

RESEARCH ARTICLE

Caring for Patients with Malignant Pleural Mesothelioma in Japan: Evaluation of a Palliative Care Educational Program

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Abstract

Purpose: This study evaluated the effect of an Educational Program on Palliative Care for MPM for Nurses in Japan. **Program:** The 5-h program consisted of lectures and care planning group work. **Materials and Methods:** This study used a pretest–posttest design with a single cohort of nurses and included a Difficulties in Palliative Care for Patients with MPM (DPCMPM) Scale with 15 items. The pre- and posttest scores were compared using a t-test. **Results:** We included 27 female nurses with a mean of 14.4 years of nursing experience. In 12 of 15 DPCMPM items, the posttest difficulty scores were lower than the pretest scores. Participants highly evaluated the program for validity, clarity, clinical usefulness, and the facilitators. The Palliative Care for MPM Handbook for Nurses was developed as an educational tool for clinical settings. **Conclusions:** The Educational Program on Palliative Care for MPM for Nurses was effective in reducing nursing difficulties.

Keywords: malignant pleural mesothelioma - palliative care - education - asbestos - quality of life

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Introduction

Malignant mesothelioma is a rare malignancy that affects the pleura, peritoneum and pericardium (Neumann et al., 2013). It is estimated that 80%-85% of mesothelioma is caused by direct asbestos exposure. Asbestos has been used extensively in such areas as construction, plumbing and working with insulation (van Zandwijk et al., 2013). With a long latency period from exposure to diagnoses of about 15-50 years, the World Health Organization (WHO) estimated that around 107,000 people die each year from asbestos-related diseases resulting from occupational exposure (WHO, 2014). Median survival after diagnosis of mesothelioma is 4-14 months (Musk et al., 2011; Utkan et al., 2013).

Malignant Pleural Mesothelioma (MPM), the most common type of mesothelioma, is almost always fatal (Yip et al, 2011; van Zandwijk et al., 2013) because there is no curative treatment. Radical resection of mesothelioma combined with chemotherapy or radiotherapy improves the survival and extent time to recurrence (Tilleman et al., 2009; Bolukbas et al., 2013). Standard chemotherapy using combination of cisplatin and pemetrexed or carboplatin (van Zandwijk et al., 2013) also prolong survival, although, benefit of further lines of chemotherapy has not been substantiated (Ceresoli et al., 2011; Mutlu, et al., 2013).

Progressed MPM causes debilitating physical symptoms such as pain, dyspnea, and cough (Berk et al., 2012; Chihan et al., 2014) weight loss (Berk et al., 2012), fatigue and sweating (Neumann et al., 2013). The management of symptoms of MPM is complicated because symptoms of this aggressive form of cancer are related directly to the accumulation of fluid in the pleura and indirectly related to pain and the debilitation of cancer and often appear simultaneously (Neumann et al., 2013). Ibrahim (2013) suggested introducing opioids in the early stages to improve the quality of life of people with mesothelioma.

Moore et al. (2010) have emphasized that understanding the specific needs of people with MPM is essential to improving care. Similar to other patients with cancer, patients with MPM experience emotional difficulties such as the shock of diagnosis (Lee et al., 2009), anxiety and depression (Dooley, 2010; van Zandwijk et al., 2010). In addition, patients with MPM experienced anger toward their employers who did not alert them to the hazard of asbestos (Lee et al., 2009), ambivalence about working in an unhealthy environment versus loyalty to company that gave them longtime employment (Lee et al., 2009), and the stress of dealing with lawsuits (Hughes and Arber, 2008).

National Comprehensive Cancer Network (2012) recommended palliative care and symptom control as central to any management plan for mesothelioma patients.

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For successful symptom management, it is advisable to introduce palliative care in the early stage of this incurable disease (Ibrahim et al., 2013) by a multidisciplinary care team (Lehto, 2014) including appropriately trained specialist nurses in the care pathway for the patient and the family throughout the course of the illness and who are able to provide a strong liaison between hospital services and primary care and can enable access to specialist palliative care services as required. (National Comprehensive Cancer Network, 2012).

