

Approach to offering remote support to mesothelioma patients: the mesothelioma survivor project

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Background: From the moment of diagnosis, malignant mesothelioma (MM) decreases health-related quality of life (QOL) in patients and their caregivers. In addition to symptoms of disease, aggressive treatments such as surgery, radiation, and chemotherapy can cause extreme side effects—chemotherapy specifically is associated with chronic fatigue, unremitting nausea, vomiting, and systemic pain. These side effects of treatments can be burdensome enough to lead to noncompliance or outright refusal of continuation of care.

Methods: The platform for the support group was remote, consisting of online and telephone domains. Participants would utilize both online and phone systems during sessions held once a week for a total of six weeks. Sessions were guided and kept closed, available only to those affected by mesothelioma. Follow-up information and session summaries were provided online after support meetings.

Results: Using a 0–5 Likert Scale, consistent attendees reported support groups as very helpful. Irregular attendees had mixed feelings ranging from extremely helpful to neutral. Eighty per cent of attendees participated in support groups prior to this project.

Conclusions: Active participation in a guided and closed support group allowed participants to share their experiences and concerns about their diagnoses comfortably, supporting transition beyond active-treatment. Online space gave participants a place to provide more reflective responses outside the main dialogue of support sessions.

Keywords: Mesothelioma; survivorship; support group; quality of life (QOL)

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Introduction

Mesothelioma is a cancer that primarily affects the pleura and peritoneum and is usually caused by exposure to asbestos. The number of individuals diagnosed with mesothelioma is increasing world-wide, particularly in developing countries where the use of asbestos is poorly regulated (1). In spite of advances in chemotherapy, radiotherapy, and surgical approaches, mesothelioma

remains resistant to treatment. According to the International Mesothelioma Interest group, overall survival has not improved, whereas median survival times vary from one month to eighteen months.

Few patients remain asymptomatic or with minimal symptoms for extended periods of time, and fewer live three years or more. Mesothelioma is often associated with unwieldy, intractable symptoms, particularly in experiencing pain and difficulty breathing. Poor prognoses

Table 1 Sessions and discussion questions

Emotional, social & mental health
How did you feel after your last treatment?
Did you feel anxiety when your doctor told you your treatment was ending?
How do you feel when someone tells you you're a hero for being a survivor?
Have you ever had feelings of guilt during your journey?
Do you think about recurrence and dying?
How do you deal with feelings of fear, sorrow, or anger when thinking or talking about living with mesothelioma?
Nutrition & physical activity
Do you feel like your tastes and cravings have change since treatment?
Do you find you don't like your favorite foods or that you have a hard time eating?
Have you found it difficult to exercise?
Do you get frustrated because you may lack energy or feel fatigued frequently?
Do find it hard to maintain a well-balanced diet?
Intimacy & body image
Do you find it difficult to connect with your partner emotional and physically?
Do you feel emotionally distant since your treatment?
Do you find your interest in being physically intimate has decreased?
Do you experience pain or discomfort when engaging in intercourse that prevents you from wanting to be physically intimate?
Do you feel that you can have an open dialogue with your partner?
Have you felt less attractive since your treatment?
Do you find yourself not wanting to go out with friends and family because your body post-treatment?
Pain management
Does your pain prevent you from engaging in everyday activities?
Do you find it difficult to meet your personal needs because of your pain?
Do you find it difficult to meet the needs of your family because of your pain?
Does your pain prevent you from sleeping 6- 8 hours?
Have you had to switch pain medications because one was no longer effective?
Returning to routine
Do you find it challenging at times to get back to your post treatment routine?
Were you able to return to work?
Do you find it challenging to get into a new routine?
Moving forward & recommendations
Now that our time is coming to an end we would like to discuss the overall effectiveness of this series

have been reported for those diagnosed with sarcomatoid over epithelioid histology, or with advanced disease, poor performance status, pain and loss of appetite.

Mesothelioma has a number of emotional consequences. A study conducted by the British Lung Foundation (BLF) reported significant impairment of emotional function and/or emotional states in patients with mesothelioma as well as in their family members (2). The BLF's study further reported a more positive response amongst patients versus caregivers in regards to supportive treatment to their emotional functioning. However, authors did not provide a definition for significantly impaired emotional functioning, thus opacifying the results of such support.

The physical, psychological, social, and financial burdens of patients being treated for various types of peritoneal cancer are often accompanied by exorbitant travel, lodging, and medical treatment expenses that can become overwhelming and burdensome to patients and their families. These financial expenditures can become even larger when treatments are postponed or canceled due to adverse effects of disease or treatment (2,3).

Recent psychological studies have demonstrated health benefits in cancer patients when sharing their illness experiences through online blogs. Blogging creates a survivor identity and facilitates a social support network for patients. Further, studies suggest that expressive writing increases self-management of chronic pain and lowers depressive symptoms (4,5).

The Mesothelioma Survivor Project is a virtual platform designed to offer emotional support to participants by allowing them to ask questions and share thoughts they may not feel comfortable voicing in a traditional support group.

Methods

The platform for the support group was remote, consisting of both online and telephone domains. Each participant received an email a week prior to support sessions with an access code to the online and phone conference systems. Participants would then utilize the online and phone systems during sessions, which were held once a week during evenings for a total of six weeks. These confidential sessions were guided (by a team of healthcare professionals consisting of: a social worker, nurse, and a member of the patients support team from the Mesothelioma Applied Research Foundation) and available only to those affected by mesothelioma—confidentiality was kept to best facilitate open dialogue. Discussion questions were designed for

Table 2 Follow-up questions

Group follow-up questions
Did you find the discussion helpful?
Did you feel the group leader allowed enough time for discussion?
Did you feel safe sharing your thoughts and feelings?
Would you attend this group again?
Would you attend this group if it was in a hangout format (video chat)?

this unique patient population—aimed at addressing their specific quality of life (QOL) concerns (*Table 1*). The platform facilitated anonymity should a patient have wished to remain so. Follow-up information and session summaries were provided after support meetings online. Additionally, each participant was provided a survey to evaluate the facilitators and overall effectiveness of the group (*Table 2*).

Results

Patients expressed satisfaction via online surveys after each session. Using a 0–5 Likert Scale, consistent attendees reported support groups as very helpful (2). Irregular attendees had mixed feelings ranging from extremely helpful (5) to neutral (3). Eighty per cent of attendees participated in support groups prior to ours. Of the patients surveyed, more than 50 per cent said they would participate in a video chat formatted support group.

Discussion

Active participation in a guided support group allowed participants to share feelings and concerns about diagnoses without feeling judged by their peers or healthcare providers. In the process, participants received the emotional, mental, and post-active treatment support they required to facilitate the transition to follow-up care.

The online portion of the platform was particularly helpful in assuaging common negative concerns like fear of healthcare provider judgment, confidentiality, self-editing, emotional backlash from loved ones, and disapproval of lifestyle post-active treatment. Analysis of support session dialogue allowed facilitators to gauge information available

to patients as well as provide information about life after active treatment. Online space (on our blogspace) gave participants a place to provide more communicative responses outside the main dialogue of support sessions.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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