Development of conceptual models investigating the health-related quality of life (HRQoL) impacts of malignant pleural mesothelioma (MPM)

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Objectives

- MPM is a rare and usually fatal malignancy. Severe, life-limiting symptoms include dyspnoea, pleural effusion, chest wall pain, and fatigue[1]. Regardless of staging, the median overall survival rate of patients living with MPM ranges between 9 and 17 months[2]. Findings from qualitative research within the wider population of mesothelioma patients and their caregivers indicates significant impacts to patients' health-related quality of life (HRQoL)[3].
- The aim of this study was to develop conceptual models of the impact of MPM on the HRQoL of patients and their caregivers, and to identify important treatment attributes.

Method

- A mixed-methods design was employed, led by qualitative considerations that featured a thematic analysis and the development of separate conceptual models of HRQoL for patients and caregivers.
- Patients and caregivers were recruited and interviewed independently of each other, and participants could take part in the study regardless of whether the corresponding patient or caregiver also participated.
- Individual, semi-structured interviews were conducted with people living with MPM and caregivers (N=40) in the UK (n=9) and Australia (n=31) **(Table 1)**. Interviews queried patient experiences of symptoms, general and specific quality life impacts, and treatments. Caregiver interviews additionally queried the experiences of daily caregiving activities and the impact of treatment on caregiving.
- Patient occupations during working life varied, but mostly included mechanical and electrical engineering or warehouse work, as well as construction and tradespeople, followed by teaching, administration, and retail or sales work.
- Caregivers were all primary caregivers and were predominantly spouses or partners of the patient, although fewer were also children (n=1) or a niece (n=1).

Table 1. Patient and caregiver characteristics

Characteristic	Patients (n=22)	Caregivers (n=18)
Age (mean)	69 years	62 years
Age (range)	57-81 years	37-75 years
Patient time since diagnosis (mean)	3 years	2.4 years
Patient time since diagnosis (range)	2 months – 10 years	2 months – 10 years

- Supplementary to the core qualitative analyses, participants also completed HRQoL or caregiver-specific questionnaires, including a newly developed EQ-5D-5L respiratory bolt-on completed by patients and the CareQoL-7D by caregivers.
- The study design and interim findings were reviewed by a panel of HEOR and mesothelioma experts.

Results

- People living with MPM described their experiences of living with the disease and these descriptions were grouped into four overarching themes **(Figure 1)**.
- Themes showed the debilitating burden of breathlessness, fatigue, and pain:

'Very, very breathless. I can't do anything. If I do anything, then I'm breathless'. **(UK participant 4)**

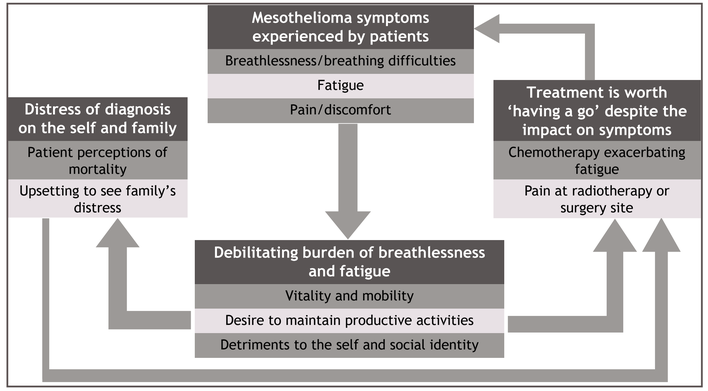
- Also described was the distress that diagnosis causes for themselves and their family, with patients describing thoughts around their own mortality even when experiencing positive responses to treatment:

'You almost feel guilty being positive about your outcomes when you look around the room and [other patients] just count time basically'. **(Australian participant 9)**

- Patient participants expressed their hopes for pursuing effective treatment despite uncertain outcomes and likely exacerbation of some symptoms, notably fatigue resulting from chemotherapy and chest or back pain at the site of radiotherapy or surgery:

'You don't know what's happening. That's the only way I can express that. You would like to know if you are going to be OK or not and you'll never know that. You don't know that, if it's all kind of worthwhile'. **(UK participant 1)**

Figure 1. Patient conceptual model



- Caregivers described their experiences of providing care for someone living with MPM. These were grouped into five overarching themes **(Figure 2)**.
- Themes included responses describing a range of caregiving duties and the need to reduce or stop work to enable these duties, as well as limitations to social and leisure activities.