In Eastern Asia, mesothelioma incidence was low due to under diagnosis and recent industrialization (Lee et al., 2009; Bianchi and Bianchi, 2012). The cases of mesothelioma are expected to increase in the near future. (Bianchi and Bianchi, 2012). Japan, a country famous for its large number of earthquakes and fires, is one of the world's highest importers and users of asbestos (Furuya et al., 2013). The government has cautiously moved forward in developing standards of asbestos control (Furuya et al., 2013). In 1995, the first year statistics documenting MPM mortality became available in Japan, there were 500 deaths and by 2012 the number had jumped to 1,400, a 180% increase (Furuya et al., 2013; Japan Ministry of Health, 2013). Although the National Comprehensive Cancer Network offers the translated MPM guidelines in Japanese (National Comprehensive Cancer Network, 2012), the medical professional struggles to manage the complex needs of people with MPM. Research demonstrated that Japanese patients with MPM suffered from pain and dyspnea due to undertreated symptoms (Nagamatsu et al., 2012). Since educational resources are limited, Japanese nurses have relied on care that has been effective for other forms of cancer but unfortunately that strategy has failed to manage symptoms of MPM (Nagamatsu et al., 2012). Therefore, patients with MPM are disadvantaged by the lack of effective treatment, high symptom burden, traumatic and distressing medical interventions, and rather complicated procedures to claim their asbestos-related benefits. In summary, applying routine lung cancer care to patients with MPM in Japan has often failed (Nagamatsu et al., 2012).

There have been many reports on the importance of palliative care for MPM because of the high mortality rate and burden owing to symptoms (Scherpereel et al., 2010). Given that the typical survival is only around two years (Cihan et al., 2014) there is an even more urgent need to manage symptoms of MPM and to improve patients' quality of life (QOL). Clearly nurses need to acquire new knowledge and skills for symptom management for patients suffering with MPM.

In response to these needs, our team, including a palliative care physician from the United Kingdom and from Japan, a respiratory physician and an oncology specialist nurse, developed a palliative care educational program and handbook for nurses in Japan focused on patients with MPM. Previous research documented the effectiveness of a two-day program in decreasing nurses' difficulty managing care for patients with MPM (Nagamatsu et al., 2014). The question was, would this five-hour program also be effective in decreasing nurses' sense of difficulty in providing palliative care for patients

with MPM? This study aimed to evaluate the effect of both the Educational Program on Palliative Care for Patients with MPM and the Palliative Care for MPM Handbook for Nurses in Japan.

Materials and Methods

This classic one-group pretest-posttest design included a questionnaire as the pretest before the educational program intervention and the same questionnaire as the immediate posttest with a purposive sample of 27 nurses. The study was conducted on November 25, 2012.

Program

The five-hour program, in a workshop format, consisted of lectures and group work. One of the authors of this study, specialized in palliative care for MPM, provided the main lectures: *Palliative Care and Hospice in the UK and Multi-dimensional Symptom Management in MPM*, which included medication management. Japanese oncology nurses presented a lecture on *Symptom Management in Japan*. Participants then formed five small groups, each supported by a facilitator. The goal of the groups was to develop care plans to manage difficult cases using the material they had learnt from the lectures.

Program handbook

The handbook was printed using A4 size paper and contained the following: (1) symptoms of MPM; (2) the cause of pain and dyspnea in MPM; (3) the multi-dimensional management of symptoms of MPM; (4) the management of dyspnea (medications, indwelling pleural drain, hand-held fan, psychological support); (5) types of pain (inflammatory pain, neuropathic pain, bone pain, breakthrough pain) and (6) pain management methods (medications and cordotomy). We also described the pain reported after extrapleural pneumonectomy, which is the typical surgery for MPM in Japan, but this is no longer the standard practice in the UK.

Sample and recruitment

Nurses with approximately two years or more of clinical experience were recruited as participants. Advertisement letters were sent nationwide to the heads or nursing directors of health care facilities (including hospitals with respiratory wards or palliative care wards, cancer hospitals, home visiting nurse stations and health care centers). Recruitment was also conducted through the Mesothelioma Nursing Japan website established by the researchers.

Evaluation tools

Difficulties in Palliative Care for Patients with MPM (DPCMPM) Scale: We used the Difficulties in Palliative Care for Patients with MPM (DPCMPM) Scale before and after the educational intervention. This is a novel 15-item self-report inventory developed for this study by palliative care nurses, pulmonologists and a thoracic surgeon based on the difficulties of nurses who experienced caring for patient with MPM (Nagamatsu et al., 2012). The DPCMPM consists of four subscales

about care of patients with MPM: Symptom management and maintenance of QOL (four items), Spiritual care (five items), Care of family (two items) and Care coordination of medical services (four items). Five expert nurses who had experience in caring for more than 50 patients with MPM established the content validity of the DPCMPM scale and modifications were made as necessary.

Participants responded to items in a 5-point Likert scale (*very difficult=5; difficult=4; neutral=3; not difficult=2; not at all difficult=1*). A total possible score ranged from 10 to 50 and was summed to indicate overall difficulty. A higher score reflected more difficulty. Pre-workshop DPCMPM scores indicated participants' difficulties based on their actual experience with patients and post-workshop score represented the participants' anticipation of difficulty in the care of people with MPM.

