




Dying of mesothelioma: A qualitative exploration of caregiver experiences

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Abstract

Objective: To explore the experience of family caregivers of people with mesothelioma with focus on end-of-life issues.

Methods: A qualitative sub-study using semi-structured interviews and thematic analysis.

Results: Fourteen caregivers were interviewed; 11 were bereaved. The overarching theme was the impact of patients' diagnosis, treatment and death on caregivers and families. Three main themes were identified: (i) information provision and decision-making; (ii) grief and bereavement; and (iii) involvement and timing of palliative care. Caregivers initially had minimal knowledge of mesothelioma and wanted more information. Prognostic uncertainty caused distress. Grief and bereavement sub-themes were (i) coping and personal priorities; (ii) reflections on dying; and (iii) reflections on care. Caregivers highlighted the importance of creating meaningful events, having hope, 'doing something' and support from family and external sources. Reflections on dying contrasted regret after a 'bad', often unexpected death, with 'good' deaths. Care was made difficult by challenges navigating the health system and perceived gaps. Caregivers reported late referral to palliative care.

Conclusion: Lack of information caused challenges for caregivers. Grief and bereavement outcomes varied and may have been adversely impacted by lack of engagement with palliative care. Integrated care with lung cancer coordinators and improved palliative care access may reduce caregiver burden.

KEYWORDS

bereavement, carers, communication, dying, lung cancer, palliative care

1 | INTRODUCTION

Malignant pleural mesothelioma (MPM) has high symptom burden (Mercadante et al., 2016) leading to patient distress and significant dependence on caregivers and contributes to the uniquely challenging

practical and psychological experience for patients and their caregivers. Despite a small cohort who live significantly longer (Linton et al., 2014), for most, the extremely poor prognosis creates uncertainty in predicting trajectory and care needs. Late referral to palliative care and avoidance of death discussions have been reported to leave

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caregivers unprepared for the terminal phase and patient death (Guglielmucci et al., 2018; Lee et al., 2009). Other key areas where mesothelioma differs from lung cancer, which it is commonly grouped with, are hopelessness, external but sometimes conflicted blame and the burden of legal claims (Ball et al., 2016). Mesothelioma caregivers have been stated to have high levels of emotional morbidity, with anger (89%), anxiety (84%), depression (80%), feelings of isolation (79%) and fear (57%) (Moore et al., 2010). Despite this, there has been little research undertaken to investigate caregiver experiences (Harrison et al., 2021; Sherborne et al., 2020), emphasising the importance of this study in strengthening the evidence base and establishing a wider understanding. Therefore, our aim was to explore caregivers' experience providing end-of-life care for people with mesothelioma.

2 | METHODS

This is a secondary analysis of a larger qualitative study involving interviews with MPM patients, family members of MPM patients (both alive and deceased) and mesothelioma health professionals which aimed to explore experiences of decision-making about care and treatment. Secondary analysis was undertaken in response to the wealth of data shared by participants about end-of-life experience. (Supp 2) All participants gave written informed consent. The study was approved by the Concord Repatriation General Hospital Health Research Ethics Committee (HREC/12/CRGH/122) and conforms to the European Medicines Agency Guidelines for Good Clinical Practice.

2.1 | Research team and reflexivity

Two experienced female researchers (AW, HD) conducted the interviews. AW, a research officer, was trained in qualitative research methods by HD, a behavioural scientist with expertise in qualitative cancer research and psycho-oncology. Two medical oncologists, JV and SK, and two palliative care physicians, DM and JL, completed the interdisciplinary team.

Participants were not previously known to the research team except Participant 001 who was an acquaintance of the interviewer from a previous clinical trial. The interviewers are likely to be influenced by their extensive previous work in mesothelioma as well as concurrent interviews conducted with patients and clinicians as part of this project. Researchers practiced personal reflexivity while coding. During framework development and application, coders (JV, HD, JL, DM) engaged in reflexive discussion to interrogate coding decisions.

2.2 | Participants

Caregivers were defined as individuals providing informal care to a person with MPM or who had done so prior to their death from

MPM. Caregivers were recruited through the Asbestos Diseases Foundation of Australia (ADFA), a community-based organisation providing support to people living with asbestos-related diseases and their families, and the Asbestos Diseases Research Institute (ADRI). Purposive sampling was undertaken via ADFA meetings and newsletters, and the ADRI website, with participants self-selecting to take part by responding to advertisements as noted above.

