Practical Wisdom: Competencies Required in Alleviating Suffering in Palliative Care

JOAKIM ÖHLEN, Institutes of Nursing and Health Care Pedagogics, Faculty of Health and Caring Sciences, The Sahlgrenska Academy, Göteborg University, Göteborg, Sweden

Abstract / The aim of this article is to reflect upon the competencies required to alleviate suffering in palliative care. The knowledge to prudently and wisely act in a situation involving human relationships can be defined in terms of practical abilities and contextual skills. In the setting of the care of the very ill and dying, practical wisdom such as the carer’s ability to meet the suffering person and to act with sensitivity and openness, becomes important. From this, learning to alleviate suffering emerges as receiving insight and wisdom from the suffering person’s experience of suffering. This means that the testimony of suffering persons—what they have endured, given up and experienced—becomes as significant as theoretical and practical knowledge of suffering. The professional carer needs to learn how to be open to and interpret what the suffering person, living with suffering and death in the midst of life, can teach.

Résumé / Le but de cet article est de réfléchir sur les aptitudes requises chez un soignant pour soulager la souffrance des malades en soins palliatifs. Cette expérience qui nous fait agir avec prudence et sagesse dans une situation comportant des relations humaines peut se définir en terme de connaissances pratiques et d’aptitudes à s’adapter à un contexte. Dans le cadre des soins dispensés aux grands malades et aux mourants, cette sagesse de nature pratique, telle que l’habileté du soignant à entrer en relation avec la personne qui souffre, à se comporter avec sensibilité et avec ouverture d’esprit prend beaucoup d’importance. Ainsi donc, apprendre à soulager la souffrance se révèle en fait comme l’apprentissage de la sagesse qui nous est transmise à travers l’expérience de la personne qui souffre. Ce qui veut dire que le témoignage des personnes qui souffrent—ce qu’elles ont du tolérer, abandonner ou vivre—revêt autant d’importance que les connaissances d’ordre pratique et théorique sur la souffrance. Le professionnel se doit d’apprendre avec ouverture d’esprit à interpréter ce que la personne qui vit avec la souffrance et la mort peut lui enseigner.

INTRODUCTION

The evolution of hospice care into palliative care has meant a change in underlying concepts, and a change in meaning. The heritage from the hospice philosophy of care, guided by Christian love, has more or less been replaced by the principle that palliative care is concerned with active control of symptoms—containing troublesome symptoms to enable the patient to lead as good a life as possible despite the life-threatening illness (1). Several authors have recently wondered what unexpected consequences this might have for practice (2–4). Cassell was the first researcher to argue that the suffering person, rather than his or her symptoms, should be the focus of the palliative care (5). Corner and Dunlop are of the opinion that the concept of symptom is problematic, since it diverts attention from the patient as a person with unique experiences and life conditions, to focus instead on the carer and universally defined interventions (2). George puts forward a similar view to that of Cassell, claiming that the goal of palliative care is not to control the symptoms, but to alleviate suffering (3). Urquhart uses similar arguments to shed light on suffering in relation to palliative care as seen from a nursing perspective. In her view, by focusing on patients’ suffering, experiences of patients in their life situation are highlighted. Taken together, these changes in the underlying concepts of care mean the carer must behave in a knowledgeable and supportive way. From this, it follows that alleviation of suffering as a principle for palliative care does not mean that patients with severe symptoms are abandoned, or conversely, that only their physical symptoms are addressed, but that they are approached as persons and that efforts are made to understand their symptoms from the perspective of their life and world. There is need, therefore, for correspondingly complex competency in professional carers (4).