Participants' satisfaction form: Participants provided feedback for the program by responding to the following four items: 1) satisfaction with the overall program; 2) the content was easy to understand; 3) the content was helpful in solving your clinical problems and 4) the facilitator was supportive. The program was evaluated according to the items using a 5-point Likert scale (*5=very much agree to 1=never agree*). Higher scores indicated more positive feedback for the program.

Comment form: This program was the first educational program about palliative care in MPM therefore, it was important to capture as much feedback as possible. Participants were encouraged to provide written comments about their experience of the program in an open-ended format.

Data analysis

Descriptive data analyses were conducted to identify characteristic demographics. The pre and post educational program mean score for each item, total subscale score and total DPCMPM scores were examined using the paired t-test for the items and the Wilcoxon signed-rank test for the subscale scores based on score distribution. Data

were analyzed using the Statistical Package for the Social Science (SPSS version 19). A difference was considered significant when the corresponding P-value was 0.05 or less. The comments from participants were qualitatively analyzed by content analysis.

Ethical considerations

The Research Ethics Review Board of St. Luke's College of Nursing (approval no. 12-043) approved this study. The study was conducted based on the ethical principles of avoiding harm, voluntary participation, anonymity and protection of privacy and personal information. Participants were informed that this program included research activity. The purpose, procedure and confidentiality of the study were explained verbally at the outset of the course and were also provided in written format. Participants were informed that nonparticipation would not disadvantage them. Data were collected from those who wished to participate and who completed the informed consent form.

Results

Participants

Attending the Palliative Care for MPM program were 27 female nurses (response rate 100%). Although the mean number of years of work experience was 14.4 (range of 1.9-40) and the majority (70%) worked in a respiratory ward most (70%) had little or no experience of caring for patients with MPM. Whereas the inclusion criteria indicated two years of work experience, one nurse had one year and nine months plus experience with patients with MPM, therefore, she was included in the sample.

Evaluation of the program on palliative care for MPM

An item-by-item analysis indicated that 13 of the 15 DPCMPM item scores at post-workshop were significantly lower ($p>0.001$) than the pre-workshop scores (Table 1). The scores of all four subcategories also decreased after

Table 1. Difficulty Scores for Pre-and Post-Workshops

| Subscales | Items | Pre-workshop | | Post-workshop | | P-Value |
|---|---|--------------|-------|---------------|-------|---------|
| | | Mean | SD | Mean | SD | |
| Symptom management and maintenance of quality of life | Control pain and dyspnea | 4.15 | 0.86 | 3.37 | 1.25 | <0.001 |
| | Ensure symptom management | 3.93 | 1.04 | 3.33 | 1.11 | 0.007 |
| | Manage symptoms by patient request | 4.37 | 0.84 | 3.11 | 1.05 | <0.001 |
| Care of family | Maintain the QOL of a patient | 3.85 | 0.82 | 2.78 | 0.95 | <0.001 |
| | Draw out the feelings of a family | 3.67 | 1.04 | 2.85 | 0.99 | <0.001 |
| Spiritual care | Minimize misunderstandings between the patient and his/her family | 3.78 | 0.86 | 3.48 | 1.01 | 0.133 |
| | Draw out the honest feelings of a patient | 3.63 | 1.12 | 3.44 | 1 | 0.408 |
| | Respond to patients who say "I do not want to die" | 3.63 | 1.25 | 3.07 | 1.17 | 0.026 |
| | Diminish patient's psychological, social, and spiritual pain | 4.04 | 0.94 | 3.33 | 0.88 | <0.001 |
| Care coordination of medical services | Ease pain of a victim of asbestos exposure | 4 | 0.92 | 3.15 | 1.03 | <0.001 |
| | Ease pain of a patient who cannot find effective treatment | 4.26 | 0.98 | 3.37 | 0.93 | <0.001 |
| | Support a patient where he/she wants to die | 4.04 | 0.98 | 3.3 | 0.95 | <0.001 |
| | Work with other departments to ensure that the patient's wish is fulfilled | 3.22 | 1.09 | 2.41 | 0.97 | <0.001 |
| | Work in a team with same goal | 3.15 | 0.99 | 2.63 | 0.97 | 0.020 |
| Subscale scores | Foster understanding in a physician who thinks negatively regarding palliative care | 3.63 | 1.04 | 2.67 | 1.21 | <0.001 |
| | Symptom management and maintenance of quality of life | 16.3 | 3.07 | 13 | 3.82 | <0.001 |
| | Care of family | 7.5 | 1.46 | 6 | 1.95 | 0.001 |
| | Spiritual care | 19.6 | 4.17 | 16.1 | 4.15 | <0.001 |
| Total | Care coordination of medical services | 14 | 3.33 | 11 | 3.52 | <0.001 |
| | | 56.78 | 10.55 | 46.04 | 11.64 | <0.001 |

