Making Health Care Whole

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Integrating Spirituality into Patient Care

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Contents

Figures

Tables

Foreword

Rachel Naomi Remen, MD

As health professionals our relationship with the spiritual dimension of life is intimate but often unaware. This became clear to me some years ago when I was a part of a seminar Joseph Campbell ran for physicians on the experience of spiritual reality. The doctors who had gathered together were uncomfortable with the topic, uncertain of what spiritual reality had to do with us and with our work. Recognizing this, Campbell opened the session by projecting images of sacred art on a screen before us, paintings and sculpture and tapestries.

One of these works remains clear in my memory, a small bronze of a dancing Shiva, the god of creation, from a museum in Europe. I remember being struck by the beauty and joy of the little figure, dancing with abandon in a ring of bronze flame, one foot lifted high in the air and the other resting on the back of a little man, crouched in the dust, completely absorbed in something that he was holding between his hands. Looking more closely, I could see that the focus of his attention was a leaf. Others, too, were struck by the beauty of the figure, but we were all trained observers and posers of questions and so one of us spoke up and asked Campbell, "What is that little man doing there?"

"Aha," Campbell exclaimed, "That little man is someone who is so caught up in the study of the material world that he does not know that the living god is dancing on his back."

There was a long silence and Campbell looked at us sitting there in our white coats, suits and ties . . . and smiled.

There is little in our highly technological training that encourages us to recognize or respond to spiritual reality, yet the spirit is a part of our daily lives as health professionals. Our medical culture often limits the ways that we think, the ways that we see things. It interprets our experience for us in ways that are often constricted and small. But

life is larger than these interpretations, more filled with mystery and wonder and awe. More worthy of gratitude. Things happen that cannot be predicted or measured or even explained, things that cannot be controlled but only witnessed. When we become fully present at such times, we open a doorway of meaning and possibility for our patients and for ourselves as well.

In essence, we have traded mystery for mastery and paid a great price. We have lost the ability to meet honestly with the unknown to wonder together with our patients on the deeper meanings of things, to share questions as well as answers. We have forgotten how to listen.

Mystery is not an idea, it is an experience—a willingness to let the mask of habit that makes things familiar fall away in order to catch a glimpse of something different. The head of a large urban emergency room once told me of such an epiphany in his work. It had been a busy night on his service and he was called to attend to a woman about to deliver a baby. A quick examination confirmed that the delivery was so imminent that there was no time to call an obstetrician, no time to even move her from the gurney into a treatment room. So with nurses holding her legs on their shoulders he successfully delivered her little girl right there in the ambulance bay of the emergency room.

"Rachel," he told me, "this was the sort of thing I used to pride myself on, intense experiences that confirmed me in my sense of myself, my skill, and my technique."

"And this was different?" I asked him.

"Very." he replied.

The delivery had gone perfectly. He was holding the baby below the placenta with the back of her head in his palm, suctioning her nose and mouth, when suddenly the infant's eyes opened and she looked deeply into his eyes. In that moment he stepped past his usual way of seeing and realized a simple thing: he was the first human being that this tiny child had ever seen. He felt his heart go out to her in welcome and was surprised to discover tears in his eyes. In that moment years of cynicism, numbness, and resentment simply vanished and were replaced by an unfamiliar feeling. It took him two days to identify it but eventually he recognized that it was gratitude for being the person who got to welcome her.

We both fell silent. "A holy moment, Rachel," he told me. "I've

missed a lot of them. So I look for them on purpose now and they are everywhere."

As health professionals we often meet people at the thresholds of the world, welcoming them when they are born and letting go of their hands as they die. Yet little in our training prepares us to have comfort with the unknown or even to recognize the spiritual nature of such meetings. Many of us still question whether "spirit" is an appropriate concern of health professionals, daunted by the word itself with its whiff of holiness, its sense of being the prerogative of those who are expert in such matters, specially trained or even called. But what if "spirit" is seen in another way, as a dimension in all relationships and all people, a yearning for a larger connection and a deeper meaning that is just a natural part of our being? What if we could learn to trust a part of ourselves that is not acquired but inborn, unashamed by a lack of explainability? What if we could let go of the need to understand and simply be there for one another?

