Psychosocial well-being among patients with malignant pleural mesothelioma

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Abstract

Objectives. The investigators conducted a psychosocial needs assessment of mesothelioma patients through self-report measures of quality of life (QOL), coping, depression, and social support.

Methods. Patients with malignant pleural mesothelioma (MPM) ($N = 67$) completed a battery of assessments at a single timepoint after being approached during routine medical oncology clinic appointments or by letter.

Results. Participants were predominantly male (70.0%; $n = 47$) and ranged in age from 35 to 83 years old ($M = 65.61$, SD $= 9.71$). Most participants were white (88.0%; $n = 59$), and 10.0% ($n = 7$) were identified as Hispanic. The majority were married or living with a partner (93.0%; $n = 62$) and had some college or more education (64.0%; $n = 43$). Fourteen percent of participants ($n = 11$) endorsed significantly elevated depression symptoms. No significant demographic or clinical differences in depressed compared to nondepressed participants were observed, with a trend toward those identifying as Hispanic and those who were divorced as being more likely to be depressed. For the total sample, the most frequently endorsed coping strategies were active coping, emotional support, and acceptance.

Significance of results. The present study did not identify any clear correlates of depression or QOL among patients with MPM. This research contributes to the small literature on psychosocial functioning in patients with MPM and provides putative directions for future larger studies and the development of interventions to provide appropriate support to diverse patients with MPM.

Introduction

Malignant pleural mesothelioma (MPM) is a progressive, debilitating, and almost universally fatal disease usually caused by asbestos inhalation occurring typically more than 30 years before diagnosis (Delgermaa et al. 2011; Guglielmucci et al. 2018; Hajok et al. 2014; Kuschner et al. 2012; Moore and Darlison 2011). Asbestos has an extremely long industrial lifespan, and there are repeated opportunities for contamination during production, maintenance, and abatement (Park et al. 2011). Available information regarding prevalence is biased toward developed regions that have known historical uses of asbestos and the resources to diagnose asbestos-related diseases (Park et al. 2011). Estimates suggest that as many as 43,000 patients die of mesothelioma each year worldwide (Driscoll et al. 2005). However, it is also estimated that one unreported mesothelioma case exists for every 4 to 5 reported cases (Park et al. 2011). The incidence of mesothelioma was expected to peak between 2010 and 2015 (Arber and Spencer 2013); however, the enduring presence of asbestos within the built environment is likely to result in continuing cases of mesothelioma for decades to come (Brims et al. 2016).

The long latency period of MPM results in peak incidence during late middle age, with the average age of diagnosis at age 72 (American Cancer Society 2019; Arber and Spencer 2013). Prognosis remains poor despite multimodal interventions with heavy treatment burden in which quality of life (QOL) may be sacrificed for short-term survival gains. Most treatments involve chemotherapy, radiation, and/or surgery (National Comprehensive Cancer Network 2016). Median survival for patients with this disease is less than 1 year (Brims et al. 2016), with most patients dying within 18 months of diagnosis (Moore et al. 2010). Patients often experience pronounced, intractable physical symptoms, particularly pain and breathlessness, persistent cough, decreased appetite and weight loss, fatigue, sleep disturbance, and sweating (Arber and Spencer 2013; Chapman et al. 2005; Mollberg et al. 2012). Psychosocial distress is a serious issue for patients with MPM (Arber and Spencer 2013). Psychological distress can be more pronounced than physical distress for some patients (Ribi et al. 2008). As the disease

advances, patients may feel a loss of control over their lives, disease, and treatment as well as a loss of self-esteem (Arber and Spencer 2013). Complicated medicolegal and financial concerns contribute to a reduced QOL in some patients (Arber and Spencer 2013).

