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What is This?
Health Care Interactional Suffering in Palliative Care

Tan Seng Beng, MRCP¹, Ng Chong Guan, MPM², Lim Ee Jane¹, and Loh Ee Chin, MRCP¹

Abstract
A secondary analysis of 2 qualitative studies was conducted to explore the experiences of suffering caused by interactions with health care providers in the hospital setting. Interview transcripts from 20 palliative care patients and 15 palliative care informal caregivers in University Malaya Medical Centre were thematically analyzed. The results of health care interactional suffering were associated with themes of attention, understanding, communication, competence, and limitation. These 5 themes may serve as a framework for the improvement in interaction skills of health care providers in palliative care.

Keywords
health care interactions, suffering, palliative care, thematic analysis, psychosocial issues, Malaysia

Introduction
Understanding suffering requires comprehension of all aspects of a person, which consists of a body and a mind; multiple roles, relationships, and a cultural background; a past, present, and a perceived future; and a transcendental dimension.¹ Suffering is a state of severe distress associated with actual or perceived threat to the intactness or integrity of a person.¹,² It is a perceived impending destruction of a person,¹ perceived helplessness in the face of the threat, and the exhaustion of personal and psychosocial resources of coping.³,⁴ The key to restoration of the integrity of a person lies in healing and caring in a holistic manner. Healing involves helping patients to reconstruct their sense of wholeness, independent of illness, recovery, or death,⁵ and to discover the meaning of their existences via various means, such as life stories, arts, and rituals.⁶,⁷ Caring requires an interest in humanity. The secret of the care of the patient lies in the caring of patient.⁸ In modern health care, suffering, healing, and caring have received little attention compared to the advances in medical science in diagnosing and managing diseases. This widens the gap between the 2 important goals in medicine—the curing of disease and the healing and caring of the sick person.

Although alleviation of suffering is universally considered as the fundamental goal in medicine,⁹,¹⁰ the focus of modern health care on diseases and bodies diverts us from seeing patient as a whole person. Suffering is experienced by person not bodies.¹ Paying attention to diseases and bodies does not offer a promising solution in palliating suffering. Furthermore, the biomedical approach itself can be a source of suffering for patients, reminding us of primum non nocere which means “above all, do no harm.”¹¹ Health care has been reported to increase patients’ suffering.¹²-¹⁴ Health care interactions can harm patients. These harmful interactions are unethical. Every effort should be made by all health care providers to improve their interaction skills in order to avoid contributing to the suffering of patients and caregivers, especially in the palliative care setting.

From the 2 previous thematic analyses on suffering in palliative care,¹⁵,¹⁶ it was noted that the health care system contributed to suffering in palliative care patients and their caregivers. Therefore, a secondary analysis was conducted to deepen the understanding of these experiences of suffering caused by interactions with health care providers. Secondary analysis is a valid mode of clinical enquiry used to generate new knowledge, new hypotheses, or support for existing theories.¹⁷,¹⁸ In this article, self-collected data from the 2 qualitative studies¹⁵,¹⁶ were used for an in-depth supplementary analysis¹⁹ of health care interactional suffering that was partially addressed in the primary studies.

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Methods

Two qualitative studies on the experiences of suffering in palliative care were conducted in the University Malaya Medical Centre in Malaysia from November 2010 to May 2012, after approval from the ethics committee in the University Malaya.15,16 The studies used convenience sampling for recruitment. A total of 20 adult palliative care patients and 15 informal caregivers were interviewed for an average time of 26 minutes for each person. The 28 interviews in English were transcribed verbatim. The 4 Chinese interviews and 3 Malay interviews were transcribed and translated into English. These transcripts were introduced into NVIVO9 (QSR International Pty Ltd, Doncaster, Australia) for thematic analysis based on Braun and Clarke.20 From the 35 transcripts, 1085 experiences of suffering were coded. Themes generated from these experiences were reported in the following articles: (1) the experiences of suffering of palliative care patients in Malaysia15 and (2) the experiences of suffering of palliative care informal caregivers in Malaysia.16

