Original Article

Psychosocial Care Provided by Physicians and Nurses in Palliative Care: A Mixed Methods Study

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Abstract

Context. Psychosocial care is an important component of palliative care, which is also provided by physicians and nurses.

Objective. The aim of this study was to explore the experiences of physicians and nurses in palliative care regarding the process of psychosocial care, the difficulties, and the support needs from "psychosocial care professionals."

Methods. A two-phase mixed methods study was conducted. In the first phase, 16 physicians and nurses with palliative care experience were recruited. A semi-structured interview was used to collect data about their experience of providing psychosocial care, and these were analyzed using thematic analysis. In the second phase, 88 physicians and nurses completed an online survey that was developed from the qualitative results.

Results. Qualitative results revealed three themes: 1) the contents of psychosocial care included not only disease-related events but also emotional and family support, 2) providing psychosocial care was a dynamic process including assessment, interventions, and evaluation, and 3) there were difficulties from the participants themselves, patients and families, and the system. Participants also reflected on what they did and the influences of providing care on themselves. Quantitative results showed that the most common psychosocial care was discussion about the progress of the disease and future care plan; the difficulty was the long-term problems in families; and the psychosocial care professionals most needed were social workers and clinical/counseling psychologists.

Conclusions. Understanding the process of psychosocial care and integrating it with specialized mental health care in a team could improve the quality of psychosocial care in palliative care. J Pain Symptom Manage 2017;53:216–223. © *2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Psychosocial care, physicians, nurses, medical staff, palliative care, Taiwan

Introduction

Palliative care is comprehensive care that integrates physical, psychological, social, and spiritual care, aimed at improving quality of life and achieving a good death for patients with terminal illness.[1] Multidisciplinary teamwork, including various kinds of health care professionals, provides integrative care to relieve patients' total pain.[2,3] When disease progresses to terminal stage, psychosocial and spiritual concerns raise. A high proportion of patients with terminal illness experience psychological distress and emotional disturbance.[4,5] Not only patients but also their families are the targets of psychosocial care. Caring for patients with terminal illness can cause burden, psychological distress, and anxiety[6] and a grief reaction after the patient has passed away.[7] A national survey in Japan showed 27% of caregivers in palliative home care had the need of psychological support.[8]

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Accepted for publication: August 10, 2016.

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0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2016.08.019

Psychosocial care is an important component of palliative care, and its goals are to improve psychological and emotional well-being, including self-esteem, disease adjustment, communication, social functioning, and interpersonal relationships.[9] It focuses on not only emotional well-being but also family relationships, community, culture, and religious belief.[3,10] Health care professionals can establish a warm atmosphere for patients and families to express ideas and feelings; furthermore, they can also provide specialist psychosocial care.[10]

The U.K. National Institute for Health and Care Excellence guidelines suggest four levels of psychosocial care based on patients' distress. In levels 1 and 2, all members in the team provide general psychosocial support and conduct psychological distress screening. In levels 3 and 4, mental health specialists, such as clinical psychologists and psychiatrists, assess psychological distress and diagnose mental disorders and provide specific psychological interventions.[11,12] Although mental health specialists can provide psychosocial care, physicians and nurses are still in the front line for the provision of immediate emotional support and psychosocial care.

Providing emotional support and psychosocial care is a major task among nurses in palliative care.[13,14] It can be integrated in basic care through listening, comfort touching, empathy, encouragement, and company.[15] Nurses respect patients' values, empower them, help them to find meaning, enhance the connections between patients and families, and preserve their own integrity.[16] Many factors may influence that physicians and nurses provide psychosocial care. They worry about patients' coping ability,[17] lack time and communication skills,[17,18] lack support from other specialist mental health professionals,[19] and lack cooperation in the multidisciplinary teamwork.[20] A qualitative study exploring the barriers for nurses who cared for patients with cancer revealed that nurses lacked knowledge regarding what to say and how to communicate, build up relationships, and provide support.[21]