According to Ricoeur (6) and Frank (7), the personal experience of living within one’s own body is the foundation of human suffering, which also means that suffering and alleviating suffering appear from within the experiencing human’s perspective and world. Suffering may
overturn the life of the person and "...is experienced when some crucial aspect of one's own self, being, or existence is threatened. The meaningfulness of such a threat is to the integrity of one's own experience of personal identity" (8, p.626). Insight into the meaning of experiences of suffering (9–12) has often been omitted in discussions of the competencies required in palliative care. There is, therefore, a need to explain how the ability to encounter suffering and enable its alleviation in palliative care practice may be understood. The aim of this article is to illuminate the competencies required to enable alleviation of suffering in palliative care through reflection on the kind of knowledge gained from patients' experiences of suffering. The article will focus particularly on competencies of relevance to everyone caring for severely ill patients; examples will also be given from nursing. As a source for this reflection, an example of a severely ill person's experiences during one of his last days of life is presented.

An Exemplar of Suffering in the Palliative Care Context

The following situation arose during a visit to a palliative home care patient who was ill with metastatic intestinal cancer. He was participating in a project which focused on the meanings of alleviated suffering in the context of palliative care.

I met an elderly man in T-shirt and briefs sitting in his kitchen. I saw indications of ascites, and his skin and the whites of his eyes were clearly icteric. He had a fatigued and listless gaze, and was short of breath. When we said hello to each other and shook hands, he raised his eyes slightly. He told me that he had changed for the worse since we had talked over the phone in the morning. I realized that, in his situation, he probably did not want to meet a researcher. However, he asked me to sit down and stay with him for a short while. He puffed and blew, which made me say: "It's hard work for you now, isn't it?" He replied quickly, "Yes, it's the damn cancer which is growing. And have a look at this bleeding. There was only one of them the other day. What causes it?" He showed me about five red spots of coin size on his forehead. "Yeah, what does cause it?" was my reply, and I tried to affirm his worry with my eyes and approach. I thought quickly about his liver failure and coagulation disorder, his worries and anxiety, but I said nothing. I thought, "No, I will not say anything right now." I hoped I had affirmed to him that I had listened and tried to understand. He told me he had been promised a bed at a hospice ward. We sat in silence for a while, and then I asked him, "What's most difficult for you now?" He said, "Well, I am so tired. I'm tired. And I have to make a move and leave, and pack up. To leave and break up, that's difficult."

Hands-On Skills and Personal Ability

For the reflection on competencies required to enable alleviation of suffering in palliative care, I will dwell on Aristotle's understanding of the nature of knowledge (13). Aristotle views human action as a practical skill. From this perspective, knowledge can be understood as (a) episteme, knowing something about something, (b) technê, being able to do (create, manufacture) something, and (c) phronesis, being able to take action in a prudent and wise manner. Episteme is attained through intellectual activities, through reflecting, abstracting, drawing conclusions, and the like. Technê is reached by creating or making something that becomes functional, useful, and aesthetic. Phronesis is achieved through human relationships and the practical training of being with other people. These forms of knowledge give the framework for reflection on what kind of knowledge carers need to acquire to be able to alleviate suffering.

First, then, knowledge can be knowledge about suffering and alleviating suffering. Carers need to know, for example, what suffering and alleviating suffering are, and how they may be perceived by an individual with a life-threatening disease who is in need of palliative care. It can be expressed as the carer's understanding and knowledge of, for example, how the changed body of the individual becomes obviously present when subjected to suffering and vulnerability, as illustrated in the exemplar above. The man interpreted the red spots on his forearm as part of his cancer. Knowledge of bodily experience in illness can, therefore, help in understanding his conclusion that the cancer was alive and growing.

Secondly, knowledge may be in the form of hands-on skills that can provide the basis for alleviating suffering. This knowledge is related to things the carer does, acts, or performs, which may facilitate the patient's daily life or improve a particular situation. In other words, being able to shape and do something so that it becomes safe and smooth, and both functionally and aesthetically appealing. This can be seen in, for example, the carer's ability and skills at arranging a room that is inviting, restful, and comforting—a bathtub, a bed, a dining area—or in applying a bandage properly so it is secure and func-
tional. In assisting the man in the exemplar, it would be important to have the skills to help him rest in a position which would decrease the discomfort caused by his edema and his difficulty breathing.

