

A Witness Of the Human Spirit

BY JUDI SCHWERIN, RN

One of the critical elements that undergirds my commitment to patient care is the vantage point I have had in witnessing the human spirit. Harry Truman once said, "The way in which you endure that which you must endure is more important than the crisis itself." Patients in acute care facilities experience crises in varying degrees of severity. Some patients meet this challenge by mustering a great internal strength. This previously untapped resource can provide the patient, her family, and her care givers a sense of well-being, peace, and fortitude in times of pain, helplessness, and weakness. In my clinical experience two patients have best illustrated this human spirit.

RICH IN SPIRIT

"Lynn" was a 20-year-old woman newly diagnosed with Type I insulin-dependent diabetes mellitus. Recently married, she was unemployed, and her young husband worked long hours at a local car wash. Lynn was a young woman with limited formal education who now had a chronic

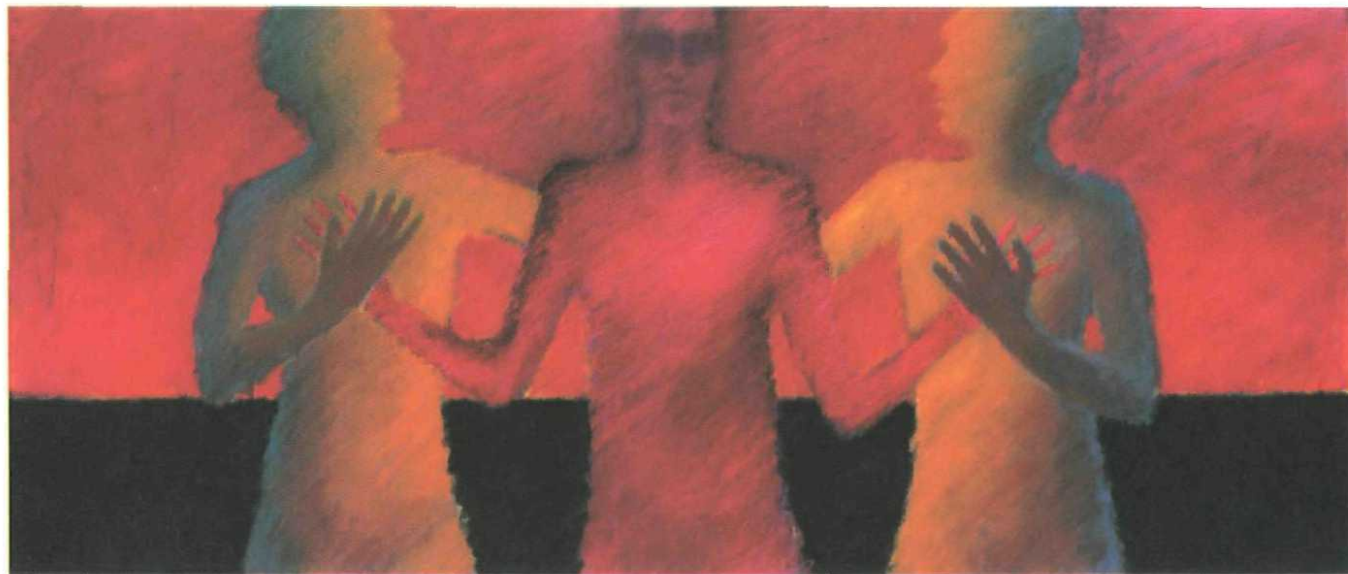
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illness, no health insurance, and minimal financial resources. I found her circumstances disheartening. As a diabetes clinical nurse specialist, I am well aware of the life-long demands of diabetes, both in terms of dollars and emotional stamina.

My partner in diabetes education had informed me that Lynn learned quickly and was attending and actively participating in classes and individual sessions with her family. To cope with diabetes effectively at home, Lynn and her family learned the basics of diabetes management, such as the importance of daily blood glucose monitoring. She had no money, however, to purchase a meter, an essential tool for the long-term health of a person with diabetes.

When I met her, Lynn greeted me with a big smile and twinkling eyes. She and her mother explained that Lynn's health was very important to them. They believed that one way they could afford a blood glucose meter was to make and sell mop dolls. Sure enough, in one day they acquired most of the money needed to purchase a meter.