In Taiwan, the first palliative ward was established in 1990 and Hospice Palliative Care Act has been passed in 2000. Psychosocial care is one part of training courses for specialist physicians and nurses in palliative care.[22] Taiwanese nurses in palliative care provided holistic care through close relationships and needed to deal with the negative belief about palliative care and faced the stresses and frustrations from the work.[23] A survey of educational needs among physicians in palliative care identified that how to manage psychosocial issues ranked second, just next to pain management.[24]

Little research has focused on how physicians and nurses provide psychosocial care in the context of palliative care. Therefore, the aim of this study was to explore the experiences of physicians and nurses in palliative care regarding the provision of psychosocial care, the related difficulties, and the support needs from "psychosocial care professionals."

Methods

Participants

The participants were physicians and nurses who had worked or were working in palliative care, including hospital-based palliative care team, wards, and home care.

Study Design

A two-phase mixed methods study was conducted to explore a new topic combining the strengths of qualitative and quantitative methodologies to obtain deeper understanding. An exploratory design was used, conducting a qualitative interview followed by a quantitative survey. After the completion of qualitative and quantitative analyses, the integration of two kinds of data was mainly based on the qualitative results, and the quantitative results were supplementary material.[25] Before the beginning of the study, ethical approval was obtained from the research ethics committee at the Buddhist Tzu Chi General Hospital (IRB101−110).

For the first, qualitative phase, potential participants were recruited using snowballing sampling. The researchers interviewed the physician and nurses in the researchers' hospital first and then asked the participants to introduce potential participants in other hospitals. It could recruit the participants who met the inclusion criteria and enhance their willingness to join. The researchers explained the aims and procedures of the study, and informed consent was obtained from those willing to participate. A semi-structured interview was used to collect data including 1) what psychosocial issues had participants encountered when caring patients with terminal disease and their families, 2) how did participants deal with psychosocial issues, 3) did they have any difficulties about psychosocial issues and how did they solve them, 4) what was their experience working with psychosocial care professionals, such as clinical psychologists, social workers, and chaplains, and 5) how did they cooperate with psychosocial care professionals for improving the quality of psychosocial care.

All interviews were recorded and transcribed verbatim. Data analysis was based on the principles of thematic analysis.[26,27] First, the researchers read the transcriptions repeatedly to familiarize themselves with the data and developed the initial codes. Open coding was used and 502 initial codes were developed.

Next, the codes were summarized into 40 categories based on the similarity of meaning and five potential themes identified. Subsequently, the researchers reviewed the themes and checked the connections between the codes and the themes and the relationships between themes. In the end, three themes and 10 categories were identified and definitions and names for each theme were generated. In addition, the participants were invited to review the results.

The second phase involved an online quantitative survey containing three sections that were developed from the qualitative results. As the complementary information of quantitative data, the three sections included the contents of psychosocial care provided by medical staff (15 items; 4 = always, 1 = never), the difficulties in providing psychosocial care (17 items; 4 = strongly agree, 1 = strongly disagree), and the support needs from psychosocial care professionals (five items; 4 = very much, 1 = not at all). Demographic characteristics including age, gender, position, and working experience and years in palliative care were also collected.

Content validity was evaluated by six senior experts in palliative care (three nurses, one physician, one clinical psychologist, and one social worker; the mean number of working years in palliative care was 15.67, ranging from 11 to 20 years; two of them had PhD degrees, three master degrees, and one a bachelor degree). The experts evaluated the relevance of the items (4 = highly relevant, 3 = quite relevant, 2 = somewhat relevant, 1 = not relevant).[28] The content validity indices were 0.95, 0.95, and 0.99 for each survey section, respectively. The survey was made available on a Web site, and the address was sent by social network and e-mail to potential participants. Descriptive statistics were used to analyze data.