2.3 | Data collection

Single interviews (range 12–77 min) were conducted individually either via telephone or face-to-face in participants' homes or ADFA or ADRI offices, from January to June 2013. The interview guide was pilot tested with representatives of ADFA and is available in Data S1. Each interview was audio-recorded and transcribed verbatim. Recruitment to the main study stopped after thematic saturation was achieved in each group.

2.4 | Data analysis

This qualitative study used thematic analysis with a framework approach (Gale et al., 2013) to explore the experience of caregivers providing care to mesothelioma patients. As this was a secondary analysis, the first five caregiver interview transcripts were read (JL, DM, JV, HD), and an initial coding framework created. Application of the initial framework to the next five transcripts resulted in framework refinement without addition of new coded information indicating thematic saturation had been achieved. This was confirmed by the coding of the final four transcripts where no new themes were identified. All authors read the transcripts to identify themes and iteratively developed the coding framework using tables in Microsoft Word (Gale et al., 2013). Transcripts were independently coded by two researchers (JL, DM) and compared to results from JV and HD who each coded seven transcripts.

3 | RESULTS

Fourteen caregivers participated in interviews; 11 were bereaved, and three were caring for a family member with MPM at the time of the interview. All caregivers spoke English as their primary language; 13 were wives and one was a daughter. Caregivers had a median age of 65.5 years (range: 51–79), 11 had not completed high school, seven were retired at the time of patients' mesothelioma diagnosis, and four stopped work to provide care (Table 1).

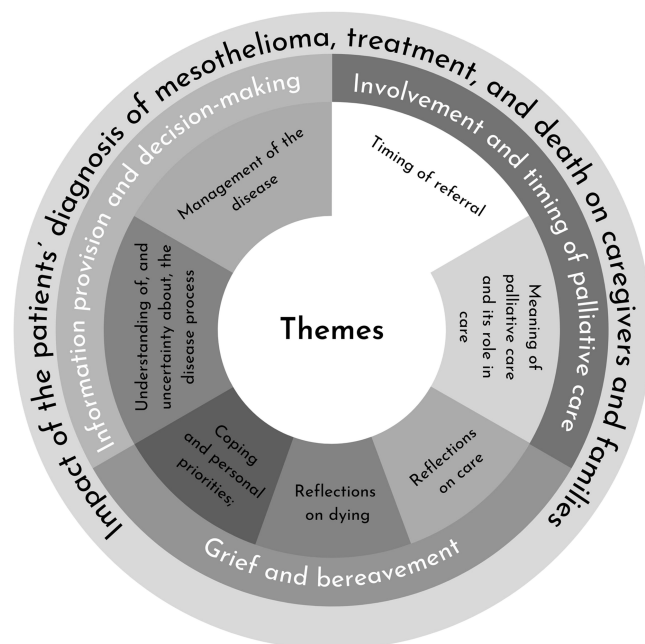
3.1 | Themes

The overarching theme pervading all interviews was the impact of the patients' diagnosis of mesothelioma, treatment and death on

TABLE 1 Caregiver participant characteristics

Participant ID	Age (years)	Relationship to patient W = wife Dg = daughter	Level of care Da = daily L = less than daily	Patient status at time of interview	Work status during patients illness H = home duties O = other R = retired S = stopped W = working	Education <HS = did not complete high school U = university	Location* 1 = metro 2 = regional 3 = rural
				D = deceased ATx = alive on treatment TxB = on treatment break W = alive & well			
001	51	W	Da	D	S	U	1
002	54	W	Da	D	S	U	2
003	66	W	Da	D	H	<HS	1
004	74	W	Da	D	R	<HS	2
005	74	W	Da	D	R	<HS	1
006	64	W	Da	D	R	U	1
007	62	W	Da	TxB	S	<HS	1
008	60	W	Da	D	O	<HS	1
009	71	W	Da	ATx	R	<HS	2
010	79	W	Da	D	R	<HS	2
011	69	W	Da	D	R	<HS	2
012	65	W	Da	D	S	<HS	3
013	70	W	Da	W	R	<HS	2
014	63	Dg	L	D	W	<HS	2

Note: *Location was classified as either (1) metropolitan centres representing those people residing in major cities; (2) regional people residing in regional centres (usually with a large hospital available but may not have specialist services); or (3) rural location meant those living outside major cities or towns.

**FIGURE 1** Overarching theme, themes and sub-themes

caregivers and families. It was powerfully reinforced through their ongoing distress in recounting their experiences.