Considering that an occupational exposure potentially caused the disease often leads to resentment directed toward the responsible organization (Kozlowski et al. 2014). Stress and effort involved in seeking compensation can be a further complicating factor for mesothelioma patients (Kozlowski et al. 2014). However, the compensation is helpful to many families since those exposed are often industrial workers. An awareness of the occupational origin of the disease and potential human responsibility involved in the exposure can worsen patients' conditions (Di Cesare et al. 2016) and patients may be confronted with depressive symptoms, fears, anxieties, guilt, shame, and rage for an "unfair" diagnosis (Guglielmucci et al. 2018). Denial is a predominant coping strategy early on among mesothelioma patients once informed of the increased risk of the disease after asbestos exposure (Guglielmucci et al. 2018; Lebovits et al. 1981, 1983). One study of mesothelioma patients found that 65% of patients who had direct or indirect asbestos exposure denied any anger toward the asbestos industry. Several patients even expressed gratitude toward the industry for providing them with a good job even after being informed about the link between asbestos exposure and mesothelioma (Lebovits et al. 1983). After receiving information about this link regarding exposure, the patients flatly denied its relevance to them (Lebovits et al. 1983).

The most common symptoms reported by patients with MPM are shortness of breath (37%), tiredness (32%), general pain (29%), worry (22%), chest pain (21%), cough (20%), sweating (20%), and constipation (19%) (Muers et al. 2008). Despite the heavy symptom burden and poor prognosis, there has been little psychosocial research on mesothelioma and little is known about the QOL after diagnosis (Moore et al. 2010). The available evidence suggests that patients feel isolated, poorly informed about treatment options, and highly distressed by the illness and its cause (Moore et al. 2010). Individuals with mesothelioma experience psychosocial distress from the first months of receiving the diagnosis (Arber and Spencer 2013; Kozlowski et al. 2014). Few studies examine how patients cope with an MPM diagnosis, what special problems exist for MPM patients, their QOL, and specific psychosocial needs. A recent scoping review revealed only 17 studies that focused on psychological functioning in patients with MPM (Sherborne et al. 2020). The reviewers identified 3 major themes based on these studies including "The Passing of Time," "Dealing with Difficult Feelings," and "Craving Good Communication." They concluded that additional research is needed to understand the nuances of the MPM patient experience. Thus, there is a need to understand the primary psychosocial concerns for patients with MPM so that mental health interventions can be appropriately tailored to their needs.

This study sought to identify the prevalence of MPM patient-reported symptoms and coping strategies with a battery of self-report measures of QOL, depression, and social support. A secondary aim was to assess MPM patient needs for assistance in managing the disease. Relationships between depression and coping strategies were explored in order to identify opportunities for future targeted intervention. This research builds a foundation for developing a more in-depth intervention to identify topics important to this population and to provide support to patients with mesothelioma.

Method

Participants and procedure

This cross-sectional study was approved by the Memorial Sloan Kettering Cancer Center (MSK) Institutional Review Board/Privacy Board (IRB#11-066). Patients with MPM were screened and recruited at MSK between 2011 and 2013. To be eligible for participation, patients had to be 18 years or older, fluent in English, receiving care at MSK, and have a diagnosis of MPM. Potential participants were identified by research personnel and then approved for approach by the patient's treating physician. Participants were recruited from the Thoracic Oncology, Radiation Oncology, and Surgery services at any phase of illness. Research personnel approached eligible patients in the outpatient clinic and/or contacted them by mail. Eligible patients were informed of study procedures, risks, and benefits and offered participation. In total, 79 of 94 eligible patients agreed and provided informed consent to participate in the study; 69 patients completed the questionnaires. Ten patients dropped prior to completion of questionnaire due to anxiety associated with the disease ($n = 4$), feeling too ill to complete the questionnaire ($n = 3$), death ($n = 2$), and passive refuser ($n = 1$).

Participants completed a questionnaire-based assessment of coping strategies, social support, depression, and overall QOL during a single time point. Medical information was accessed and recorded through the medical records system. All study data were collected by trained research personnel.

Measures and data analysis

Medical and demographic information
Participants self-reported key demographic variables as well as medical history such as disease stage and treatment.

Quality of life
The Functional Assessment of Cancer Therapy – Lung (FACT-L; Cella et al. 1995) is a measure of QOL with physical, emotional, social, and functional subscales and an additional concerns subscale constructed with lung cancer–specific questions. Total scores range from 0 to 144, with higher scores indicating better functioning.