Thirdly, knowledge may be in the form of practical wisdom—the core knowledge that underlies the carer’s attempts to alleviate suffering. The person who is suffering needs to meet a fellow being who acts wisely and prudently. The suffering person can receive both comfort and strength, and thereby the courage to face life, from fellow beings who are present and who show, through their actions, that they will be by her or his side and will try to share the hard times, even if that is not really possible. It is a question of being responsive to situations in which the patient is about to lose dignity. It is also a question of demonstrating one’s will in a responsive way, and providing caring help and support so that the dignity of the suffering person is preserved. This can be illustrated, for example, by the carer’s ability to adapt to the patient’s lived rhythm and time. In our example, there is a need respectfully to show this man that his difficulties with leaving home might symbolize his struggle with approaching death.

Of course, it is not possible to prescribe prudent behaviour for a carer, such that the patient experiences these abilities in the carer. That is determined by the actual situation. Acting in an appropriate fashion demands something personal from each carer. A common characteristic of this ability is the carer’s skill at responding to the patient and the immediate situation.

The three forms of knowledge—episteme (theoretical knowledge), technē (hands-on skills), and phronesis (personal ability)—are each other’s prerequisites. Any one of them alone is not enough. The ability to act prudently and wisely presumes theoretical knowledge about suffering and alleviation of suffering, as well as hands-on skills, as described above. On the other hand, neither theoretical knowledge nor hands-on skills are enough unless practical wisdom and prudence have been developed. If the task of palliative care is to alleviate the suffering of patients and their family members, then phronesis becomes the knowledge aimed at learning about alleviating suffering. In my opinion, what is essential with this form of knowledge is that it highlights the carer’s wisdom, coupled to knowledge of a theoretical and practical character. However, it is to some extent possible to act in a good way in a problematic situation without having an intellectual insight into the set of problems in question, and without being able to give an account of them. Nevertheless, this reflection indicates that being able to act wisely and prudently in practice is the form of knowledge that determines a carer’s ability to provide good care.

Wisdom and Prudence

Carers can attain wisdom regarding how to behave towards people who suffer, through their own experiences in similar situations. The practical knowledge “...has to be exercised in social practices where I manage the reality and live in it. I train myself in good or bad ways of doing things, developing a good or a bad character, and good or bad virtues” (14, p.185). This can lead to the development of the desirable practical ability.

This ability focuses on the skillfulness in relating to others that a person can acquire through practice, so their own actions are perceived as good by them. It is, therefore, possible to distinguish between skilled and unskilled actions in these regards. The development of practical sense and wisdom will be manifested as virtues shown in the habits of the carers. On the other hand, bad habits and unfamiliarity tend to leave the suffering person abandoned in suffering. For instance, in the example above, the fragile situation required the man to be encountered sensitively and openly. In such situations, there is need of something in excess of the fingertipsgefühl, of just practical skills such as changing a dressing or helping a disabled person to move.

The ability to act with sensitivity and openness in a situation is, therefore, required. This is what Aristotle calls hexis. It can be understood as the embodied practical ability and competence to adapt one’s actions to the situation. To learn about alleviating suffering, carers need to be able to learn to become responsive and open in encounters with patients and their families. They also need to have insight into what habits can create the conditions for alleviating suffering, as well as when such habits are appropriate. As Weismans points out, it is important to make a distinction between these habits, and the jargon and routine expressions that too often substitute for them (15). Wisdom is not superficial. “Appearances are often confused with substance, and what seems to be a combination of experience, culture, and wisdom may only be a certain age, somber bearing, facility with words, and penchant for uttering obscure and self-evident platitudes” (15, pp.51–52). The suffering person can recognize this. In acting sensitively and openly, there is an implicit acceptance of respon-
sibility for the other person as a basis for the relationship. This kind of sensitivity and openness is characterized by carers' actions that arise from proper and appropriate intentions. Thus, actions that can serve to develop sensitivity and openness are not habits, in the sense of not being thought out or of being unconscious. They include, but are not restricted to, taking responsibility for one's actions as well as for the well-being of one's patients. They also include being responsive to the other—something that develops informally in the relationship. Theoretical insights into such responsiveness can be gained from, for example, the ethics of relationships and virtues (6,16). As an example, exceptional and fragile situations in life can be transformed into ordinariness and experienced as comforting through caring actions (17). Similarly, nursing culture can be characterized as a community of care (18). This contributes to a context-sensitive approach for palliative care ethics (19).

