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Suffering

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Suffering

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FOREWORD

Reading the professional literature, one often gets an impression that *pain* and *suffering* are used as synonymous terms. The articles in this book provide cogent reminders that such is not the case. Pain as response to disease or injury is not the same as that sense of disruption and fractured identity experienced as suffering. Although pain can contribute to suffering, suffering as lived experience occurs when the meaning of a person's life situation has been ruptured by one or more salient changes that bring a diminished sense of what it means to be human.

The dimensions of lived experience that can be precursors to suffering are (a) bodily changes that interfere with one's physical or mental access to the world; (b) interferences with interpersonal relationships and connections to other people; (c) discrepancies between one's ideals and principles and one's actions, resulting in a loss of personal integrity; and (d) disconnection between identified purpose in living and a sense of belonging to an ordered world or being part of a coherent belief system (2).

Serious illness contributes to suffering because it impinges to a greater or lesser degree on all of these dimensions that give meaning to human existence. Powerful symbols of death, disability, and unrelenting pain, diseases such as cancer and AIDS create situations that foster alienation and anguish in patients, fear and exhaustion in family members, helplessness and loss of control in health care providers.

For each person, suffering is a private experience. It derives from a unique biographical journey through time in interaction with a current life situation that threatens some aspect of personal identity. Yet the meanings ascribed to suffering and the behaviors used to express suffering to others are learned through interpersonal transactions and

social activities in particular cultural contexts that Kleinman (1) calls local moral worlds. In other words, suffering occurs as part of an ongoing flow of interpersonal engagements in which participants are guided in their relationships by deep aspirations and goals, perceived threats, and beliefs about ultimate meanings such as the nature of life and death and the position of humans in the universe.

Through interpersonal experiences in the context of their everyday lives, people are introduced to religious and other cultural meanings of suffering. They learn to associate cultural meanings of suffering. They learn to associate anguish and distress, markers of suffering, with certain types of events, such as bereavement after the loss of a loved one and catastrophic accidents in which survivors are overwhelmed by mass destruction, death, and human misery. Through experiences in families and neighborhoods they learn ways of responding to distress in other people; they learn ways of protecting themselves from being engulfed in feelings of despair in response to perceived miseries in others.

Although suffering is assumed to be a universal human experience, across cultures ways of responding to suffering in oneself and in others vary considerably. Differences in perceptions, expectations, and overt behaviors can lead to conflicts and misunderstandings when people from different cultural backgrounds come together in a context of suffering.

Misunderstandings and conflicting images of suffering make it easy to isolate those who are different or to treat them in dehumanizing ways through use of stereotypes and denigrating labels. In any multicultural society, such as the United States, these negative communication patterns are not uncommon.

Contacts with the health care system for those with serious illness can lead to depersonalizing experiences for many. The culture of health care is built around medically centered diagnosis and treatment activities not to the amelioration of suffering in patients and families. The discomfort and distress associated with disease processes and the uncertainties of illness can be heightened by new experiences with tests and treatments that hurt, frequent contacts with many different providers, and difficulties in obtaining information about the current situation and the future.

Workers in health care generally are focused on controlling symptoms, implementing medical treatments, monitoring signs of recovery or movement into a chronic or terminal state of disease. Planning with

patients often centers on the illness and its management, and patients may or may not feel free to share with nurses, physicians, or social workers their real concerns and fears. Yet some patients likely are struggling with feelings of loss, worries about becoming a burden on others, fears of dying abandoned by family and friends. Opportunities to share such concerns and fears with an understanding and supportive provider can serve to counterbalance the loneliness of suffering and to promote integrity of the person.

Unlike pain, which is a symptom to be managed, suffering is an all-encompassing experience of the person that must be endured or lived through alone. Yet suffering may be more bearable in the presence of concerned others who acknowledge its existence and function as human connections during a time of personal disruption and inner struggle to find meaning. Special opportunities exist for physicians and nurses to provide that human connection in their encounters with suffering patients, family members, and colleagues. To do so requires a willingness to enter into a human-to-human engagement that is not prescribed in written guidelines and protocols and that can trigger personal feelings of discomfort and loss of control.