Relevant interview questions from the 2 studies are presented in Table 1. Thematic analysis, a widely used qualitative analytic method,20 was applied in the secondary analysis. From the 2 data sets, secondary analysis was performed to identify the experiences of suffering related to interactions with health care staff. In phase 1, familiarization of data was carried out through repetitive reading of the 35 transcripts, with particular attention to experiences related to health care interactions. In phase 2, the 1085 codes of experiences of suffering were screened for health care interactional suffering. A total of 107 initial codes were identified. The different codes were sorted into potential themes and subthemes of health care interactional suffering in phase 3 via identification of meaningful patterns across the codes. In phase 4, candidate themes and subthemes were reviewed at the level of the coded data extracts for pattern coherence. Next, the validation was done through rereading the entire data sets to ascertain justification of themes in relation to the data. Additional data within themes that have been missed in earlier coding were coded. A total of 109 codes were finalized. Then, the final themes and subthemes were named in phase 5, followed by literature review and the final write-up of the report in phase 6. The entire process of secondary analysis was conducted by the principal investigator, a palliative care physician. Another palliative care physician and 1 psychiatrist were involved independently in the review and refinement of themes.

Results

Characteristics of the 20 palliative care patients and 15 palliative care informal caregivers are presented in Table 2. From the secondary analysis, the 109 codes of health care interactional suffering were sorted into 5 themes—(1) attention issues, (2) understanding issues, (3) communication issues, (4) competence issues, and (5) limitation issues. These 5 themes were expanded into 12 subthemes. Next, a model of health care interactional suffering was constructed based on these themes and subthemes as shown in Figure 1. After revisiting the transcripts, thematic and subthematic saturation were identified within the 3rd and 11th interview, respectively. The themes and subthemes are described subsequently. The selected segments of transcripts are shown in Table 3.

Attention Issues

The 3 subthemes of attention issues are (1) a lack of timely attention, (2) a lack of full attention, and (3) a lack of professional attention. In terms of timely attention, patients described a lack of immediate attention during their time of needs. They were told to wait when they called for help. Some were scolded
by the nurses for repetitive calling. Some were ignored by the health care professionals. The waiting time to see doctors was long. Some did not have a chance to see doctors. Some did not know whom to speak to, because too many doctors were involved. When the primary doctor was on leave, patients did not know whom to see. Attention at wrong timing was also mentioned.

For full attention, doctors were criticized for not giving all their attention to patients. As a result, diagnoses were missed or delayed. During ward rounds, most doctors rushed through and skipped many details of medical information. Many nurses rushed to complete their jobs without paying complete attention to patients’ distress, as in blood taking.

Some patients complained about inadequate professional attention from the doctors and nurses, such as supervision of medication ingestion, follow-up of patients’ progress, and explanation of patients’ conditions. The feeling of being abandoned by their primary doctors was also mentioned when patients were left in the palliative care ward without being seen by the primary team.

### Understanding Issues

Regarding understanding, the 3 subthemes are (1) a lack of listening, (2) a lack of understanding of concerns, beliefs, and preferences, and (3) a lack of understanding of feelings. Patients felt it was pointless to complain about their problems, because doctors did not listen to them. Some doctors regarded themselves as God. Some nurses had wrong attitude, not listening and not learning. Patients and caregivers had to spend a lot of time to make sure that things did not go wrong. This was stressful for patients and caregivers. Besides not listening to patients’ concerns, health care providers were criticized for not listening to patients’ feelings too.

Due to the lack of listening, the health care providers could not understand patients’ concerns, beliefs, and preferences. Examples of concerns were curability of their diseases, side effects of treatment, financial constraint, family well-being, and mortality. Some patients believed that their cancers were caused by past eating habits. Some believed that cancer was a test from Satan. Many patients had strong faith in alternative medicine or miraculous healing. These beliefs were not understood and acknowledged by many health care providers. Preferred choice of treatment, place of care, and time of discharge were often ignored.

