CASE REPORT

Kodak Moments

by Roxanna Erickson Klein, Ph.D., R.N.
Dallas, TX

As an R.N. working with hospice patients in their homes, I encounter pain on a daily basis. In nearly every case, psychological elements contribute either positively or negatively to the individual's experience of pain and well-being.

Sally was terminally ill with colon cancer. In order to help, her mother had come to live with her and her husband and teenage son. As Sally's death became imminent, her husband quit his job to be with her full-time. Her preference to die at home had been discussed and was supported by her oncologist. I visited approximately three times a week for the last four months of her life.

Despite the obvious presence of many accommodations within the household, the patient and her family chose not to discuss her illness. Rather they behaved as if nothing out of the ordinary was occurring. Additionally, they all were reluctant to discuss pain or other symptoms. This made it difficult to assess appropriateness of her current medications.

As a part of hospice protocol, alert patients are asked about levels of pain they are experiencing. When I asked Sally if she felt pain "right now," I was consistently told the pain was eight to nine on a scale of ten. When discussing pain, Sally became lost in elements of her illness that were so large and overwhelming that it would diminish her resources to manage.

On many occasions, Sally would seem to be doing quite well despite her physiological status. I never doubted the accuracy or sincerity of her reports, but there seemed to be a mismatch between what she reported and what I observed in her behaviors. The inconsistency of her reported suffering, which included prolonged, persistent and excruciating pain, contrasted sharply with her behaviors. For example, Sally often carefully selected color coordinated outfits, she personally answered the doorbell when others were unavailable, she planned and participated in family meals and engaged in other voluntary activities.

Sally was conservative in giving herself supplemental doses of medication. In contrast, when asked if she needed additional medicine for her pain, she consistently replied in the affirmative and would accept all that was offered. After large supplemental doses, she would report only a small reduction of the pain — from eight to seven.

When I asked Sally, "Tell me about your pain yesterday," she described a broader range, perhaps three to nine. She was unable to explain whether or not medication had helped. She often reported the pain "just went away" and she couldn't account for the change.

I learned that the most effective way of helping her was to be very specific and limit my inquiry. I would say, "I'm not asking about how you feel now, but I want to know everything about how your pain was yesterday." With this approach, she gradually was able to become very precise about the circumstances in which her pain waxed and waned.

Next, I instructed the family how to be vigilant for nonverbal cues, and to be active in offering medication when pain was suspected. For example, sleeping through a favorite television program might be recognized as a clear signal. I also requested they become conscientious in keeping records about what she was given, and how she seemed to respond. We then used this information to adjust her dose. Her husband kept a careful record of her medication but his notebook was kept privately and never discussed in front of her.

One evening as I was working with her in the family setting she preferred, she told me the pain the previous day had ranged from nine to two. Seizing this opportunity, I deliberately and carefully instructed her to be attentive each time she noticed the sensation of *the pain going away*. I advised her to focus on those moments, to enjoy them, to experience them to their fullest, and to memorize them. We talked about being aware of when those moments occurred, no matter how few they may be, and capturing them. Her husband spoke of "Kodak moments" and how blessed we all are to have treasured instants that can be caught, and held on to, even frozen in time. I then suggested that once those moments are identified, they can be reviewed. She might even be able to memorize the sensation, and to practice them at another time. With enough practice, the patterns of releasing pain could be recalled and even re-experienced.

Sally's husband and a visitor became enthusiastically involved in this teaching. They suggested that she savor and expand the times when she felt well and to disregard and "just forget about" other times. Sally responded happily to these suggestions. Within a week, the whole family was participating in helping her enjoy the good times, and "block out" the bad ones.

Sally was active and able to participate in family living until her death. Her husband reported that on the day she died, she squeezed his hand and smiled as she drifted away.