Results

Qualitative Phase

Sixteen medical staff were contacted and all of them participated; four were physicians and the rest nurses. The mean number of working years in palliative care was 8.31, and the mean interview length was 72.38 minutes (Table 1). Three themes were identified: 1) contents of psychosocial care, 2) the dynamic process of psychosocial care, and 3) difficulties and reflections.

Contents of Psychosocial Care. Physicians and nurses dealt with various psychosocial issues when caring for terminal patients and their families; four categories emerged. The first one was *disease-related events*, including telling diagnosis and prognosis, making medical decisions (such as receiving palliative care or not, do not resuscitate [DNR] or cardiopulmonary resuscitation, discharge plan), providing psychoeducation, and delivering information.

> G: Because my position was in the hospital-based palliative team, we had to deal with truth telling quite often, tell the patients and their families that the treatment did not work and the disease could not be cured. Did they want to choose palliative care or sign the DNR order?

The second category was *psychological and emotional aspects*. Medical staff helped patients and families cope with terminal disease and end of life to improve adjustment. Negative emotions caused by the disease were another focus, including depression, anxiety, fear of death, and death anxiety.

> I: Facing death is not easy. Patients and families may have a lot of negative feelings, such as anxiety, worries, and fear, fear of death. They need emotional support and we can play the role in the front line.

Table 1
Demographic Characteristics of Qualitative Interview Participants

No	Gender	Hospital Type	Working Years in Palliative Care	Position	Working Experience
A	Male	MC	3	Resident physician	W, HC
B	Female	MC	12	Nurse	W, HPCT
C	Female	RH	7	Attending physician	W, HC, HPCT
D	Female	MC	2	Nurse	HPCT
E	Female	MC	9	Nurse	W
F	Female	MC	17	Head nurse	W, HC
G	Female	RH	7	Attending physician	HC
H	Female	RH	4	Nurse	W
I	Female	RH	16	Nurse	HPCT
J	Male	RH	10	Attending physician	W
K	Female	RH	10	Nurse	W
L	Female	MC	12	Nurse	HC
M	Female	RH	10	Nurse	W, HPCT
N	Female	RH	2	Nurse	W, HPCT
O	Female	MC	8	Nurse	HPCT
P	Female	MC	4	Nurse	W

HC = Home Care; HPCT = Hospital-Based Palliative Care Team; MC = Medical Center; RH = Regional Hospital; W = Ward.

The third category was *family aspects*. Caregivers and other family members were also the targets of palliative care. Regarding family interactions, medical staff played a bridging role to facilitate communication and solve the conflicts between patients and their families. They also helped caregivers cope with stress and go through grief.

H: We took care of not only the patients but also their families. In Taiwanese culture, families have a great influence on patients' psychosocial well-being, and they also have a lot of stress. In the end, they have to face loss and experience grief. We provided family-centered care.

The fourth category was *other issues*, including suicide, unfinished business and wish fulfillment, economic support and social resources, and spiritual issues.

F: Did the patients have any unfinished business or wishes? We would help them to finish them, maybe to go home, to see someone, to eat something, and this could let them leave peacefully, without regret.

Dynamic Process of Psychosocial Care. Providing psychosocial care was a complex dynamic process. First, the physicians and nurses mentioned *the core of care*, which involved special characteristics: truly caring, passion, and interest in patients and families. Medical staff wanted to do more for terminal patients than just their duty to comfort them and relieve their suffering. This helped establish trust relationships, which was essential for providing psychosocial care. In addition, they adopted an attitude showing that they did not expect patients and families to achieve any goals, such as feeling better, becoming strong, showing positive emotions, or stopping crying. They just were with patients and families without a purpose.

K: Truly caring is important, patients can feel if you are truly concerned about them or just because of duty. And we cannot set a goal or expectation about how they should be, we should maintain a purposeless attitude to approach them, instead of changing them or doing something.

D: The trust relationship between us and patients and families is the foundation of care; without it, we cannot deliver any care.