*Items analyzed using Wilcoxon signed-rank test; ** Subscale scores and Total analyzed using paired t-test

Participants' satisfaction

All participants rated the program either very high or high in satisfaction regarding: the overall program; easy to understand content; helpful in solving clinical problems and supportiveness of facilitator (data not presented).

Comment from participants

The written comments from participants provided a more poignant picture of the nurses' dilemmas. There were requests to provide a detailed regimen for symptom management in MPM and for educational equipment that could be used in a clinical setting and that could be shared with health care staff at their workplace (*italics indicate raw data*).

"Tell us what exactly medicine we should give to our MPM patient in hideous pain. I need to show my physicians because they are not sure what they should prescribe." (Nurse 2).

"I could not find any handbooks about palliative care for MPM. I need more copies [of the handbook] to share with my colleagues." (Nurse 14).

"I learnt the theory today. However, it is useful if we have an actual handbook. It is good for me and easier for junior nurses." (Nurse 20).

"The handbook in A4 size is too big to carry in the ward. I want to have a smaller one." (Nurse 15).

The physician (Clayton) from the UK impressed participants with her communication skills. Participants commented that they were eager to learn how to use these communication skills in a terminal care setting.

"Communication with MPM patient is tough. I was impressed by the way the English physician communicated with her patient. If I were a patient, I want to be talked to in the same way she did." (Nurse 5).

"I want to learn more about how to communicate with a dying patient."(Nurse 3).

There were positive comments regarding care planning group work. This provided implications and indications of what nurses should do and how nurses could provide support and empathy to their colleagues who experienced difficulty in caring for patients with MPM.

"The case study helped me understand how to translate theory into a real situation." (Nurse 3).

"It was difficult to make a care plan during the group discussion. We found we needed to ask many questions to the patients and family. And it was what we need to do in the clinical situation." (Nurse 15).

"I thought myself as useless because I failed to the control symptoms of a patient. Empathy and understanding by other nurses and instructors encouraged me a lot. Now I think that was all I could do. Support from other nurses is so helpful." (Nurse 23).

Development of the palliative care for MPM handbook

As indicated by participants' comments, there were

Palliative Care in mesothelioma Handbook for Nurses

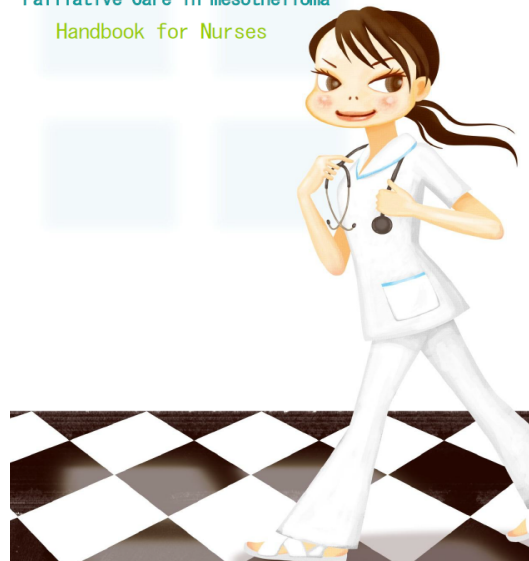


Figure 1. Cover of the Handbook

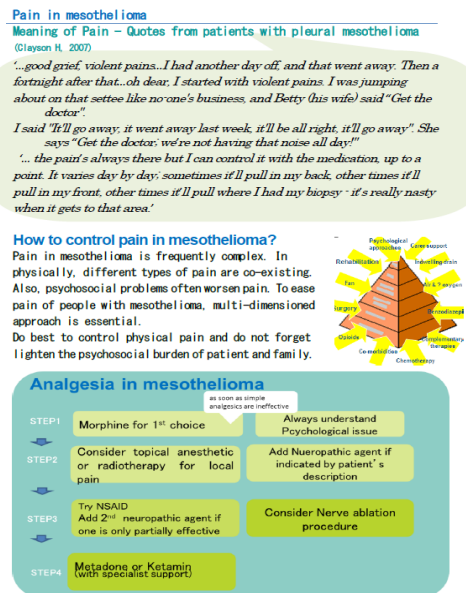


Figure 2. Analgesia in Mesothelioma

requests for educational equipment that could be used in the clinical setting. To meet these needs, we modified the program handbook based on the participants' comments and our observations. We integrated this information into a smaller size (B5 size: 176 mm×250 mm) handbook (Figure 1) with colorful pictures, a symptom management model, analgesia in mesothelioma, (Figure 2) useful references and communication skills. The handbooks were distributed to medical facilities that provided care to patients with MPM. The content of the handbook is available on the Mesothelioma Nursing Japan website.

