropriate:

> I would have liked to have gone home with a package like that, I think, of information to look at on my own when I was feeling ready for it. (P8)

Some patients and carers delved into past patient stories in a search for meaning and clarity about their circumstances. This kind of information was potentially harmful if it was read at a time when the patient or carer was already feeling down:

> And some of the books are sad – some of the patients don't survive, and you're reading this and it got my husband in a very depressed state at one stage, or a couple of times anyway. You think I don't think I'm going to read any more. (C3)

Content of information is predominately negative (informational)

Participants expressed unease about the content of mesothelioma-related information provided, which was perceived as predominantly negative:

> The side-effects and things, you know? None of that was good… (P7)

This sometimes generated a sense of hopelessness in the patient, detracting from the quality of the patient's remaining time. There was a general avoidance or discounting of statistics found on the internet regarding the poor prognosis of mesothelioma, as these were seen to be outdated or irrelevant:

> The big thing is finding information that's up to date and takes into consideration up-to-date situations. (P2)

Other patients reacted by avoiding information that might cause them to think about their unfortunate situation:

> Well I could go on the internet and the more you go on the internet, the more depressing it gets, so I shut that out the back of my mind, you know. (P3)

Theme 3: coping strategies ranged from antagonism to acceptance

Not going down without a fight (emotional)

Some participants characterised their cancer journey as a *battle* in which their cancer was an enemy or obstacle to be conquered, with this fighting spirit demonstrating participants' capacity for resilience, even amidst seemingly unfavourable circumstances:

> Well look – I ain't going away without a fight! I'm not going to roll over and play dead – that's not me! So I'll go down kicking and screaming until the living end! (P5)

Patients' resilience in the face of challenging circumstances was acknowledged by carers:

> He goes in, has his chemo and goes home – and as I said, goes to work! He is so – he's just – I don't know what it is with him, it's like he's not going to let this beat him. (C6)

Acceptance of the situation (emotional)

In contrast to the subtheme above, some participants reported acceptance of their situation as a way of coping:

> I'm trying to work out – I mean I know it's there, and he's going down a little bit now, so I'm just accepting each day - what happens... (C2)

Their own situation is unique (psychological)

A common perception between both carers and patients was that their case was unique and not subject to the statistics that they read:

> So that was the best thing that ever could be for us, as a couple – because all the statistics that we were given about after an operation, generally you've got two years maybe more, but you know – these are all based on

> previous patients. But because Richard was one of a kind, we had no statistics to think about and it helped us because he was the first ever to have no live cells, so therefore he can be the first one to survive this and have a long life. (C1)

Theme 4: the emotional and physical load of caring for the patient is significant

Hard supporting patient as well as family (social)

Caregivers fulfilling spouse and carer roles reported a significant emotional load due to these dual responsibilities. These carers often had close contact with the patient and healthcare team and detailed knowledge of the patient's disease state and progress, resulting in difficult decisions regarding with whom and how much to share about patients' circumstances. Carers sometimes inhibited expression of their own emotional turmoil to protect other family members to the detriment of their own emotional wellbeing:

> I find I hold back with a lot of things I'd like to say… (C4)

Challenges associated with being a carer (practical)

In addition to the emotional impact of mesothelioma, carers also described struggling with the physical and practical demands of caring, which is often perceived to be a full-time responsibility. This physical load in particular can completely consume a carer's resources, leaving them with little capacity to complete their other responsibilities:

> I feel guilty now if I don't come home straight from work. If I go to the shops I think oh, I should be at home with him. I've never felt like that before, we've always done our own thing you know, and now I feel as though I have to be home with him. (C5)

Theme 5: carers need one-on-one support

Carers need formal support from professionals/services (practical)

Carers valued one-on-one support and reflected positively on instances when they received it. Support primarily came from two sources: (1) case workers (i.e. registered nurses assigned to coordinate the medical, psychosocial and practical aspects of an individual patient's care) and (2) interactions with other mesothelioma carers. The case workers' special position in the patient's care allowed them to bridge the gap in medical knowledge as well as provide carers with emotional support:

> I: Was Kim a particularly helpful resource that you found?
> C: Yes. Yes – always thought you could pick the phone up and ring, you know when Larry had a bit of a problem we could always call Kim, yeah. (C3)

Case workers were also able to talk intimately with the carer, and this emotional support was viewed very positively by carers:

> She was ringing me, as I said, a couple of times a day, and it started off 'how was Robert last night? Did he get a good night's sleep?' And then it became more and more and then it became about me, you know 'how are you feeling? Are you coping?' and all this. And it became this – I almost was glad to hear her voice. She was someone that understood. She was someone that gave me medical advice, but also personal advice, just support. (C1)

Carers' need for peer support (emotional)

The second source of support appreciated by carers was other mesothelioma carers. Being familiar with the mesothelioma experience, these carers were able to provide support that acknowledged the various disease-specific nuances encountered by carers:

> I wanted to talk to people, but they were [not] going through the same thing. And there was no one there for me. I mean it's no good talking to someone who's got breast cancer – it's no good talking to someone who's got bowel cancer. I wanted someone who's going through – like you two are. (C6)

There was also a need for information targeted toward carers with advice about what to expect in the future:

> I think it's good to have in there something that you can put in there, especially for your next of kin or whatever, you know like so they can understand it a bit more too. (P6)

Discussion

This study is one of few investigations into the challenges experienced by, and the needs of, mesothelioma patients, and one of the first to concurrently explore these issues in carers. Challenges and needs were reported across the cancer trajectory relating to receiving and coping with the diagnosis, accessing balanced (where possible) and timely information, providing emotional and practical support and accessing formal and informal assistance.