Secondly, *essential attitude and skills* were mentioned. Medical staff needed to be warm, patient, and sensitive and know how to listen, show empathy, be supportive, and provide company to patients and families. These skills are helpful for understanding what patients and families feel and think and getting close to them.

D: Listening and empathy are important, as they help us to understand what they think and feel. We need to learn how to be company, stay with them; it is not easy.

Third, *psychosocial care was a dynamic process*. Like in medical interventions, medical staff observed and assessed patients and families in terms of psychological and emotional status, and social relationships. When detecting psychosocial needs or problems, they performed interventions based on their assessment and followed up the effects. Patients' psychological status was affected by their physical condition, which was the patients' primary concern. A majority of medical staff revealed that they started with physical care and then talked about psychosocial issues as patients' and families' defensiveness decreased through physical care. Staff had to be sensitive to modify their care appropriately. In addition, they practiced teamwork and cooperation with other psychosocial professionals and when they could not handle a problem, they referred the patient to appropriate professionals.

I: Initially, I will collect information and understand what they need. Sometimes it is a good way beginning with physical problems, which are their primary concerns. When we have a trust relationship, then we can discuss some issues deeper. And what we should do or how to do it may depend on their needs or problems.

Difficulties and Reflections. Difficulties related to the medical staff themselves, patients and families, and the system were identified. The *difficulties related to medical staff themselves* included lack of skills and emotion interference with work. Unlike with physical problems, staff lacked standardized ways to provide psychosocial care, for example, they did not know how to talk or ask questions, provide company or deal with silence, or answer questions and respond appropriately. In addition, dealing with psychosocial issues required empathy and sensitivity; therefore, it is inevitable that medical staff would be influenced by care experiences in their emotions, beliefs, and values. Some medical staff expressed that they did not know how to calm their own heart and mind, or keep the boundary.

G: Sometimes I do not know what to say and worry I may say something wrong and hurt patients and their families … After the care, I would think about the experience, what they say, what I cannot do, and something touches me. Definitely the care experience will influence me, with both a positive and a negative side.

The *difficulties related to patients and families* included patients' physical condition, long-term conflicts

between patients and families, and lack of family support or resources.

A: Family relations are a very important factor at the end of life. However, long-term family problems cannot be solved quickly; conflicts, anger, or misunderstandings may make patients leave with regret. However, without families' help, we cannot do a lot.

The *difficulties related to the system* included excessive workload without enough time and lack of support and teamwork from psychosocial care professionals.

A: I do not have enough time, too many patients to care for. I need psychosocial professionals to help us; however, these resources are not enough.

Caring for terminal patients was a touching experience, which made medical staff *reflect*, for instance, about the true relationships and interactions between medical staff and patients and the meaning of accepting what patients were. For example, what were the patients' real needs, and how to satisfy them? Did medical staff have the ability to meet them? They also thought about whether they were the right person, with personal traits fit for this field, suitable for caring for terminal patients. In addition, they improved their abilities by reflecting on care experiences.

B: Sometimes I think I am the one who got benefits from the caring experience.

Quantitative Phase

A total of 88 physicians and nurses completed the survey. Most were women (97.73%), aged 41–45 (37.50%) and 36–40 (28.41%) years, and nurses (70.45%). Regarding working experience, 26.14% had 6–10 years and 79.55% had experience in wards (Table 2).

Regarding psychosocial care content, the most common idea was that physicians and nurses discussed the progress of the disease and future care plan. Second, they helped patients and families deal with the negative emotions and stress from the terminal disease. Furthermore, they also helped the communication, either between patients and families or between patients and families and the medical team.

Regarding the difficulties, the most common one was the ingrained problems that cannot be solved in a short time, such as personality or conflicts between families. In addition, lack of time because of excessive workload, lack of standardized ways to provide psychosocial care, and the interference of physical conditions may influence care. The psychosocial care professionals most needed by participants were social workers and clinical/counseling psychologists (Table 3).