'It's redefined what I do every hour of the day'. **(Australian participant 1)**

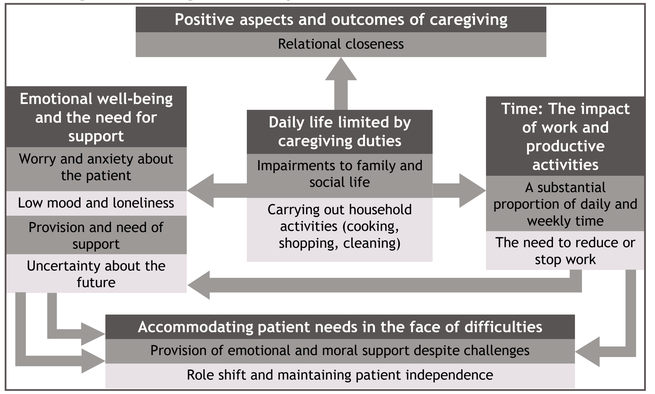
'My life was a lot more independent than it is now... but we do spend loads of time together'. **(Australian participant 25)**

- Caregivers described an emotional burden of providing care, including worry and uncertainty about the future, with the expectation that the intensity of caregiving would increase as the patient's MPM progressed.

'Yes, there's times where I become very emotional, you know, but I never let my husband see. I never let him see that'. **(UK participant 6)**

- Caregivers also expressed a desire for additional emotional and practical support, and further described challenges when accommodating a patient's needs while faced with their own difficulties, as well as positive relational impacts of caregiving.

Figure 2. Caregiver conceptual model



- Patients were asked what they thought was the most severe symptom they experienced when at it's worst, whereas caregivers were asked what they thought was the most severe symptom for the patient they cared for **(Table 2)**.

Table 2. Most severe patient symptom

Patient symptom	Patient (n=22)[a]	Caregiver (n=17)[b]
Breathing difficulties	13	7
Pain	7	5
Fatigue	6	6
Mood or distress	2	2

[a] [b]Multiple participants provided more than one response

- There lacked consensus across caregiver responses when asked what aspect of caregiving they thought had the most impact on their quality of life **(Table 3)**.

Table 3. Most impactful aspects of caregiving

Aspect of caregiving	Caregiver (n=15)[a]
Increased physical tasks	3
Providing emotional support	3
Uncertainty, fear, and anxiety	3
Seeing physical and psychological changes in the patient	3
Fatigue	2
Cooking and assisting with weight maintenance	2
Mood and distress	2

[a]Multiple participants provided more than one response

- Patients were also asked what they thought were the most important characteristics of a treatment for MPM. Some participants responded with more than one attribute **(Table 4)**.

Table 4. Most important treatment attributes reported by patients

Treatment attribute	Patient (n=19)[a]
Extend life	10
Delay progression	10
Reduce specific symptoms or impacts	3
Minimise side effects	3
Quality of care from those administering treatment	1

[a]Multiple participants provided more than one response

- Evident within the qualitative themes was also an increased impact on both patients and caregivers when patients were more severely ill.
- Responses to HRQoL and caregiver-specific questionnaires supported the qualitative themes.

Limitations

- Interviews were conducted during the COVID-19 pandemic while social distancing guidelines were in place. Some participants reported that these restrictions had directly impacted patients' experiences of living with mesothelioma and their overall quality of life. Specifically, interruptions to ongoing treatment for patients, and reduced participation in social and leisure activities for both caregivers and patients, were highlighted. Where necessary, any additional impacts that participants attributed to COVID-19 restrictions were isolated from the impacts attributed to MPM and were not included in the conceptual models.
- The present study does not feature descriptions of caregiving experiences from bereaved caregivers and therefore the conceptual models may not include insights into issues regarding end-of-life care and bereaved. Further work resulting from this research is currently underway to conduct qualitative interviews to describe how MPM can impact the HRQoL of bereaved caregivers that had provided care for a person diagnosed with the disease.

Conclusions

- The patient and caregiver interview responses and questionnaire responses identified a substantial burden of MPM on patients and caregivers, demonstrated through the associated qualitative themes and conceptual models.
- This study offers perspectives on the most impactful aspects of living with MPM or caregiving for someone living with MPM, as well as the relative importance of treatment attributes for patients.

References

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