... [husband] was diagnosed with the disease, but we all lived it. Participant 003

Within this overarching theme, three distinct themes were identified: (i) information provision and decision-making; (ii) grief and bereavement; and (iii) involvement and timing of palliative care (Figure 1) (Data S3).

3.2 | Information provision and decision-making

This encompassed two sub-themes: (i) understanding of, and uncertainty about, the disease process; and (ii) management of the disease. Early on, participants reflected a limited understanding of mesothelioma, disease development and progression. There was mixed awareness of its terminal nature, the dying process and what that meant practically for patient and caregiver.

... [respiratory physician] said it was mesothelioma. And I said 'what does that mean?', not understanding what the word was. And she just said 12 months ... I think it should have been explained what mesothelioma meant Participant 004

Prognostic uncertainty caused significant distress for caregivers.

I tend to feel a bit like the French you know, you have got your head on the block and you are waiting for la guillotine. You know you have got no idea what to expect. And that makes it hard. Participant 013

I was just scared stiff too for what might happen and how it was going to happen. Participant 009

Some participants indicated rapid deterioration of the patient meant they had no time to prepare for death.

His condition just deteriorated so rapidly we just did not talk about it. Participant 001

Advanced care plans were rarely discussed but when they had been it was helpful in ensuring the patients' wishes were respected.

... he did not want it [life support] ... they all went in and touched his hand and kissed him and then they came back and said that he, you know, he had gone. Participant 003

Differences in acceptance of death between patient and caregiver were evident, with some patients accepting their imminent death but caregivers not, or vice versa.

... well actually I think he already had begun looking towards a demise and I think it was probably more me who did not accept that ... Participant 002

So all through that day he kept telling me he loved me and I went and sat beside him and I said to [husband] if you want to go it's okay, you know, if you feel that you are ready do not hold on just go. You know I would rather that you know that you are out of pain, you are not suffering anymore. Participant 003

Reflecting on care, participants indicated challenges within the medical system. There appeared a mismatch between information provided by clinicians and information needed that led to unmet needs and participants seeking information from other sources.

Bit more information would've been nice ... Yes and possible treatment or the, how it progresses ... really, you have got no idea. Participant 013

... I found out a lot about the services that are available for meso that nobody else knew, and I'm thinking why do they not know, why is not all of this out there? Participant 006

Participants felt the healthcare system failed to inform or properly support caregivers and consequently accessed a wide range of information sources of varied reliability. Some sought information about complementary therapies from outside the mainstream healthcare system, including Chinese medicine, acupuncture and dietary restrictions.

... I scared myself right in the beginning ... looking up all the statistics and everything and I thought ... no I cannot do this ... I did not want to have that extra pressure on me, although it was probably too late by that stage I already had those figures in my head. Participant 001

... cut down on sugars a lot and mainly tried to make your body alkaline more than acid ... build up the protein and build up the potassium more than sodium and different little things like that we did. Participant 012

Participants reflected limited options for active anti-cancer treatment and none reported perceiving best supportive or palliative care as a treatment option.

Well we just decided that the chemotherapy was the only option we had ... there was either that or nothing and maybe that might give him a bit longer life. Participant 009

3.3 | Grief and bereavement

This was depicted through three sub-themes: (i) coping and personal priorities; (ii) reflections on dying; and (iii) reflections on care. The experience and reflections of bereaved versus non-bereaved caregivers differed, with non-bereaved caregivers focused on maintenance of hope and managing, rather than being able to reflect on their fears and the future.

In the sub-theme, coping and personal priorities, participants expressed the importance of 'meaning-making' in a difficult situation. People able to do so seemed more positive in their reflections, finding the process of creating and living meaningful events sustaining.

... I would say to a family make the most of every day that you can. Do whatever you want to do, anywhere you want to go you go and you do it ... I find it very sad ... so many that is diagnosed with it that they die a terrible death in a hospital or a nursing home. I just look back and I think how lucky ... we had meditation music, we had candles, perfumed candles, and the whole works you know. Participant 010

We did not have a lot of time but he had quality ... Like we did a lot of things together, we took a lot of photographs and we went on short trips and ... we went up to [city] for his nephew's 21st and as we walked away he said goodbye to everybody that was there Participant 003

By contrast some did not actively engage in planning for end of life; for some, death seemed remote.

Well, because [name] was improving we did not talk about the end of his life and um then his condition just deteriorated so rapidly we did not talk about it. Participant 002

Hope was identified as important. For some, hope for a longer life, for others, to not suffer.