Table 2
Demographic Characteristics of Online Quantitative Survey Participants

Variable	*n* (%)
Gender	
Male	2 (2.27%)
Female	86 (97.73%)
Age (years)	
21–25	4 (4.55%)
26–30	11 (12.50%)
31–35	15 (17.05%)
36–40	25 (28.41%)
41–45	33 (37.50%)
Position	
Attending physician	8 (9.09%)
Nurse	62 (70.45%)
Nurse specialist	7 (7.95%)
Case managers	11 (12.50%)
Working years in palliative care	
Less than 1	11 (12.50%)
1–5	22 (25.00%)
6–10	23 (26.14%)
11–15	20 (22.73%)
16–20	12 (13.64%)
Working experience (multiple choice)	
Wards	70 (79.55%)
Home care	40 (45.45%)
Hospital-based palliative care team	42 (47.73%)

Discussion

This study used a mixed methods research design to explore the experiences of physicians and nurses in providing psychosocial care for terminally ill patients and their families. The results revealed the contents of psychosocial care and not only disease-related events but also emotional and family support. Providing psychosocial care was a dynamic process for which physicians and nurses needed skills and special characteristics. They found difficulties related to themselves, patients and families, and the system and also reflected on what they did and the influence of providing care on themselves.

Regarding the contents of psychosocial care, disease-related events were the important components. It is the physicians' responsibility to deliver the diagnosis and prognosis of the illness to patients and families and to discuss the option of palliative care and the future care plan.[29] Understanding the information about their prognosis is related to the patients' perceptions of their physical condition.[30] When patients realize the severity of their illness and their limited time, they can think about future care and the preparation for death. In addition, negative emotions and death anxiety have been noticed to arise from the recognition of the terminal illness. Patients need psychosocial support and "someone to talk to."[31] Physicians and nurses helped patients cope to improve psychological well-being.

In the last period of life, families take on important roles in Taiwan. They assume the responsibility of care and influence patients' adjustment. Physicians and

Table 3
Contents of Psychosocial Care, Difficulties, and Support Needs From Psychosocial Care Professionals

Survey Items	Mean (SD)
Contents of psychosocial care	
1. Discuss the progress of the disease and future care plan	3.48 (0.76)
2. Help patients and families deal with the various negative emotions, e.g., depression, worry, hopelessness, and anger	3.32 (0.74)
3. Help patients and families to cope the stress from the terminal disease	3.26 (0.81)
4. Help the communication between patients and families	3.25 (0.78)
5. Help the communication between patients and families and other medical professionals	3.21 (0.81)
6. Help patients and families deal with death anxiety	3.18 (0.84)
7. Tell the disease was terminal/tell the diagnosis and prognosis of the disease	3.14 (0.93)
8. Discuss the medical decision of whether receiving palliative care or home care	3.14 (0.92)
9. Help families deal with loss and grief	3.00 (0.82)
10. Help families with the preparation of the funeral	2.93 (0.95)
11. Deal with spiritual or religious issues	2.92 (0.80)
12. Help patients and families complete unfinished business	2.76 (0.86)
13. Help with financial difficulties of families	2.49 (0.71)
14. Deal with patients' suicide ideation and behavior	2.13 (0.74)
15. Help children adjust to the loss of their relatives	2.05 (0.76)
Difficulties in providing psychosocial care	
1. Ingrained problems, e.g., personality or conflicts between families, cannot be solved in short time	3.17 (0.63)
2. Lack of time due to excessive workload	3.03 (0.81)
3. Lack of standardized ways to provide psychosocial care	2.98 (0.83)
4. Interference from patients' physical condition, e.g., symptoms, too tired, delirium	2.97 (0.71)
5. Personal experiences and values will influence psychosocial care	2.69 (0.80)
6. Lack of consensus in medical team, e.g., ways to provide psychosocial care	2.69 (0.72)
7. Lack of skills or abilities	2.68 (0.78)
8. Lack of suitable indices to ensure effectiveness	2.64 (0.79)
9. Lack of support from other psychosocial professionals, e.g., clinical psychologists, psychiatrists	2.62 (1.05)
10. Do not know how to evaluate the effects of psychosocial care	2.52 (0.87)
11. Worry about saying something wrong that hurts patients and families	2.39 (0.85)
12. Do not know how to assess patients' and families' psychosocial status and needs	2.25 (0.92)
13. Do not know how to keep professional boundary with patients and families	2.17 (0.88)
14. Do not know how to cooperate with other psychosocial professionals, such as what they can do and what they need	2.08 (0.92)
15. Do not know how to deal with patients' silence	2.08 (0.88)
16. Do not know how to provide company or do something when providing company	2.06 (0.80)
17. Emotion was influenced by patients and families and cannot be detached from care	1.99 (0.67)
Support needs from psychosocial care professionals	
1. Social worker	3.75 (0.44)
2. Clinical/counseling psychologists	3.68 (0.56)
3. Chaplains/spiritual care professionals	3.65 (0.57)
4. Other alternative therapy professionals, e.g., art, amore, music therapists	3.45 (0.52)
5. Psychiatric physicians	3.22 (0.62)