Years ago a man with terminal cancer who came to one of Commonweal's cancer retreats pressed a poem into my hand as he left. He had crafted it from the words of others because it spoke of his experience of mystery and healing at the end of life and the relationship he hoped to find with the professionals who accompanied him there and cared for him.

> I had a dream
> That honeybees were making honey in my heart,
> out of my old failures.
> There is no wrong or right.
> Beyond the wrong and the right, there is a field.
> I'll meet you there.

Embracing the mystery in our work may require us to first heal the wounds of our training. The way I was trained, the father of health care could easily have been John Wayne. Reality was narrowly defined and for many years I believed that anything real was evidence based, and what could be described in numbers was truer than what could only be described in words. But perhaps the things that are most real are those that cannot be expressed in numbers or even words but only directly known. Our lives are transformed by such experiences.

Sometimes life-threatening illness may be the setting in which such a transformative experience of may occur.

In the process of treatment for recurrent cancer, one of my patients underwent a radical transformation. As a child of atheistic and intellectual parents, he had no religious upbringing or spiritual inclination and had immersed himself in the world of competition and business with much success. While formerly his business had been the focus of his life, now his cancer and its treatment required him to spend several months in the quiet of his living room.

As the fatigue of his chemotherapy took hold, he simply surrendered to this silence and spent hours on his couch dozing in the company of his cat. One afternoon, as he lay drifting in and out of sleep, he found himself looking at the opposite wall and it seemed to him that one of the books on the bookshelf stood out from the others in an odd way. Getting up for a closer look he saw that it was the Bible that the clergy who had performed his marriage years ago had given to him and his wife. Taking it back to the couch he opened it for the first time and started to read the story of the beginning of the world. He was surprised to feel a deep response to the simple words, how real and familiar and terrifying the formlessness and darkness felt to him and how it seemed to be somehow connected to the recent events in his life. And then he encountered the statement with which the world begins: "*Let there be light*." He lay there for a time feeling the great power in these words wash over him.

As he ruminated about this, he suddenly realized that these words were addressed to him personally, that he could act in ways that increased the light in the world. He had never considered this possibility before but over the next days and weeks it became a more and more compelling thought, until he recognized it as a deep yearning in himself to live in a certain way. That perhaps the goal of life was not to be wealthy or succeed in business or to leave a financial inheritance to his children as he had thought. Perhaps he might use whatever time was left to him to bring more light into the world. Perhaps this was the inheritance he could leave to his children.

Life-threatening illness may encourage a return to that which is most genuine in each of us. It may initiate a turning away from a false self, the person whom we have been taught to be or whom others have

wanted us to be, to embrace the person we most deeply are for the first time. As such, the end of life may be a healing, a movement toward an integrity that is unique for each one of us. At times of significant illness a door may open and the familiar may fall away to be replaced by something never before seen but always known and deeply recognized. These doors open only one way. Once this is seen there is no going back. These transformations are often spiritual in nature. In such moments of profound change it is as if our true life is offered to us, a life transparent to our deepest values.

Working with such people at the edge of life may change our sense of perspective and task. It may cause us to see health care as a spiritual path and ourselves as spiritual beings. A colleague, a prominent cancer surgeon in our community, made this discovery in a dramatic way through his own experience of life-threatening illness. Some years ago he was shocked to discover that he had a malignancy and needed cancer surgery. He had never been ill before and he took this as a personal affront. Unwilling to reveal his vulnerability to his colleagues and students he took a vacation, arranged to be hospitalized at another institution, and persuaded his wife to tell no one.