For a lack of understanding of feelings, patients described a lack of empathy from doctors. Sometimes doctors asked patients too many questions. Some doctors were not emotionally attached to their patients, and some doctors ordered investigations or performed procedures without considering patients’ feelings. There were instances where doctors transferred patients to the palliative care ward without exploring patients’ fears of staying with other sick patients. For nurses, they were seen as being emotionless when they did their blood taking hastily without paying attention to the patients’ distress.

### Communication Issues

The 2 subthemes of communication issues are (1) a lack of communication of medical information and (2) a lack of communication of empathy and hope. Patients were unable to get the entire picture from their doctors, because their doctors were rushing. They expressed frustration because of a lack of medical information to guide their decision making. They were not given adequate explanation about the side effects of treatment,
Table 3. Selected Segments of Transcripts.

Attention issues
The services of nurses here are quite slow. You don’t expect them to be like private hospital. They take some time to come. You don’t expect them to come immediately because they have so many patients. (Patient 15)
The nurses are quite nice. I only met one nasty one. I was pressing the bell a few times because I needed something. So she came and said, “What do you want? Tell me. Don’t call me again and again.” (Patient 13)
I don’t like staying in the hospital. I don’t know why. I can tell you one thing. Once I was in a general ward, I told the nurse to lower down the bed. The second time I told her, “Please lower down the bed a bit”. She still ignored me. (Patient 8)
I don’t want anybody to come when I want to sleep. If I’m tired, you come here. It’s not the right timing. (Patient 10)
The doctors, in a way, skipped over quite a lot of details and didn’t follow-up as thoroughly as what they really should have done. That caused complications. (Caregiver 15)
I wish someone can just walk in, talk to me and take out the feeling, the phobia feeling. I’m scared of death. On one hand, I want to go off fast. On the other hand, I’m scared. (Patient 3)

Understanding issues
Okay, the nurses, there are some fundamental problems . . . . They don’t have the training. They don’t have the attitude. They don’t follow training. They don’t listen and don’t learn. (Caregiver 15)
Sometimes I feel lonely. No one knows my pain. Maybe they can see, they know, or see something, but they can’t hundred percent understand what is happening inside me. (Patient 12)
I argued with the doctor. She said, “I have seen worse cases than yours.” You have seen many cases, but you haven’t tried. Try not to eat one week and see what happens. (Patient 10)
The doctors are very good. But shall we say, some of them, or all of them could use a little bit more compassion perhaps. They are highly trained, you can see that they know what they do, they know precisely what to do but sometimes, they lack a little bit of compassion. (Caregiver 14)
I don’t know about the nurses. They are human, right? So, I think, they have to deal with sick people every day. They can be quite “emotionless,” or “feeling-less.” (Caregiver 4)

Communication issues
Sometimes I asked the doctors about my condition, but then they didn’t tell me clearly. They just told me roughly, “something like that, like that.” (Patient 1)
There’s not a lot of patient information available. The only comments that you are going to get are verbal comments from the doctors and perhaps a limited amount of simple information. (Caregiver 15)
He keeps on complaining that certain doctors are so direct in talking. They tell you right to the point of how many months you have left. I feel that they shouldn’t tell right in front of him because having told him that he has cancer is already bad enough. And then you tell that he has how many more months to live. It’s quite difficult for him to take it. (Caregiver 9)
I’m still praying, though the doctors have given up on him. They said, “The cancer is bigger now. We can’t do much.” (Caregiver 11)
The doctor explained everything, and said, “There is no more hope already”, you know . . . But I still hope to find an alternative way to cure my daughter. (Caregiver 2)