Depression
The Zung Self-Rating Depression Scale (Zung 1965) measured depressive symptoms as reported by the participant. For this analysis, participants' scores were categorized into 2 levels: depressed (50–80) and not depressed (20–49). Scores indicate levels of depressive symptoms that may be of clinical significance.

Coping
Participants were asked to complete the Coping Orientation to Problems Experienced Inventory (Brief COPE) (Carver 1997), which measured self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Each of the 14 subscales consist of 2 items, with subscale scores ranging from 2 to 8.

Social support
The Social Support Questionnaire – Short Form (Sarason et al. 1987) measured perceived emotional support and conceptualized

social support into 2 basic elements: the number of individuals perceived as available (quantity of support) and overall satisfaction with it.

Data analysis

Patient characteristics are described both overall and by Zung depression status. Categorical variables (e.g., gender and cancer treatment indicators) are compared between depressed and not depressed participants using Chi-square test. Continuous measures (e.g., COPE and FACT-L) are compared using independent samples *t*-tests, with Cohen's *d* for effect sizes also reported. We used pairwise deletion, so that if a single variable (e.g., education) was missing for a participant, that participant was only excluded from analyses including the missing variable. This strategy maximizes the analytic sample size by utilizing all available data. Analyses were conducted in SAS version 9.4.

Results

Participants were predominately male (70%; *n* = 47) and ranged in age from 35 to 83 years old (*M* = 65.61, SD = 9.71; see Table 1). Most participants were white (88%; *n* = 59), and 10% (*n* = 7) identified as Hispanic. The majority were married or living with a partner (93%; *n* = 62) and had some college or more education (64%; *n* = 43). Forty-two percent of participants (*n* = 28) were retired, while 25% (*n* = 17) reported current employment. Nearly one-third of participants described their disease as locally advanced (22%, *n* = 15) or metastatic (10%, *n* = 7). The majority of participants were undergoing chemotherapy treatment at the time of study participation (67%; *n* = 45). Fourteen percent of participants (*n* = 11) endorsed significantly elevated depression symptoms. No significant demographic or clinical differences in depressed compared to nondepressed participants were observed, with a trend toward those identifying as Hispanic and those who were divorced as being more likely to be depressed (Table 1).

For the total sample, the most frequently endorsed coping strategies were active coping, emotional support, and acceptance (Table 2). Potentially harmful coping strategies such as substance use, disengagement, and self-blame were the least frequently reported. Participants reported uniformly satisfactory QOL across domains on the FACT-L, with the highest ratings for social and family well-being (*M* = 23.12, SD = 3.97). When examining differences between depressed and nondepressed participants, the majority of subscales on the COPE and FACT-L were not significantly different between groups. However, there were significant differences with small to large effects on the positive reframing (*M* = 3.32, SD = 0.75 vs. *M* = 2.35, SD = 0.79, *d* = 1.24), humor (*M* = 2.36, SD = 1.00 vs. *M* = 1.63, SD = 0.73, *d* = 0.95), and acceptance subscales (*M* = 3.77, SD = 0.47 vs. *M* = 3.27, SD = 0.71, *d* = 0.75), such that those in the depressed subgroup reported more frequent use of these strategies.

Discussion

The present study did not identify any clear correlates of depression or QOL among patients with MPM. However, trends suggested that Hispanic and divorced participants were potentially more likely to be depressed than others. These findings are consistent with past psycho-oncology research, which found that Hispanic individuals with cancer endorsed significantly worse depression and QOL than Whites (Luckett et al. 2011). Thus, these observations suggest that when evaluating and identifying patients with MPM who may be at