The contributors to this collection of essays help to inform us about the many ways by which pain and illness can interfere with the ongoing life experience of being human. Some remind us of the special vulnerabilities of infants and children, the poignant experiences of persons with AIDS, the impact of living with cancer on the daily lives of patients and families, the meaning of survivorship. Some explore relationships between theoretical perspectives on pain and suffering and empirical observations about patients and families. Others consider the meaning of suffering from the professional perspectives of medicine, theology, and nursing. Together these essays are reminders of just how much pain and suffering are part and parcel of the work world of health care. They also are reminders that professional providers have many opportunities to make a difference in the lives of suffering people, not only by attending to the relief of pain and other distressing symptoms but also by listening to their underlying concerns and being present with them during moments of despair. Caregiving may well be an art form that brings together professional expertise and know-how with a sense of when a situation calls for human-to-human communication and concern more so than expert knowledge and skill.

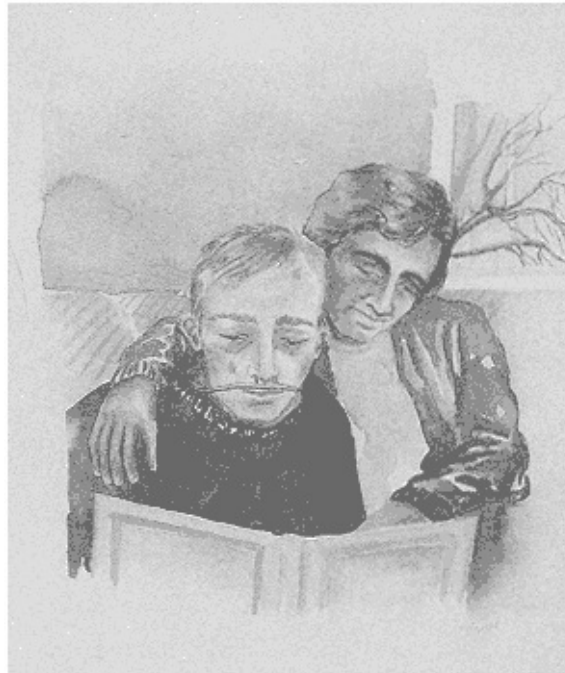
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PART ONE

THE EXPERIENCE OF SUFFERING



Sharing a Final Chapter

Chapter 1

An Understanding of Suffering Grounded in Clinical Practice and Research

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Richard H. Steeves, PhD, RN, FAAN University of Virginia

The two of us, Kahn and Steeves, first began to work together in the 1980s, when we were graduate students at the University of Washington School of Nursing. We had both been drawn to work with Jeanne Quint Benoliel, who was renown for her work in the fields of breast cancer and death and dying. It was during an independent study with Dr. Benoliel in which we explored together the intricacies of phenomenological and hermeneutic approaches to research, an area that was new to the three of us, that we began to formulate the research interest in suffering and meaning that has dominated our scholarly careers to date.

Initially, Kahn brought with him a background in comparative religion and anthropology. Steeves, on the other hand, had a master's degree in fine arts in creative writing and brought with him an abiding interest in the way people make meaning in their lives through the use of language. It was Jeanne Benoliel's suggestion that we study suffering, a suggestion that immediately made sense to us both. From Steeves' point of view, the experience in life that was most difficult to make sense of and thus was most important in terms of making meaning was suffering. From Kahn's point of view, suffering was a quintessential human experience that transcended the boundaries of human culture understanding how people suffered and made meaning of their suffering would provide insight into the fundamental nature of humanness. Perhaps there are other, more powerful reasons for both of us to be drawn to the subject of suffering, but these remain deeply hidden and personal, best left for others to interpret.