Competence issues
I’m not very happy. I’ve pain all the time. I’m taking pain-killer all the time. I’m taking morphine. But I still have pain. Actually I still have pain. (Patient 6)
It’s painful. He made a hole here and cut me from the left, then from the right. I screamed but I had no voice. I said I didn’t want. It hurt. I couldn’t stand the pain. (Patient 9)
I’m scared of a lot of things. I’m scared of dying, scared of nobody going to take care of me because I’m not married, scared of troubling people for taking care of me . . . . The doctors cannot help me too. I don’t think they are helping me. They gave me anxiety pills. That’s all. But, deep inside, the feeling is still there. (Patient 3)
Of course I am stressed, especially when he is restless, when he passes motion, or when he seems to have a temper around. (Caregiver 3)
My experience with the nurse, it’s just poor care. They don’t know how to handle things. And, every little thing is, you have to wait, because they have to make phone calls. They have to call the doctors. And then whatever doctors tell them over the phone, that’s all they do. (Patient 11)
So, we found that the frustrating things to me are that, like here, you find that there is no coordinator to tie in all this. It’s like you depend on your first doctor to lead you to the second, to the third, to the fourth. But even after that, it’s like each does their job and they go back to their places. There is no overall team, which, strictly, should be the palliative care team, who should be the lead coordinator, and overall manager. (Patient 11)

Limitation issues
At the moment, with the current technology, they don’t have the medication to cure the cancer. What they have is only to control it, or maybe to help me to live a little bit longer, but not really to cure it, to cure one hundred percent. This makes me very sad. (Patient 12)
Until now, doctors just put her on drugs to reduce her pain. I mean, even in this ward, it’s for those who’re just waiting for the time to, you know, to pass on. (Caregiver 4)

(continued)
such as chemotherapy and morphine. They were also not given enough information about what to expect next. This ignorance was incredibly stressful for both patients and caregivers.

Concerning communication of empathy and hope, doctors were criticized for being too blunt and direct in breaking the news of cancers and prognoses. There was a lack of consideration of patients’ feelings. Examples were reprimanding a patient’s late presentation, blaming the patient’s lifestyle as a cause of the disease, and giving insensitive dietary advice. In addition, sometimes doctors said nothing more could be done. Some doctors said there was no more hope. Some did not offer reassurance. These left many patients feeling devastated.

**Competence Issues**

Regarding competence, the 2 subthemes are (1) a lack of competence in palliative care and (2) a lack of multiprofessional cooperation. Many patients complained of uncontrolled pain or analgesic side effects. The lack of knowledge and skills in palliating cancer pain, procedural pain, and other distressing symptoms contributed to unrelieved suffering. Psychosocial distress such as fear of death was not adequately addressed by the health care team. For caregivers, seeing terminal restlessness was mentioned as a great stress. Lack of competence of general nurses in handling palliative care issues was described. Lack of empowerment of nurses to palliate patients’ symptoms was commented.

Regarding multiprofessional cooperation, frustration from the lack of a primary physician to coordinate the multidisciplinary care of patients with cancer was expressed. Different teams were not working as one. Different doctors communicated different information. Poor communication within the multidisciplinary team led to many unwanted complications.

**Limitation Issues**

Subthemes of limitation issues consist of (1) medical limitation and (2) professional limitation. As far as the medical limitations were concerned, many patients expressed their suffering due to limitations in medicine. These included failure to cure, to reverse functional decline, to prolong survival, and sometimes even to palliate. They were frustrated, because doctors could only help to reduce pain and discomfort but unable to cure their diseases. Doctors also could not guarantee the success of their treatments. Sometimes patients went through serial unsuccessful treatments. Some patients mentioned that health care providers were not helpful in reducing their emotional distress. A few patients expressed their frustration over prognostic uncertainties. A few asked for hastening of death due to unbearable suffering.