nurses cooperated with families to care for patients together. However, families were also recipients of palliative care. Their burden when assuming the care responsibility and their grief reaction after the patient's death were targets of psychosocial care.[32]

The core of psychosocial care was the relationship between physicians and nurses and their patients. Similar to the findings of previous qualitative studies, trust, kindness, warmth, compassion, and genuineness were important in the nurse-patient relationship.[33–35] By establishing trust relationships, physicians and nurses can deliver care to relief psychological pain, improve adjustment to illness, and lead to a good death experience.[33]

Despite the various kinds of problems or needs, there was a certain process of psychosocial care. Medical staff assessed patients' psychosocial needs, provided interventions, and evaluated the effects.[36] In a dynamic process, physicians and nurses delivered psychosocial care through personal (e.g., connecting and developing relationship) and professional interaction (e.g., knowledge, symptom relief, and practical assistance).[35] They integrated psychosocial care into routine care.[37] Training programs were beneficial to improve psychosocial skills in clinical practice effectively.[38]

When physicians and nurses took a holistic approach to caring for patients with terminal illnesses and their families, it meant that they witnessed their suffering, became aware unvoiced needs, and understood their thoughts and feelings. However, this experience might bring negative emotional responses, such as feelings of powerlessness, frustration, sense of loss, burnout, and even anger about the health system.[39] Physicians and nurses reflected on the process about what they did, the reaction of patients and families, the relationships, and their values about work and life. Reflection, self-awareness, and self-care helped them keep working in this field.[40]

Based on the contents of psychosocial care, physicians and nurses need training about communication, truth telling, and psychosocial care skills.[21,32,41] They also need multidisciplinary teamwork that different health care professionals should cooperate and communicate well.[42] Specialized supports from psychosocial care professionals can solve the difficulties and provide peer supports.[43] In addition, the medical

system can decrease workload for them having time to deal with psychosocial issues.[21]

Mixed methods research design could gain depth understanding of physicians and nurses' experience, and the quantitative results could enhance generalizability about the most common psychosocial care provided by them. However, our interpretation was mainly based on qualitative results. The sampling of participants for the quantitative survey was done through the Internet; therefore, they may not be representative of the whole population. Physicians and nurses have main responsibility on physical care and treatment, and the results may be not appropriate to apply to other psychosocial care professionals. Future studies could explore the integration of psychosocial care into physical care and teamwork and training for improving psychosocial care abilities.

Disclosures and Acknowledgments

This study was supported by the project from the Ministry of Science and Technology (MOST 103-2410-H-006 -033). The authors have declared no conflicts of interest.

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