Discussion

Effectiveness of the educational program on palliative care for MPM for nurses

In this study, the DPCMPM scores at pre and post-

workshop were compared. Since the post-workshop DPCMPM scores were significantly lower than the pre-workshop scores, it is possible that the workshop contributed to easing anticipated difficulties of nurses providing palliative care for MPM. The learning strategy contributed to this success.

First, we selected learning through conventional lectures rather than e-learning; the latter is learner-centered and offers flexibility for time and location and cost-effectiveness while being potentially available to a global audience with unlimited access to knowledge. Conversely, learning through conventional lectures has the advantage of allowing for immediate feedback, being familiar to both the instructor and student, motivating students and cultivating a social community (Avillion, 2009). We selected the conventional style because this program was the very first to provide knowledge about palliative care for MPM to nurses in Japan and our priority was to obtain immediate feedback. In addition, conventional lectures provide greater opportunity to communicate directly with nurses from different workplaces and provide mutual support. We believe that this approach helped to decrease difficulties experienced by nurses.

Second, the program maximized learning outcomes using multiple learning methods. Avillion (2009) stressed that innovative teaching strategies are needed to meet the needs of nurses with different learning styles, thereby contributing the best possible learning outcomes. The presentation on the palliative care system in the UK motivated participants, while lectures on palliative care provided the required knowledge. Group work conducted after these lectures involved care planning for difficult cases then provided an opportunity to practice critical thinking and to apply the newly acquired theory to actual situations (Avillion, 2009). Inviting participants to provide details of difficult cases raised enthusiasm and provided a real-life context.

Communication skill needs

The scores for two DPCMPM items did not decrease significantly in the post-workshop results, as follows: “to draw out honest feelings of a quiet patient” and “to adjust the gap of willingness between patient and family.” Requests from participants indicated that they wished to improve their communication skills further when managing patients with MPM. Mitsuhashi and Toda (2011) reported that quiet terminally ill patients were often in extreme spiritual pain; MPM patients with such pain kept away from health care staff and family members (Nagamatsu et al., 2012). The care of patients with spiritual pain is difficult and causes suffering among nurses (Lehto, 2014). Nagamatsu et al. (2012) reported that nurses experienced strong distress when attempting to communicate with patients with MPM who could not accept their disease and prognosis. In addition, improving the relationship between patients with MPM and their family requires sensitivity in fully understanding the multiple causal factors together with the ability to empathize and use appropriate communication skills to facilitate reconciliation (Lehto, 2014). In conducting programs in the future, an additional module

on communicating with patients in spiritual suffering and managing nurses’ compassion fatigue (Lombardo and Eyre, 2011) should be considered.

Implications

Patients struggling with MPM have complex physical problems compounded by emotional and spiritual pain. Nurses and other medical professionals caring for patients with MPM and other complex lung cancer symptoms could greatly benefit from the MPM program and handbook.

Limitation

The sample size in this study was small and included many participants without the experience of caring for patients with MPM. For progression of the program, it is recommended to use larger samples collected from a variety of workplaces and for different durations. In addition, the lack of a control group was an obvious limitation; however as this was the first attempt to provide the program, it was not considered feasible to establish both intervention and control groups. The immediate evaluation of participants after the workshop reduced the internal threats of history and maturation. With the post-workshop evaluation period right after the program the long-term effect of the program, particularly after applying knowledge and skills to the clinical setting, should be evaluated. The DPCMPM questionnaire only asks for participants’ perceptions. Ideally, the next step should include observations in the clinical setting to evaluate attitude and behavior changes after the program.

Finally, this program was developed based on difficulties experienced by nurses who care for patients with MPM in Japan, which may limit its use in countries with different cultures and care systems. However, the program can serve as an example for those countries that desire to make culturally relevant modifications.

In conclusion, the five-hour Palliative Care for Patients with MPM educational program was effective in reducing perceptions of difficulties experienced by nurses caring for patients with MPM. Based on the feedback and requests from participants, we also revised and disseminated the Palliative Care for MPM Handbook for Nurses.

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