With respect to professional limitations, issues were raised regarding doctors’ persistence on treatments despite failure of multiple lines of chemotherapies. On the other hand, it was common for grieving caregivers to pressurize health care staff to maximize support for their dying relatives. Doctors’ boundaries were pushed when caregivers requested treatment that the doctors have not actually given before. At times, caregivers sought permission to institute alternative medicines in the hospital. Doctors were asked to keep patients in the hospital for respite despite bed constraints. Doctors were asked by caregivers not to disclose information to patients. Furthermore, comments were made, which criticized doctors who did not take risk to put patient care first when hospital rules and politics were involved. Other comments included primary doctors could not attend to patients while on leave and nurses could not offer 24 hours assistance. Finally, late referral to the palliative care team was mentioned despite the presence of unrelieved physical and psychosocial symptoms.

**Discussion**

The model of health care interactional suffering (Figure 1) indicates that attention, understanding, communication, competence, and limitation are 5 crucial components in the health care encounter. Recent advances in medical science seem to promote an attention-deficit culture among health care providers. The depth and diversity of medical diagnoses, coupled with the emphases on efficiency and productivity, force health care providers to rush and multitask during their medical encounters. Because of time pressure, health care providers face great challenges in offering their attention needed by patients and caregivers. From the results, deficiencies were noted in providing timely, complete, and professional attention.
Health care professionals did not attend to their patients or caregivers at the correct timing, wasting a lot of time unnecessarily. During the encounter, full attention was not offered because the doctors were rushing. Adequate professional attention was not provided, either in the form of attention to the patient as a whole person to understand the illness experience or attention to the underlying disease for the sake of making a correct medical diagnosis. In addition, the feeling of abandonment was also described due to the lack of follow-up attention from the primary team. Being with dying, a crucial element in end-of-life care for those who work with the dying and the bereaved, cannot be actualized with an attention-deficit health care culture. The healing encounter with physical, psychological, and spiritual presence cannot occur without appropriate attention from the health care providers.

To understand the experiences of patients, a combination of listening carefully to patients’ expressions, watching patients’ nonverbal behaviors, and attuning to patients’ feelings and perspectives is necessary. In the study, patients complained that some health care providers were not good listeners. Many of them seemed to apply a paternalistic approach in communication, that is, “I talk, and you listen.” Comments were made that doctors regarded themselves as God. Due to time constraints, many were interested in only the medical agenda per se, neglecting the psychosocial aspects of care. Concerns, beliefs, and preferences were not explored. Feelings were not listened to. This biomedical approach is not only inadequate in addressing patients’ suffering but is in fact contributing to the suffering experiences. Listening deeply to the experiences of patients or caregivers can be a form of spiritual care. Listening to patients’ fears, hopes, pain, and dreams; being attentive to all dimensions of the patients and their families—body, mind, and spirit; or serving the whole person—physical, psychological, social, and spiritual, is inherently a spiritual activity. In other words, a form of whole-person empathy based on our perceptual capacity of listening, seeing, and empathic imagining is paramount in understanding a patient as a whole person with many symptoms, concerns, beliefs, preferences, and feelings.

Communication weaknesses pointed out in the study is consistent with a recent article showing poor knowledge in communication strategies in the majority of health care professionals who worked with patients receiving palliative care. Fragmented communication training with superficial content in most educational institutions is far from adequate to equip health care professionals with the skills needed to discuss various palliative and end-of-life issues. Patients not only complained of a lack of communication with regard to medical information but also a lack of sensitivity in communicating such information. Empathic communication that involves recognizing emotional cues, inviting emotional expression, and acknowledging the patients’ feelings was lacking in the description by patients and caregivers. Verbal and nonverbal communication of empathy via allowing expression of thoughts and feelings were deficient. Communication of hope, an essential element of palliative communication, was also lacking. This was aggravated by the often unintentional eroding of hope with the common sayings of “nothing much can be done” or “there is no more hope.” At another extreme, clinicians were described to sustain unrealistic hope by abstaining from truth telling or telling patients about futile treatment options because of reluctance of dealing with their own feelings of impotency in the face of their patients’ terminality.