Table 1. Participant characteristics overall and by depression criteria

	Total *N* (*N* = 67), *n* (%)	Depressed (*N* = 11), *n* (%)	Not depressed (*N* = 56), *n* (%)	*p*-value
Gender				
Male	47 (70%)	6 (55%)	41 (73%)	0.216
Female	20 (30%)	5 (45%)	15 (27%)	
Ethnicity				
Not Hispanic	60 (90%)	8 (73%)	52 (93%)	0.081
Hispanic	7 (10%)	3 (27%)	4 (7%)	
Race				
White	59 (90%)	9 (82%)	50 (91%)	0.649
Black, African, or American	3 (4%)	1 (9%)	2 (3.5%)	
Native American/ Alaskan Native	0 (0%)	0 (0%)	0 (0%)	
Asian/Pacific Islander	1 (2%)	0 (0%)	1 (2%)	
Other	3 (4%)	1 (9%)	2 (3.5%)	
Marital status				
Married/living with partner	62 (93%)	9 (82%)	53 (95%)	0.091
Single	0 (0%)	0 (0%)	0 (0%)	
Divorced/ separated	3 (4%)	2 (18%)	1 (2%)	
Widowed	2 (3%)	0 (0%)	2 (4%)	
Education				
Less than high school	8 (12%)	1 (9%)	7 (13%)	0.578
High school graduate	14 (22%)	2 (18%)	12 (22%)	
Partial college	19 (29%)	2 (18%)	17 (31%)	
College graduate	10 (15%)	3 (27%)	7 (13%)	
Graduate school	14 (22%)	3 (27%)	11 (21%)	
Disease stage				
Localized	34 (57%)	7 (78%)	27 (53%)	0.397
Locally advanced	15 (25%)	1 (11%)	14 (27%)	
Metastatic	7 (12%)	1 (11%)	6 (12%)	
Unsure	4 (6%)	0 (0%)	4 (8%)	
Received surgery				
No	58 (88%)	9 (82%)	49 (90%)	0.611
Yes	8 (13%)	2 (18%)	6 (11%)	
Received chemotherapy				
No	21 (32%)	5 (45%)	16 (29%)	0.288
Yes	45 (68%)	6 (55%)	39 (71%)	
Received radiation				
No	57 (86%)	9 (82%)	48 (87%)	0.638
Yes	9 (14%)	2 (18%)	7 (13%)	

Note: All percents represent valid percents.

Table 2. Patient-reported symptoms and coping mechanisms

	Total N (N = 67), M (SD)	Depressed (N = 11) M (SD)	Not depressed (N = 56) M (SD)	Effect size	p-value
Brief COPE					
Denial	1.42 (0.60)	1.45 (0.72)	1.41 (0.58)	0.07	0.827
Positive	2.51 (0.86)	3.32 (0.75)	2.35 (0.79)	1.24	<0.001
Self-distraction	2.45 (0.88)	2.86 (0.95)	2.36 (0.85)	0.58	0.085
Active coping	3.16 (0.81)	3.32 (0.64)	3.13 (0.84)	0.23	0.494
Substance use	1.07 (0.23)	1.05 (0.15)	1.08 (0.25)	−0.15	0.655
Emotional support	3.49 (0.67)	3.41 (0.58)	3.50 (0.69)	−0.14	0.683
Instrumental support	2.81 (0.85)	3.05 (0.99)	2.77 (0.83)	0.33	0.327
Disengagement	1.22 (0.49)	1.18 (0.46)	1.22 (0.49)	−0.08	0.799
Venting	1.89 (0.77)	2.20 (0.82)	1.84 (0.75)	0.48	0.170
Planning	2.79 (0.93)	2.86 (0.98)	2.78 (0.92)	0.09	0.779
Humor	1.75 (0.82)	2.36 (1.00)	1.63 (0.73)	0.95	0.005
Acceptance	3.35 (0.70)	3.77 (0.47)	3.27 (0.71)	0.75	0.027
Religiosity	2.87 (1.20)	3.09 (1.09)	2.83 (1.22)	0.22	0.509
Self-blame	1.28 (0.53)	1.23 (0.61)	1.29 (0.52)	−0.11	0.742
FACT-L					
Physical well-being	18.60 (6.23)	19.27 (8.25)	18.47 (5.84)	0.13	0.700
Social/family well-being	23.12 (3.97)	22.44 (4.64)	23.25 (3.86)	−0.20	0.539
Emotional well-being	17.51 (4.64)	19.45 (3.96)	17.13 (4.70)	0.51	0.130
Functional well-being	16.49 (5.78)	18.45 (7.78)	16.10 (5.30)	0.41	0.220
Lung cancer subscale	18.63 (4.68)	20.18 (5.25)	18.32 (4.55)	0.40	0.231
Trial outcome index	53.72 (14.27)	57.91 (19.68)	52.90 (13.03)	0.35	0.290
FACT-G total	75.73 (16.00)	79.62 (20.51)	74.96 (15.07)	0.29	0.381
FACT-L total	94.35 (19.42)	99.80 (25.33)	93.28 (18.13)	0.34	0.312
SSQ support	3.87 (2.21)	4.44 (2.38)	3.75 (2.17)	0.31	0.349
SSQ satisfaction	5.65 (0.56)	5.65 (0.49)	5.65 (0.58)	0.01	0.974