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mation on building relationships with suppliers, an important aspect of TQM.

Discussion of medical decision making and care-effectiveness evaluation would have enhanced the book's usefulness for healthcare purchasers. The authors do outline processes needed for the development of formal, data-sharing relationships between providers and purchasers of care.

Because this book does not provide practical approaches for implementing quality management, healthcare administrators may find it too theoretical. The details it provides about sophisticated scientific approaches for quality assessment and measurement may be helpful to some managers, however.

Students may find the details about future directions overwhelming, but the book is a useful reference for students interested in the quality management profession.

For researchers seeking information on futuristic quality systems currently being developed, this text is ideal.

In general, *Health Care Quality Management for the 21st Century* provides a comprehensive discussion of the various traditional and futuristic quality management, assessment, and improvement methods. Some chapters contain significant detail, while others (e.g., the one on ambulatory care) give little information about past successes, current methods, or future approaches under development. Because different writers authored each chapter, some overlap and are redundant.

Quality professionals, policy developers, or researchers whose interest lies in macro-level quality improvement will find the book useful. As a how-to text for the student or quality professional seeking guidance in implementing quality management, the book is of little value.

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As I discussed Lynn's health with them during the next few days, Lynn, her husband, and her family inspired me. They perceived the diabetes as a challenge for them to express their love and support for one another, to confirm their belief in the gift of life, and to identify a sense of purpose and peace irrespective of the circumstances. I know frustrations with diabetes will continue for Lynn and her family, but I am convinced that, although not monetarily rich, Lynn is wealthy in terms of positive attitude and motivation.

FINDING JOY AND MEANING IN DEATH

"Caroline" was a 37-year-old mother from a small rural community. She had two daughters, aged 8 and 13. At age 32 Caroline had had a mastectomy. At that time several surrounding nodes were resected and found to be malignant. Numerous courses of radiation and chemotherapy followed the initial diagnosis. Since then she had been hospitalized 20 times as the cancer metastasized to her skin, liver, lungs, spine, hips, peritoneum, and paranasal sinuses. Caroline also experienced secondary problems: anemia, hypertension, recurrent pleural effusions, diabetes, massive abdominal ascites, jaundice, and cachexia.

Having recently become a nurse, I found caring for a patient facing death at the end of a meaningful life a new experience. Moreover, caring for a mother who was dying in the prime of her life was overwhelming. I distinctly remember wanting to avoid Caroline's room and distance myself emotionally from her. It became a privilege, however, to be part of Caroline's life during her last eight months as I witnessed the incredible personal strength that her faith provided.

Caroline reframed mundane daily occurrences with an attitude of thankfulness as she so gently influenced the perspectives of those who cared for

her. Her communication was devoid of the facades and pretenses commonly encountered in daily life: She expressed anger, cried, discussed her fears, and made plans. Caroline had long discussions with her priest and her husband in which she tried to help her husband accept her death and prepare for a life without her.

Caroline continually nurtured her children during their frequent visits to the hospital. As the cancer ravaged one body site after another and time became fleeting, Caroline began the difficult challenge not only of saying good-bye to her daughters, but of teaching them to become more independent in their self-care and the day-by-day maintenance of their home.

I, like most people, desire happy endings. Caroline's untimely death could never be construed as happy, but we all felt a sense of joy and tremendous meaning as she died with her loved ones at her bedside. I know that Caroline felt support in her suffering and peace in coping with reality as she said the final farewell.

SHARING CRITICAL MOMENTS

Working with patients like Lynn and Caroline can strengthen the nurse's internal reserves in caring for others. Not all patients can cope with illness or death so serenely. They may not possess the necessary internal strength, or they may lack the support that loved ones can provide. The nurse has an essential role in helping these patients deal with the important issues they face.

Regardless of the situation, an integral function of our care givers' role is to support and comfort. I hope we all have had the opportunity to care for persons such as Lynn and Caroline in our practice. Sharing critical moments with people who are hurting and allowing ourselves to feel with them empowers us to complement their own healing process and witness the human spirit. □