A few months after this surgery, he stopped by my office in response to an invitation to lunch. I commented that he seemed different to me and he shared his recent experience and how it had changed the way in which he saw himself and his work. He told me that when he had awakened in the recovery room, he was in such severe pain that he was astounded. As he lay there overwhelmed by pain he slowly became aware of another experience, a sense of peace so profound that it felt more like a sort of trust.

"Trust of what, Harold?" I asked him.

He fell silent. "I guess a trust of life itself," he told me.

Comforted he had let himself surrender into this peace, all the while experiencing the most horrific pain. And then a phrase from his childhood came back to him—"The peace that surpasseth all understanding"—and he found himself wondering if this was an experience of that peace. Certain that it was, he was filled with a profound gratitude for having found in himself the capacity to experience it.

"How extraordinary," I told him.

"Yes," he said, but this was only the beginning. Lying there, he

had recognized becoming the most skillful surgeon and the most admired physician in his community was not his real work. His real work was simply cultivating in himself this sense of deep peace and trust of life, bringing it with him into places of fear and suffering, holding it in himself so steady that others might be able to feel it in him, to trust it and take refuge in it in dark times just as he was taking refuge in it now.

Perhaps our best work as health professionals is not about something we do but about something we are, something we become and bring into all our relationships. Perhaps others can recognize what we bring to them because it is the direction in which they are already moving. Perhaps in our presence they can move in that direction less afraid.

Entering the spiritual realm with someone at the end of life often does not require special expertise or training; it may simply require us to listen without judgment and to ask a few of the simplest of questions. Rather than seeking ways to introduce the concept of spirit to people at such times, we may simply need to remember that we and our patients are already on spiritual ground and become willing to listen and to wonder together. Questions of a spiritual nature often arise spontaneously at the close of a lifetime. "What matters now?" "What is really important?" "What can be trusted"? Simply asking such questions aloud may become an invitation to shared discovery and a deeper connection. People often have spontaneous thoughts or dreams or memories of spiritual importance that they are willing to share as well.

One of my patients, an internationally known architect, shared such a memory with his wife and me late one afternoon as we sat on either side of his hospital bed in the little study of his home. At the time he was desperately sick with cancer and waiting to find out if his latest tests would show that there was further treatment available for him. It did not seem likely. The house was still and as we sat together I could feel the weight of his wife's anxiety and his own as well. I felt a longing for a place of ease and safety, just a few moments of respite. I imagine that we all did.

As he lay in bed, struggling to breathe, I asked him if he could remember a place or time when he had felt safe. Without hesitation, he

began to describe his childhood, the fields and the woods, the sound of the birds at sunrise, and then he remembered a story. It had happened when he was very small and lived in a house at the end of a dirt road that ran alongside a small river.

Often in spring the river would flood. Once as he was walking along the road after a flood he found a rainbow trout, washed up from the river, struggling to live in the shallow drainage ditch. Small as he was, he was horrified by this beautiful fish, trapped and struggling in too small a place. It was a big fish but somehow he managed to get it up into his arms. Carrying it across the road, he waded into the river a little ways and set it free. Deeply moved, I asked him what he remembered most clearly about this. He said he remembered the moment when the fish between his hands realized it was once again part of the river.

There are many meanings in every story. On one level this is a beautiful childhood memory shared by a very sick man. On another it is a story about a man whose compassion goes back to his very beginnings. But I think there may be deeper readings still.

Certain practices run through all the branches of Buddhism. One of these celebrates the promise of enlightenment and freedom from suffering. In China, Japan, Nepal, and Korea, live fish are bought at the market, taken to bodies of running water, and set free. These fish symbolize the promise of a return to the Source that is our true home.

There is also a Buddhist teaching concerning the death of one who has accumulated the power to free others and help them to live well. The death of such a one is called "taking on the Rainbow Body" and it is believed that at death the physical bodies of such men and women vanish into a rainbow of light.

