

#### **EDITORIAL**

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# What nursing can learn from a proper appreciation of the five stages

O que a enfermagem pode aprender de uma apreciação adequada das cinco fases Lo que la enfermería puede aprender de una apreciación adecuada de las cinco fases

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When Dr. Elisabeth Kübler-Ross published her now-famous book, *On Death and Dying* (1969)<sup>(1)</sup>, she wrote that she "had over 200 interviews over a period of almost three years" (p. 250) and she described a theoretical model of five "stages" (denial, anger, bargaining, depression, and acceptance) experienced by these adults as they were living out their journey after a diagnosis of a terminal illness.

In this book Kübler-Ross described nurses as "the most helpful assistants" in her work (p. 245). She reported that some nurses were angry at physicians about the ways they avoided communicating the seriousness of an illness to patients, or about the use of "many unnecessary tests they ordered as a substitute for spending time with [patients]" (p. 250). Also, "Many nurses felt a great lack of training in this area and had little instruction as to their role in the face of such crisis" (p. 251). However, Kübler-Ross wrote that over time attitudes changed and nurses "have been both students and teachers to us and have contributed a great deal to the seminar" (p. 252).

Many nursing and other textbooks continue to teach the five-stage model for understanding coping with dying 50 years after its original appearance<sup>(2-3)</sup>. In the interim, numerous things have changed including causes of death, longer living/dying trajectories, new cure-oriented interventions, increased life expectancy, new and intensified challenges for family care providers, improved attitudes toward communication with patients and truth telling, and the development of the hospice/palliative care movements. As a result, I think nursing educators and textbooks should teach this theoretical model, but only if they do so in light of a critical perspective concerning its strengths and weaknesses. In addition, I believe that nurses should only include this model in their clinical practice with a keen awareness of its limitations and potential pitfalls.

#### ARE THERE FIVE STAGES IN DYING?

In naming these phenomena as "stages", Kübler-Ross used a term that is familiar in many medical diagnoses of disease. Further, she wrote as if all or most individuals she interviewed did move from one of these five stages to the next in the order given. However, there actually is no example in *On Death and Dying* of a single individual who is traced through all five stages. Although the very language of "stages" used by Kübler-Ross implies a linear ordering of experiences in dealing with a terminal illness, when she commented on what she called these "defense mechanisms" or "coping mechanisms," she also wrote that, "These means will last for different periods of time and will replace each other or exist at times side by side" (p. 138). And elsewhere, she wrote, "I hope I am making it clear that patients do not necessarily follow a classical pattern from the stage of denial to the stage of anger, to bargaining, to depression and acceptance. Most of my patients have exhibited two or three stages simultaneously and these do not always occur in the same order" (1974, pp. 25-26)<sup>(4)</sup>.

What has developed around the "five stages" is a kind of modern myth that all people ought to cope with a terminal illness in this linear, sequential way. If they do not do so, some care providers conclude

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that their patients have somehow failed to die appropriately or that they have failed to facilitate that objective. Contrast this with what Kübler-Ross wrote when she made clear that, "It is not our goal... to push people from one stage to another" (1974, p. 36).

In fact, the way each individual copes with dying is as unique as the way in which that individual has lived his or her life. The so-called "five stages" are merely five prominent ways in which some people cope with dying; they are not the only ways to do so and they do not justify claims that all people cope with dying in these or any other predictable and orderly ways. As a result, we could harm people if during the very pressured and precious time at the end of their lives we impose on them a rigid, universal, theoretical framework that satisfies our desires for simple solutions but does not respect their distinctive needs and does not help them achieve what they wish for in an appropriate death.

Our obligation as care providers is not to settle for relying on descriptions derived solely from a single theorist's intuition-based counselling procedures – or on mere summaries and even distortions of those descriptions. To the extent that those descriptions have led to a theoretical model, we must recognize that it has received no independent, objective validation or empirical support since its initial appearance 50 years ago. If we do not improve end-of-life education on these and related matters, the *Tratado Brasiliero Sobre Perdas e Luto* rightly warns that the result will be "greater suffering at the end of life" (5), an outcome Kübler-Ross struggled against.

## ARE THERE ALTERNATIVES TO THE FIVE STAGES?

Instead of engaging in "staging" how individuals die, I suggest that we focus on four areas of task work that are typically found in coping with dying: (1) physical tasks; (2) psychological tasks; (3) social tasks; and (4) spiritual tasks<sup>(6-10)</sup>. This means that a care provider should ask: (1) How can I help the person for whom I am caring to satisfy his or her bodily needs and minimize his or her physical distress in ways that are consistent with his or her other values?; (2) What can I do to maximize that person's psychological security, autonomy, and richness in living?; (3) How can I contribute to sustaining those interpersonal attachments that are significant to the person and to maintain selected interactions with social groups within society or with society itself?; and (4) What can I do to help address issues of meaningfulness, connectedness, and transcendence and, in so doing, foster hope?

This is consistent with what Kübler-Ross wrote (1969, p. xi) when she advised her readers: (1) "to refocus on the patient as a human being" – in other words to recognize that those who are coping with dying are still alive and often have "unfinished business" they want and need to address; (2) "to include [the person] in dialogues, to learn from [the person] the strengths and weaknesses of our hospital management" – in other words, to listen actively to all those we seek to serve and identify with them in their own tasks and needs [see the attached page on Active Listening Techniques]; and (3) to invite those who are coping with dying "to be our teacher so that we may learn more about the final stages of life with all its anxieties, fears, and hopes" – in other words, to learn from those who are coping with dying in order to come to know ourselves better, as limited, vulnerable, finite, and mortal, but also as resilient, adaptable, interdependent, and lovable.

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