In the light of the meaning of suffering, the concept of wisdom appears to be relevant. Wisdom can be said to relate to carer actions that make alleviating suffering possible—honesty, inspiring hope, listening attentively, acting flexibly and responsively. In other words, training oneself to act wisely and prudently. This ability can be understood as arising from the attempts of carers to familiarize themselves with life in general and, above all, to be open to encountering suffering, issues related to the edges of life, and life's sometimes awful situations. Younger describes wisdom as arising from familiarity with the shadow of one's own life and the ability to face suffering (20). Weisman believes that, together with experience and culture, wisdom constitutes a cornerstone in the ability to alleviate suffering. He argues that wisdom is having knowledge about how people provide answers to and, perhaps above all, raise and have the courage to listen to, the questions surrounding difficult situations in life (15). Being open to encountering one's shadow opens up possibilities for personal growth.

We can familiarize ourselves with our own conceptions, be they conscious or those we hesitate to express in words, about disease, suffering, vulnerability, and death, as well as shame and guilt, by familiarizing ourselves with the shadow of our own life. People who have suffered and who have kept an open mind towards life as it has unfolded have often developed such familiarity. Thus, there are great similarities between the wisdom developed by those who have suffered and that of good carers. Herein lies much of the strength of carers' sensitive and open actions that makes alleviation of suffering possible. Both the patient's and the carer's wisdom is related to awareness that death is inevitable, a fact not always evident in our culture. Such an insight can open the mind to compassion and caring. For carers, it is the key to acting with sensitivity and openness. It parallels the wisdom a sufferer can gain from their suffering, which gives potential for growth and maturity.

Erikson's psychosocial development theory focuses on human maturity along the life span. According to this theory, wisdom is a personal strength that can develop at an advanced age (21). Carers face a well-known dilemma in learning to alleviate suffering; how to bridge the gap between the carer's maturity, at the start or in the midst of adult life, and an understanding of the patient's struggle to attain wisdom at the end of life. Erikson's theorizes that people develop wisdom from the perspective of a long life. Young people in the midst of life do not have comparable perspectives. There is no solution to this dilemma. However, patients have reported that many carers have shown a pre.sentiment of what the wisdom at life's end may be about (22–23). On the other hand, if the goal for carers is to develop wisdom (in the sense of Erikson), this will probably be not only unrealistic, but also a burden, especially to young carers, who may be justified in feeling that they lack the prerequisites to reach this goal. Instead, a realistic goal appears to be to awaken their curiosity, and their interest in listening to and trying to learn from the wisdom of patients. Carers, particularly in palliative care, are exposed to so much suffering and sadness, as well as love and demonstrations of the human spirit, that they may begin to develop wisdom before they have lived a long life. This is why it used to be said that medicine is an ennobling profession. This leads to further reflections on how it might be possible to evoke and foster carers' personal growth and maturity while they acquire the theoretical knowledge and hands-on skills they need. To be able to exercise wise and prudent actions, the carer's longing—desire—to develop sensitivity and openness to the world of the suffering person needs to be awakened.