The themes derived from this study overlap somewhat with key concepts from a recent systematic review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer, which included only five papers focused specifically on mesothelioma patients [21]. There was consensus that the experience of diagnosis was particularly stressful and that the information and outlook associated with mesothelioma was primarily negative. We observed some more adaptive coping strategies for dealing with mesothelioma's poor prognosis, such as fighting spirit or acceptance, in addition to the hopelessness identified in the review [21]. Perhaps prognostic information was delivered in a more hope-inspiring manner to participants in our study. Patients' concerns about burdening their carer were a key concept in the review [21], but actual carer experiences were not reported.

Previous studies acknowledge the diverse reactions that patients and carers may have to a cancer diagnosis [11, 15, 22]. Coping during diagnosis has been associated with improved quality of life later in treatment and better self-care during survivorship [22]. However, the requisite adaptation associated with a mesothelioma diagnosis may be particularly challenging, given its poor prognosis. One potential approach to restabilising the patient and carer in the first few weeks after receiving a diagnosis of mesothelioma is the involvement of a case worker. Patients and carers in this study identified these individuals as an important source of practical and emotional support. In this instance, case workers were registered nurses employed by the Asbestos Diseases Research Institute (ADRI) to provide telephone, face-to-face and group-based support to mesothelioma patients and their families. There are presently two ADRI case workers responsible for supporting NSW mesothelioma patients and carers. This model of care could be extended to all mesothelioma patients and carers by training additional registered nurses or social workers to provide telephone-based support.

Timing of information provision was not always appropriate, leading patients and carers to seek alternative but potentially less credible sources of information, such as from peers and the internet. Patients and carers should be advised of the potential downsides of searching for information online (e.g. the predominance of 'horror stories') and directed to credible sources of information, such as Cancer Council Australia's *Understanding Mesothelioma* booklet, which is available online and in hardcopy. Conveying information about what to expect during the cancer journey is an important yet challenging task for the health care team. Information should be provided in a manner that is responsive to people's preferences, easily understood and recalled and relevant to the particular circumstances of the patient [23]. This can help those affected by cancer to make informed decisions about care and set goals [24].

There is hesitancy among some clinicians when delivering information to those with limited life expectancy because of fear of harming the patient or carer [25]. Patients and carers may also have differing views about the appropriate amount, timing and content of information they want to receive. These findings support an approach whereby clinicians and involved healthcare workers consider communicating information and statistics regarding mesothelioma incrementally. To do this, clinicians should routinely check in with patients to determine information needs, including when they want to receive information and the desired level of detail [23]. Clinicians also need to actively elicit and respond to the evident emotional concerns of mesothelioma patients and their carers and provide multidisciplinary referrals (e.g. to psychological counselling) where appropriate. Multidisciplinary care of those affected by mesothelioma is recommended from diagnosis to ensure a consistent management approach that addresses the full spectrum of biopsychosocial needs of patients and carers [1].

It is clear that a mesothelioma diagnosis has significant consequences for both patients and carers. Carers reported struggling to manage their usual roles and responsibilities with the new physical and practical demands of caregiving, consistent with studies of other cancer carers [26]. For carers, the importance of accessing both formal and informal supports to cope with the practical and emotional consequences was clear. Whilst some carers placed particular emphasis on contact with case workers, they may not be accessible to all patients.

There is preliminary evidence for the benefits of a telephone-based dyadic intervention in improving psychological functioning, self-efficacy for managing symptoms and working together as a team in advanced lung cancer patients and carers [27]. The application of a similar intervention to mesothelioma warrants further examination given the similar challenges experienced by these groups [21]. Carers also highlighted the importance of contact with other carers who share similar experiences, potentially achieved through support groups. However, establishing mesothelioma support groups is challenging, due to the small numbers diagnosed with mesothelioma and that significant symptom burden and poorer prognosis may inhibit participation [28]. An online support group incorporating a forum where advice and support could be provided asynchronously may help overcome these barriers.

Study limitations

All patients and carers were recruited from three hospitals, which represent the main treatment centres for mesothelioma in NSW, the most populous Australian state. This sampling method means that the experiences of those affected by mesothelioma from other states or with advanced disease receiving palliative treatment outside hospitals are not well represented. Ideally, such patients and their carers would have been included through purposive sampling. We acknowledge the active role of the researchers in generating themes, as it seemingly introduces a degree of subjectivity to our analysis. However, it is consistent with the critical realist theoretical framework used for this analysis, which posits that as qualitative data does not directly reflect the reality attempting to be understood, some level of interpretation is necessary [20]. Consistency between theoretical assumptions and analytic claims is considered fundamental to high-quality qualitative research [17, 29]. Further, to reduce subjectivity, two interviews were double coded early in the analysis phase and differences in codes were resolved through discussion.

Conclusions

This study provides a useful framework for understanding the challenges and needs of mesothelioma patients and their carers with the potential to inform the development, implementation and evaluation of targeted supportive care interventions. Quantitative research is needed to ascertain the prevalence and severity of challenges and needs across a broader range of patients and carers. A needs assessment tool could be administered to patients and carers by case workers or clinicians at several points throughout the care trajectory and an audit of results be conducted. Information about the level and type of support required to meet the needs of patients and carers as they progress through their cancer trajectory is also required.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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