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'People who are dying are still living,' author reminds

By Mark Wingfield

Managing Editor

"People who are dying are still living."

That's the key message of a new book based on 10 years of interviews with people who are terminally ill. And it's a message the author, David Kuhl, wants caregivers, ministers and family members to understand before it's too late.

Kuhl, a medical doctor, developed a palliative care program for cancer and AIDS patients in Vancouver, British Columbia. From that, he obtained a grant from the Soros Foundation to study the emotional, spiritual and physical issues facing those who know the end of life is near.

Dr. David Kuhl

His book, "What Dying People Want," draws on both biblical and non-biblical texts to illustrate the stories told to him by people from their mid-20s to their mid-80s who had been diagnosed with terminal cases of cancer or AIDS.

His subjects ranged from members of his own family to his own patients to individuals he never knew before.

The book begins with Kuhl's own confession of wishing he knew earlier what he knows now—a desire applied to watching both a roommate and a father-in-law die.

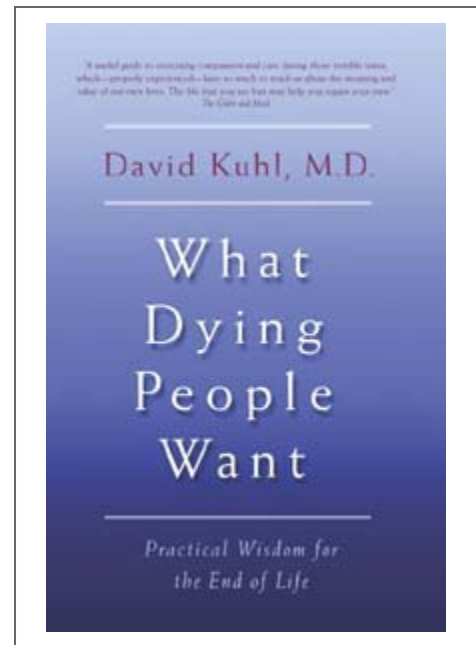
“In the case of my father-in-law, my wife and I would not have left his room the last night of his life just because the hospital staff told us to go home,” he writes. “The change in his breathing pattern was such that they must have known that he was dying. We left without saying the goodbye we would have said, without speaking the truths we would have spoken. We were not there to hold his hand even in his unconsciousness. That time was so precious, but the opportunity to complete our relationship evaded us because we didn't know what to do or to say—other than to believe the doctors and nurses.”

From this platform, Kuhl addresses health-care providers, the dying and loved ones of the dying, imploring them to demonstrate greater sensitivity and seize the time that remains.

Out of his interviews with the dying, Kuhl identifies nine common concerns, ranging from changing perceptions of time to the importance of physical touch to the need to speak and hear truth to the search for spiritual meaning at the end of life.

“For the most part,” he concludes, “they wanted to be heard and to be understood simply for who they were in the world.”

The announcement of a terminal diagnosis marks a change in the way people perceive time, Kuhl reports. It signals not only an ending but a beginning—“an opportunity to ask what the time remaining in your life means to you.”



He quotes the work of two other researchers-James Diggory and Doreen Rothman-who asked 550 people to prioritize seven consequences of death. The No. 1 concern expressed was the grief their death would cause relatives and friends.

Kuhl confirms this finding, but adds that this fear actually may reduce the quantity and quality of conversation that occurs between the dying and their loved ones.

“For some people, the need to take care of others is greater than their desire to alleviate their own fears and anxiety by speaking about those emotions,” he explains.

Anxiety may be reduced by engaging in a life review, Kuhl suggests. This exercise “simply means living in the present while looking at the past,” he writes. “It enables the individual to reconsider life events, relationships, successes, failures.”

Like Adam and Eve facing expulsion from the Garden of Eden, the pronouncement of a terminal illness moves a person into a new reality,

Kuhl contends. "Our naivete about life as we know it ends. Dying becomes part of our reality. We can't go back."

Life review ultimately should lead to an experience of transcendence, "a spirituality that extends from the core of their being to a spirit that cannot be contained," Kuhl writes.

Among a number of practical tips Kuhl addresses:

- ◆ The importance of physical touch. To illustrate the power of touch, he draws on the biblical story of the woman with a 12-year hemorrhage who touched the hem of Jesus' garment and was healed.

"People who are dying often feel 'out of touch' physically and emotionally. They feel that no one knows their experience. They feel isolated. They crave physical contact."

- ◆ The sources of pain. The physical pain of a terminal illness may be intertwined with emotional pain of regrets, conflict and mistakes made in life, Kuhl said. "Pain is always a combination of physical and psychological features, and for some it has a spiritual component as well. Pain must be assessed from the perspective of wholeness."

- ◆ The need for family members to talk openly. "When the death of a close family member has occurred, it must be talked about-again and again and again. Until that happens, meaningful topics will not be engaged, potentially intimate conversations won't get started-nothing will change until someone has the courage to speak what seems to be unspeakable."

This applies both before and after the death, and it concerns both the dying and those they love, Kuhl asserts. For those who have trouble getting started, he offers this simple formula: "I feel (name the emotion) because (state what happened)."

At several points, Kuhl offers pointed suggestions to his colleagues in the health-care profession.

Chief among his advice is to develop better communication skills: “Poor communication can render ineffective all the good in medicine, as it has the potential to increase suffering.”

Good communication skills are essential for telling a patient about a terminal diagnosis and for talking about realistic treatment options, he contends.

The book ends as it begins, with Kuhl recounting the death of a family member. But the experience of walking through a terminal illness with his sister differed from the earlier experience with his father-in-law, he reports, because of what he had learned from the dying patients he interviewed.

“We were able to do and say what needed to be done and said,” he reports. “For that, I will be forever grateful.”

News of religion, faith, missions, Bible study and Christian ministry among Texas Baptist churches, in the BGCT, the Southern Baptist Convention (SBC) and around the world.