Learning Sensitivity and Openness to Suffering

Learning to alleviate suffering through wisdom and an ability to encounter the suffering person, emerges as receiving insight and wisdom from the suffering person's experiences of suffering. This kind of learning has been called the "pedagogy of suffering" by Franks (7, p.24). "The
pedagogy of suffering means that one who suffers has something to teach...and thus has something to give" (7, p.150). The testimony of suffering persons—what they have endured, given up, and experienced—become as significant as theoretical and practical knowledge of suffering. The professional carer needs to learn how to be open to and interpret what can be taught by the person living with suffering and death. Franks also gives a motive: "The pedagogy of suffering is my antidote to administrative systems that cannot take suffering into account because they are abstracted from the needs of bodies. When the body's vulnerability and pain are kept in the foreground, a new social ethic is required" (7, p.146). The patient's suffering and vulnerability are brought to the fore, which, in turn, makes it difficult to disregard the fact that suffering encompasses a dimension with potential for growth and maturity. Suffering can open up possibilities for new understanding and for learning something about life, about the wisdom of life. People living with the knowledge that they may soon die may be struggling with phases of maturity that people of their age would not expect to face until they are much older. They may, therefore, develop a level of wisdom comparable to that attained by old people. Herein lie possibilities for palliative carers as fellow beings.

Through personal encounters and conversations with a person who has suffered, who has struggled to be open to life as it has unfolded, and who has developed wisdom, we are offered a gift. This gift can be experienced in the personal encounter with the other. The carer is allowed to share in the suffering person's wisdom and, by assimilation, to make it his or her own. Experiences of wisdom obtained from people who find themselves in the final phase of life, when the acquirer herself/himself is in early adulthood or in the midst of life, form an important part of the foundation of experiences needed by the carer in order to be open when encountering a suffering person with a life-threatening disease. Learning from people's experiences and narratives of suffering becomes as important as theoretical and practical knowledge in providing care to alleviate suffering.

In receiving insight and wisdom from the suffering person's experiences of suffering, learning about suffering takes the suffering person's experience as its point of departure. It looks at how the person has struggled in suffering, hoped and experienced lack of hope, perceived the body as unbearable, felt lonely and a sense of fellowship, and felt hurt and vulner-
able. It also looks at how suffering persons have felt others' conceptions and influences have contributed to their suffering and alleviated their suffering, their feelings of lost life, what they have learnt from life, and how they have found meaning in suffering and become wise. Consequently, as illustrated by the exemplar of suffering above, it is impossible to ignore the fact that suffering is experienced by persons in their whole being, in their life world, and in their personally experienced body. Likewise, my own experience of the encounter with the man was embodied and situated, and became personally enriching for me.

Implications for Development of Practical Wisdom

To be able to learn to provide caring that makes alleviating suffering possible, the carer needs to listen to the personal narratives of suffering people, and to receive the wisdom and insight the sufferer is able to share (e.g., 23–25). This requires that the carer is able to be present actively and to share the moment with a fellow being. The prospective carer needs to learn to be open to and to interpret what the suffering person can teach (26–27). This learning brings suffering to the fore in a way that does not make it a means for something else. It can open up a way of understanding the patient as well as oneself.

Palliative care, as caring, means both giving and receiving. Frank states that “The relations of giving...begin in a mutual recognition of need.” Thus, caring is concerned with both giving and receiving. There is also a similarity between carer and patient, as “...all persons have abundances, and all have lacks...” (7, p.149). Weisman expresses this as: “Healing is bilateral” (15, p.16). He argues that carers need continuously to encounter their own personal vulnerability. Boykin and Schoenhofer describe the similarity between carer and patient as “all persons are caring” (28, p.3), which is founded in Mayeroff's (29) caring philosophy.