Regarding competence, a lack of palliation of suffering and a lack of multiprofessional cooperation were shown in the study. Conventional biomedical approaches that focus on diseases and body parts are inadequate to address suffering experienced by patients. Although palliative care was developed precisely as a reaction to this incapacity, late referral to palliative care in the institution resulted in much un palliated suffering prior to the consultations. Poorly relieved symptoms, poor team coordination, and poor interdisciplinary communication were reported prior to the palliative care consultations. Earlier access to palliative care to provide person-centered attention to symptoms, psychological, social, and existential distress may improve the situation. In terms of optimal palliative care delivery, one study showed that care received in palliative care units might offer more improvements in care than those achieved with palliative care consultations. Another solution is to increase palliative care training for the generalists or specialists from other subspecialties, since most palliative care will be provided by generalists and nonpalliative specialists. As for team working, factors crucial for cooperation need to be actively promoted, such as close communication, team philosophy, good interpersonal relationships, high team commitment, autonomy, and competence in dealing with death and dying.

Concerning the fifth theme, suffering was related to a mismatch between expectations and limitations. For medical limitations, many patients suffered when health care providers failed to cure their diseases. For professional limitations, they suffered when health care providers maintained a clear professional boundary. In the former, it is crucial for health care providers to ascertain the true reason behind such limitations. Sometimes it is due to insensitive communication such as “we cannot help much” or “there is no more hope.” Sometimes it is due to the fear of side effects of certain treatments. Therefore, it is important for health care providers to be aware of the distinction between curing the disease and healing the sick person. We must remember “to cure sometimes, to relieve often, and to comfort always.” In the absence of cure, palliation of suffering should be continued with appropriate and timely communication of hope and empathy. For professional boundaries, the mutually understood, unspoken, physical, and emotional limits of the relationship between the trusting patient and the caring physician or provider are supposed to safeguard both the patients and the health care providers. Although sometimes crossing boundaries can enhance the therapeutic relationship in palliative care, self-awareness is absolutely important every time the boundaries are approached to avoid harming patients and oneself. Exquisite empathy, a highly present, intimate, and heartfelt interpersonal connection, without
losing sight of one’s own professional boundaries should be practiced by all health care providers.

The results of the study have serious implications. As health care providers, if we are unable to alleviate suffering of patients, at least we should not contribute to their suffering. “Do no harm” does not apply exclusively to medical interventions and procedures. It applies to every health care interaction too. Hence, the model of health care interactional suffering may serve as a guide to understand the experiences of suffering caused by such “harmful health care interactions.” It may also serve as a framework for development of good interaction skills for health care providers in palliative care and other fields of medicine. The study is limited by the number of questions asked in the interviews. Questions regarding attitude, behavior, language, and nonverbal communication were not addressed. Questions on allied health care professionals were not asked. Pediatric patients or their caregivers were not included. Community palliative care patients who were not referred to our hospital’s palliative care team were not interviewed. Noncommunicative dying patients could not participate in the study too.

To conclude, it is time for health care providers to take “harmful health care interactions” seriously to maintain the honor and the noble traditions of the medical and nursing professions. The moment we dedicate our lives to the services of humanity, we should maintain our full respect for each patient as a whole human being and to try our best to cure, relieve, and comfort them. To achieve this, we have to pay attention to the whole person completely, timely, and professionally. We have to try to understand the whole person through active listening and empathic imagination. We have to communicate empathy and hope professionally. We have to palliate patients’ suffering collaboratively and should become more self-aware of our medical and professional limitations. Finally, we would like to quote Shantideva regarding doing no harm.

Since I have given up this body
For the happiness of living beings,
Therefore, in whatever I do,
I will never cause harm to others;
And whenever anyone encounters me,
May it never be meaningless for them.

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