This man was not a Buddhist. He did not know any of this intellectually. He was an architect, a vintner, a fly fisherman, a sailor, a friend, a husband, and a father. But there was in him, as there is in us all, something that went deeper than all these things, an unconscious wisdom that was very old. "If we are quiet and listen, sometimes, without our knowing, it speaks to us directly."

And so, as we were waiting together, anxious and fearful, hoping to find that further treatment was available, I think that this part in him told all three of us this story. Perhaps it spoke to us so that we

would know where he was in his life or, even more important, so that we would understand that despite appearances, all was well.

Over many years of listening to terminally ill people, their dreams, their poems, their stories, I have come across many images for the soul, some conscious and many unconscious. I think the rainbow trout is one of the most beautiful.

Perhaps the care of the dying is not about the care of the body but the care of the soul. This presents a bit of a quandary to those trained in the skills of physical medicine. It may leave us shifting from foot to foot, anxious and uncertain for the task ahead, and cause us to fall back on treatments and medications that are both inappropriate and unwise. Little in our training encourages us to accept the limitations of our science and trust the power of relationships that are simply human, or to be at peace with things that we cannot understand, or to have the patience to wait for a natural unfolding and revelation. We are trained to fix and control, to anticipate and analyze. But the dying are not broken and everything we cannot understand may not be awry.

Caring for the soul requires that we be fully present in situations we cannot control and patient as a genuine meaning and a direction unfold. It means seeing familiar things in new ways, listening rather than speaking, learning from patients rather than teaching them, and cultivating the capacity to be amazed. It means recognizing the power of our own humanity to make a difference in the lives of others and valuing it as highly as our expertise. Finally, it means discovering that health care is a front-row seat on mystery and sitting in that seat with open eyes.

Making Health Care Whole is a gift to all health care professionals who yearn to go beyond the limitations of their training and practice their work as a calling. It enables us to be open to the mystery in our work and offers us a practical model and the tools to serve the unmet needs of our patients. It offers us permission to tend to our own souls and to grow in wisdom as well as in knowledge through this work. It can make us as well as our medicine more whole.

Preface

During the past fifteen years, there has been growing interest in and attention to spiritual care as a dimension of palliative care services. This book is based on a consensus conference and associated project activities built on nationally peer-reviewed guidelines that were developed by the National Consensus Project for Quality Palliative Care (NCP, 2004) and endorsed by key national palliative care organizations to provide spiritual care for seriously ill and dying patients. While the NCP guidelines recognize spirituality as an essential dimension of palliative care, uniformity of spiritual care practice is lacking across health care settings. Barriers to standardized implementation include varying understandings and definitions of spirituality, lack of resources and practical tools, and limited professional education and training in spiritual care.

The purpose of the consensus conference was to establish a common language and model for interdisciplinary spiritual care, identify resources and tools that have practical applications for health care settings, and develop recommendations that will advance the practice of spiritual care in palliative care settings. Achieving a consensus on spiritual care, both conceptually and pragmatically, requires engagement, deliberation, and dialogue among key stakeholders. Conference participation was by invitation. Invitees included a representative sample of forty national leaders, encompassing physicians, nurses, psychologists, social workers, chaplains and clergy, other spiritual care providers, and health care administrators. Over the following months, a consensus document was revised yet again to incorporate the feedback from conference participants. The version of the document was sent to a panel of 150 expert reviewers for additional comments.

While the focus of the conference was on palliative care, because palliative care is defined from the time someone is diagnosed with a serious illness, the material in this book is applicable to most care

across the life cycle. Support for this consensus document and consensus conference has been provided by the Archstone Foundation, a private grant-making organization whose mission is to prepare society for an aging population. The goal of this document is to advance the practice of spiritual care and inform future policy and research efforts.

1 INTRODUCTION AND OVERVIEW

Part 1 sets forth the background, research, historical, ethical, and philosophical contexts and organizational standards in place that support the importance of spirituality in palliative care and health care in general.