Becoming open to what poor care (22,30) can do to a person who is already suffering does not mean learning not to do one thing or another. It can give a deeper understanding of what it means to feel hurt, vulnerable, and at the mercy of others when it comes to managing one's daily living. Such an understanding may generate embodied memories of suffering, which can create an openness and sensitivity to the courage that is needed to be able to share one's suffering with another person. Carers may, for example, feel that they cannot ask patients about their suffering as they can about their eating or toilet habits, when, in fact, it is necessary to learn how to ask.
In relation to the literature on palliative care, the process of receiving insight and wisdom from the suffering person's experiences of suffering uses other perspectives, moral values, and theoretical foundations as the basis for describing and understanding palliative care. Seen from the perspective of suffering, the focus is on the world of the patient. The theoretical foundation is drawn from theories of suffering and complemented by theories about, for example, caring and comfort, as well as about relieving painful and troublesome symptoms. Both perspective and theory demand integration of the patient's experience of living within his or her own body. This represents a break with the tradition in palliative care literature. In the theoretical discourse on palliative care, as well as on nursing care, the body as a concept has been more or less absent. The body has been seen as equal to parts of the biological body, without conceptualizing it as a lived body. Even in promising advances in palliative care, beyond the medical model, explicit concepts of the body are omitted, although many authors are stressing and dealing personally with experiences of the lived body (9,11). Exceptions are found in palliative care research (12,23,31–32), and in nursing research (28,30–35), among others. However, the field of knowledge related to the patient's lived body has not been examined in textbooks of palliative care (1,36). This is also true of sociogerontological research. Öberg has pointed out the paradox in this situation, where physical changes are often so tangible to the aging person (37). In carers' narratives about their experiences of working in a hospice, the body has also been left out (38–39). Learning sensitivity and openness from the testimonies of suffering persons can contribute to understanding the body of the suffering and dying person as forming a natural part of the knowledge of aging, illness, suffering, sorrow, and death.

However, there is great uncertainty about what learning from personal experience of suffering might mean for current practice. Many carers have a well-developed ability to act sensitively and openly, to show interest in patients in their present situation, and to listen to what they have to say and teach. However, there are also many examples of the opposite (e.g., 22,30).

There are indications that what is important in making the alleviation of suffering possible is not what the carer should say or do, but how the carer can be actively present for the suffering person (7,20,23). Apart from this, there is a great deal that carers can do to help the suffering person with severe illness. This difference between doing and being seems to be a characteristic of the challenge faced by nurses in particular (38). It also constitutes a significant difference compared to, for example, the professional activities of clerics and psychologists. However, a similarity is that the tools of their work are their personal approach and the art of dialogue. In addition to this, nurses use themselves and their own body as their instrument of care to an equally great extent, when they concretely behave towards, touch, and have access to the patient's body. If we regard the person as embodied, the body becomes as much a part of one's personal approach as a tool for providing help and assistance. Frank expresses this as, "...the listener must be present as a potentially suffering body to receive the testimony that is the suffering body of the teller" (7, p.144).

An additional task of palliative care is to create possibilities for carers personally to handle the difficulties and suffering they may learn about in encounters with ill, dying, and suffering patients and their families (39). A palliative culture of care, based on learning from the suffering, may prompt carers to integrate death and dying as an obvious part of their own life. This is similar in nature to how the suffering person has been open to life as it unfolded. However, this may be difficult for carers to handle in their everyday lives if, at the same time, cultural barriers exist (40). It may take courage to tell one's friends and acquaintances that one encounters suffering, grieving, and dying persons every day in one's professional activities, and that one is enjoying it. That one may find joy in meeting suffering may be met with wonder and even doubt. It is therefore a challenge to create the organizational and practical conditions necessary to enable carers to develop a sense of contentedness and pride at meeting some of life's most painful experiences in their everyday life, even if they feel that other people do not understand.

There is universal value in making available to others the wisdom carers within palliative care have acquired through their encounters with suffering people. This seems very important in the light of the isolation and the existential loneliness that have been reported by people who have contracted life-threatening illness and have suffered as a result of other people turning their backs on them. It might also open up new possibilities for responding to the testimony of a suffering person in some way other than that of the immediate situation. This might give carers something in return that can provide them with the nourishment and strength to to face suffering in their daily work.
ACKNOWLEDGEMENTS

This work was made possible through economic support from the Swedish Cancer Foundation. I gratefully acknowledge the critique and encouragement received during the process from Professor Kerstin Segesten, Borås University College, Senior Lecturer Carola Skott, and Professor Jan Bengtsson, Göteborg University. My special thanks to Professor Eric Cassell and the anonymous reviewers for their valuable contribution to the final draft of this article.

REFERENCES