Note: *p*-Values for continuous variables are based on independent samples *t*-test. FACT-L = Functional Assessment of Cancer Therapy – Lung; SSQ = Social Support Questionnaire, Short Form.

increased risk for distress during their cancer treatment, clinicians should be sensitive to ethnicity and marital status. Future psychosocial intervention development should also include ethnically diverse stakeholders to ensure that interventions are culturally sensitive. Similarly, as marital status has previously been utilized as an indicator of overall social support (DiMatteo 2004), MPM patients may benefit from interventions that increase social connectedness, either to peers or other individuals (e.g., group psychotherapy and peer support programs).

Contrary to expectations, the use of positive reframing and acceptance coping strategies were higher among those who were depressed, with no difference between depressive subgroups on any other coping subscales. Each of these coping strategies can be particularly helpful for those coping with an advanced cancer diagnosis and are often the target of evidence-based psychotherapy interventions in oncology (Antoni et al. 2009; Breitbart et al. 2018; González-Fernández and Fernández-Rodríguez 2019). It is possible that depressed participants experience depressive realism (Keller et al. 2002) in which they find greater acceptance of their disease/prognosis relative to nondepressed patients, who may be less prognostically aware (Saracino et al. 2021). Similarly, they may engage in more positive reframing with a greater awareness of the severity of their disease. Conclusions about this potential relationship cannot be drawn based on the current data, but future inquiry should evaluate this possibility more systematically.

The use of humor as a coping strategy was also more prevalent in the depressed subsample. The use of humor has previously been associated with worse QOL in patients with head and neck cancer (Aarstad et al. 2008). It is possible that the use of humor in the present depressed subsample may reflect a superficial, deflective coping strategy rather than the type of humor reported elsewhere that can help patients meaningfully cope with a cancer diagnosis. Humor has the potential to be a useful clinical tool with patients and can also be a component of the focus of intervention. For example, MPM patients might be guided to appreciate humor as an experiential source of meaning in Meaning-Centered Psychotherapy (Breitbart et al. 2018) or as an opportunity for cognitive restructuring or relaxation in Cognitive Behavioral Therapy (Antoni et al. 2009).

Past literature suggests that women are more likely to endorse depressive symptoms than men (Kelly et al. 2008). Similarly, older adults are less likely to endorse any mental health symptoms, even among those with cancer (Saracino et al. 2020). Given that the present sample was primarily male (70%) with a mean age of nearly 66 years, our results may underestimate the prevalence of these symptoms due to underreporting or a genuine discrepancy in distress experience between sexes. Similarly, participants did not report time since diagnosis, so inferences about how emotional well-being and coping might change over time could not be evaluated. The study was also limited by its somewhat homogeneous sample and its cross-sectional design. Future studies should evaluate larger samples from across diverse cancer centers and other community-based settings, where patients with a potentially wider range of concerns can be evaluated across the disease trajectory. The predominately White, married sample included in the present study may not generalize to other settings and populations. Therefore, this study should be expanded to engage patients from more diverse racial, ethnic, and socioeconomic backgrounds.

Study findings related to self-reported depression, QOL, and coping strategies represent a relatively large sample of patients for this uncommon disease. This research contributes to the small literature on psychosocial functioning in patients with MPM and provides putative directions for future larger studies and the

development of interventions to provide appropriate support to diverse patients with MPM.

Conflicts of interest. The authors of this manuscript have no conflicts of interest to disclose.

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