Since our early study with Benoliel, over the past decade, we have begun to achieve, at least somewhat, an understanding of suffering that has relevance for nursing science and practice. We have done theoretical and conceptual work on the topic and have conducted empirical studies. Our work has been informed by what we have read in the literature and what the participants in our studies have told us. As well, we have gained valuable insight from our clinical work as hospice nurses. The remainder of this chapter will be a discussion of what we believe we now understand about the phenomenon of suffering. The presentation will take the form of a chronological account of how we moved from one avenue of thought to another, until our arrival at this point which we regard as a momentary interlude in our passagethus, a travelogue, so to speak, written only part way through the journey.

Early Theoretical Work

Our first work in the area of suffering was based on a critical review of several bodies of literature (1). In this work, we attempted to set forth the relevance that theoretical development of suffering would have for nursing science and to, therefore, stimulate scholarly discourse in the nursing literature about suffering. At the time, most discussion of suffering in the literature was obscured by extant conceptual confusion of suffering with physical pain. Although most authors acknowledged that suffering was different from pain and other things that could cause suffering, the distinction was never elaborated very well. When it came down to discussion of actual practice and human beings, the tendency was to consider suffering as a degree of pain or some other kind of distress, instead of a distinct experience that took place on the level of the whole person. This is a problem that Cassell noted as well in the medical literature in his classic article about suffering (2).

Based on our literature review, we advanced a theoretical definition of suffering as an individual's experience of threat to self, a meaning given to events such as pain or loss. As Spross observed, a contribution of this definition was the "recognition that suffering is not necessarily a perception or sensation but an *evaluation* of the significance or meaning of pain" as well as other potential suffering-inducing experiences (3, p. 72). The critical components for us then, and still in any definition of suffering, are the notion of whole person or self, of an event or loss that threatens that self, and that the level of this interaction is of personal experience. The prime distinction is that it is the relationship between the event and the self that determines suffering rather than any inherent characteristics of the event itself. Suffering then must be viewed as a lived experience that is unique to each person. Other recent definitions of suffering have acknowledged the subjective nature of suffering (4), (5), (6), (7).

Another line of thinking that we followed in our early work arose out of our clinical practice. In another paper, we recounted several stories that came from our practices or from colleagues in hospice nursing (8). These stories exemplified what we called "experiences of meaning." In this paper we began to explore the relationship between suffering and meaning.

What we proposed was that suffering was a threat not only to

self but to a sense of meaning in life. We eventually realized that these are one and the same. That is, the self is a set of meanings or understandings of the world and one's place in the world. A threat to the self is a disruption in the understanding of what the world is about, and this disruption is suffering.

In the narratives we explored about hospice patients and their families, we noticed that the people in them expressed the disruption of their understanding of their world by raising questions "Why does this have to happen to me?", "Why must I die now?", or "Why must I be left alone in the world?" The patients and family members wondered about how they could bear the loss of dying or the loss of their loved one. They no longer understood the existential situation of their lives and how they could continue to live in face of this lack of understanding. This lack of understanding was often expressed in terms of loss of self or part of self.

In the face of this suffering, the patients and family members in the narratives we collected had "experiences of meaning." These were discrete moments of transcendence in which they were able to step outside of their specific circumstances, their existential situations, and understand life in terms of larger patterns of meaningfulness. Examples included a person who spoke of transcending her suffering in her garden as she pruned her roses and a man who lost his suffering and regained his self for a moment in listening to music from his youth.

These narratives were collected from a small subset of hospice patients. We came to see that these discrete and dramatic experiences of meaning were only one way in which suffering could be ameliorated, and that the environmental conditions under which such experiences occurred were unpredictable. Our attention was drawn to the way conditions in the environment potentially affected the individual's experience of suffering, especially conditions related to social interaction.

The Language of Nursing Study

Our next work in the area of suffering grew out of our concern with social interaction and suffering. Specifically, we became interested in the relationships and interactions between people experiencing suffering and those who care for them. In a qualitative study, we looked at the language a group of nurses used to describe the suffering and coping