Yeah. I think you have to be positive and hope for the best. Participant 009

I'm reading about the disease and knowing what I knew I never wanted him to get there, I prayed that he would die, you know. Participant 003

Caregivers indicated a strong need to do something to arrest the disease and maintain hope. They wanted active treatments for the patients.

I wanted anything, that's how I felt, if they told me to, you know, jump in the river and swim for 50 miles I'd have done it. Participant 001

You always have that in the back of your mind well maybe it might have given you a bit more time. Participant 014

Some participants articulated the importance of spiritual beliefs in helping to cope with the disease and deteriorating health.

... he was a Catholic and he went to Mass and he believed, and his beliefs, that it helped him. Participant 011

The other major coping strategy was support, mainly from family and sometimes professional support services. Family presence and responsiveness to patient needs and how they wished to manage their illness were evident.

... but he said 'if it's only going to be for three months', he said, 'I'd rather spend the three months with my children'. See his little grandchildren. Participant 011

Some participants valued access to supports external to the families' immediate social network, particularly Lung Cancer Clinical Nurse Consultants (Lung CNC), psychosocial support services or support groups.

Good to know she's there [Lung CNC], because I think we keep ourselves more informed than maybe some other people can Participant 007

When they first told me that he wasn't going to live for very long I broke down and I just went hysterical and I could not accept it. ... I was lucky I had [psychologist] and I've had him right through. I still see him now. Participant 008

There was a contrast between caregivers who regretted a death they perceived as bad and those who recounted positive experiences of good deaths.

... Sometimes he would be gasping and you know, I would get in there and get him up and say 'you'll be right', ... And he would say I am going to die like this one day and that is exactly what happened. I could not get to him in time. Participant 004

It was incredible ... we really walked that journey with him and I have to say how grateful I am that it happened like that instead of being in a lonely bed in hospital on your own. Participant 010

There were multiple reports of caregivers not being able to navigate the healthcare system effectively, including limited referral leading to poor multidisciplinary team involvement and confusion regarding who the responsible clinician was. Gaps in care and lack of integration between teams led to limited supportive care including poorly managed pain. Participants reported slow access to equipment, meaning families struggled with insufficient aids to manage patients effectively at home.

That was one of the problems of his hospitalisation because he was between oncology and palliative care ... so and I was wondering why nobody was making decisions or taking charge and it's because nobody actually 'owned him'. Participant 001

... things were a little bit slow ... like say he needed ... to wear the nappy you know what I mean, you get to that point and a lamb's wool underlay, things like that. Well by the time he got it, it was too late, ... it was like things would come after the time ... he should have had it. Participant 014

3.4 | Involvement and timing of palliative care

Participants' experience of palliative care was synthesised into two sub-themes: (i) timing of referral and (ii) meaning of palliative care and its role in care.

Participants consistently reported late or absence of referrals to palliative care. This may have been associated with lack of understanding about palliative care and its role in symptom

management. Caregivers used phrases to describe services that could have been palliative care, such as 'pain doctor' and 'nurses at home'.

No, not until right near the end. Participant 005

I just wish that we had probably seen [palliative care specialist] a bit sooner. Participant 001

By the time they got involved he became too ill. Participant 008

Once palliative care services became involved, caregivers indicated services were responsive to their needs, with access to equipment and in-home care.

Once we got on board with palliative care, [physician] organised palliative nurses to come. And then, you know, they had the occupational therapist came and she you know brought, organised a bed and [husband] was on oxygen. Participant 001

Some participants equated palliative care to approaching the terminal phase of life, with discussion of involvement of palliative care meaning patients lost hope.

I arranged to get him in to [hospice] ... Once they told him that, I do not know whether he did not want to do it or what, but he just gave ... He just gave completely up. Participant 008

4 | DISCUSSION

Our interviews with caregivers identified their experiences related to end of life with the overarching theme the impact of the patients' diagnosis of mesothelioma, treatment and death on them. This was reflected within three key themes: information provision and decision-making, grief and bereavement and involvement and timing of palliative care. These findings highlight the substantial impact on families of a mesothelioma diagnosis and extend previous work which highlighted the need for emotional, informational and practical support for caregivers (Warby et al., 2019). This work identifies the importance of delivering patient-centred care to optimise outcomes for caregivers.

Sharing of power and responsibility between doctor and patient-carer dyad was identified as a priority area for improvement. Caregivers reported a number of decisions made that were not supported by sufficient education to make informed choices, exacerbated by their limited understanding of mesothelioma and its trajectory. This may reflect low awareness about mesothelioma in the community and lack of information provision by clinicians, creating challenges for patients and caregivers to know the questions to ask. Caregivers tried to improve their knowledge by accessing a range of information

sources. The challenges are likely compounded in mesothelioma by difficulties in prognosticating. Healthcare providers should facilitate provision of accurate, individually tailored information about the mesothelioma disease process and prognosis.

A range of beneficial coping strategies were identified including support from the health system, family and support groups. Hope was identified as an important theme: both that the person with mesothelioma would not suffer and they would survive. Balancing accurate information provision with maintenance of hope requires expertise and training (Clayton et al., 2008). Meaning-making appeared to contribute positively to coping strategies and to be associated with better bereavement outcomes (Adams et al., 2014). Accurate prognostic information may prompt families to initiate meaning-making activities. The healthcare system may facilitate positive coping methods by adopting a holistic approach including providing family-centred care, clearer communication about disease trajectory and information about support groups.

A pervasive issue was lack of integrated care inhibiting the therapeutic alliance. This manifest in numerous ways including delayed access to multidisciplinary support, late referral to palliative care and poorly defined roles of different health professionals. This hindered timely symptom control and access to equipment to care for patients at home.

Referral to palliative care was often late or did not occur, consistent with previous studies (Lee et al., 2009). When referrals were made, the scope of palliative care was commonly (or perceived) limited to practical roles such as facilitating personal care. Caregivers who had greater involvement with a palliative care professional reflected earlier referral would have been helpful. Early palliative care in cancer has been found to significantly improve quality of life (Haun et al., 2017). However, a study of early referral for mesothelioma patients did not demonstrate differences in quality of life at 12 or 24 weeks after diagnosis compared with standard care, in centres with easy access to palliative care when required (Brims et al., 2019). Our results suggest benefits may be gained in domains beyond quality of life, including access to information, preparation for death, coping and caregiver distress and bereavement outcomes. This supports findings in a recent UK study of the experiences of end-of-life care for patients with mesothelioma from the perspective of bereaved family caregivers (Harrison et al., 2022). There is an escalation of needs in the weeks before death, which in mesothelioma can be difficult to predict. The outcome measures and time points of previous studies failed to capture the issues identified by bereaved caregivers in our study.

Patients with mesothelioma and lung cancer, and their caregivers, are known to have some of the highest unmet needs of all cancer populations (Kindler et al., 2018; Warby et al., 2019). It is possible many of these needs, and identified gaps in care, such as information provision and holistic care, could be fulfilled by a cancer care coordinator. This could include tailoring care to the individual needs of the patient and caregiver, providing timely, accurate information about prognosis, disease process, access to care and equipment and referrals to palliative care.

4.1 | Strengths and limitations

Our novel study provides in-depth examination and synthesis of the experience of family members providing care to people with mesothelioma. It includes caregivers who have experienced the dying process and those not yet bereaved, providing insight into the lived experience of caring for a family member dying with mesothelioma. Themes identified are congruent with the literature, but we were able to explore these in greater depth.

Limitations include the homogeneity of the sample (all Australian); although thematic saturation was achieved, there may be experiences we failed to capture particularly due to international culture and health service differences, limiting translatability. Some participants had been caregivers some time ago, and their experience may reflect older management practices, processes, systems and understanding. This was a secondary analysis of a qualitative data set; further information may have been elicited if the interview questions had focused specifically on the caregiver experience of 'caring'. All caregivers were female, and most were spouses of patients, so we cannot comment on experiences of male or other family caregivers. The majority of caregivers were living in major metropolitan or regional centres, meaning the rural caregiver experience is under-represented.

5 | CONCLUSIONS

Our qualitative study identified major challenges for caregivers of people with mesothelioma particularly associated with lack of access to information and difficult decision-making. Grief and bereavement outcomes were variable and may have been adversely impacted by lack of early engagement with palliative care. Better integrated care involving experienced care coordinators and improved access to palliative care may relieve caregivers of some of their caring burden and reduce their unmet needs.

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CONFLICT OF INTEREST

SK declares he received honorarium (paid to his institution) from MSD, BMS, AstraZeneca, Pfizer, Roche and Boehringer. SK received travel support from Boehringer. HD declares receiving honorarium (paid to her institution) from MSD, BMS and Janssen. None of the other authors have any conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

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

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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