Hope Can Play a Transformative Role in Cancer

BY CAROLINE HELWICK

NEW ORLEANS — Hope plays an important role in the experience of cancer patients, especially those with poor prognoses, and it often follows an unexpected trajectory.

These were the findings of several studies presented at the annual conference of the American Psychosocial Oncology Society.

"While patients have a hard time defining hope, they almost always know exactly what it means to them, and they usually define its opposite as 'giving up,' " said Amy Pearson of the Lung Cancer Alliance in Washington. Her study was conducted with the National Brain Tumor Society and the Pancreatic Cancer Action Network.

Meredith Cammarata and colleagues from Mount Sinai Hospital in New York added that hope has been described as the ability to acquire belief in one's ability to control one's circumstances, a positive expectation for goal attainment, belief in possibilities for the future, and belief that one's present situation can be modified—that there is a way out of difficulties.

Others have suggested that hope is an experiential process; a relational process; a rational process; or a spiritual and transcendent process that might be determined by one's faith and belief or one's life experiences, her poster noted.

Studies further indicate that hope exists along a continuum, with goals ranging from cure to comfortable death; that hope is fluid and changes throughout the course of the illness; and that hope is dynamic, beginning with one's reaction to a diagnosis, according to Ms. Pearson's study, which examined this "hope trajectory" in 15 long-term survivors of lung, brain, and pancreatic cancers.

Although the 5-year survival rates for these cancers are approximately 30%, 15%, and 5%, respectively, the subjects in the study had survival that was double the median survival time for their tumor type. Therefore, the lung cancer survivors were required to live at least 34 months, but actually lived 4-12 years; the brain tumor survivors were required to live at least 30 months, but lived 8-21 years; and the pancreatic cancer survivors were required live at least 1 year, but actually lived 3-14 years. "We sought to better understand the meaning of hope, the role hope plays, and what contributes to hope or takes it away from these patients," she said.

The research was based on semistructured 1-hour interviews. Patients also completed an online version of the Herth Hope Index, a validated 12-item scale. From their analysis, three major themes emerged: taking control, having faith, and finding meaning.

All of the patients took at least one action involving treatment decision making. Ten sought second opinions, five researched clinical trials (and three participated), three insisted on off-label treatment, and two performed research to confirm protocols and doctors' decisions. Several continued to work and take other measures to "normalize" their lives. They protected themselves through avoidance of "negative people" and avoidance of negative information. Some made healthy lifestyle changes, which they later attributed to saving their lives.

Family, Faith Are the Main Sources

One-third identified faith as the most important factor in finding hope and in coping, and the majority called faith important. Ten said that their diagnosis had changed their lives for the better or for "a reason." Virtually all became part of a peer-support network to engender hope in other patients.

The most frequently mentioned sources of hope were family members, church and/or faith, and the medical personnel who treated them. Things that seemed to "take hope away" included dismal research statistics, negative medical personnel, death of other survivors, and setbacks in disease status.

The study validated that patients want to maintain hope—and can do so, especially when the oncology team understands the individual patient's beliefs and helps foster that patient's version of hope. (See box below.)

Other investigators illustrated how the patient's "trajectory of hope" does not necessarily correspond with their prognosis or treatment response.

Strong religious affiliation, a supportive family, cancer prognosis, and treatment plan are "not always associated with hope in the manner in which we would expect them to be," said Ms. Cammarata. She and her colleagues presented the following cases to illustrate:

► Patient No. 1 had acute myeloid leukemia and expressed minimal hope from the time of diagnosis. "Instead of focusing on getting better, she ruminated on her symptoms and the possibility of relapse," the researchers noted. "As the treatment plan and bone marrow transplant team became positive about her diagnosis, she remained hopeless. Even in remission, she refused to leave the house and obsessed over relapse. Despite having a loving support system, she was unable to accept and benefit from their support." The hope trajectory, which plotted the patient's expression of hope against the treatment course, showed that her hope plummeted continuously from baseline, with the curve continuing to fall even when the transplant appeared to be working.

► Patient No. 2 had acute lymphoblastic leukemia. Although she underwent an allogeneic transplant from her HLA-matched sister, she relapsed and died 1 year later. Her experience of hope closely matched her treatment plan, with the curve of her hope trajectory paralleling her treatment's ups and downs. "Because of the match, she was hopeful for a good response, but when she experienced chemotherapy side effects, she became depressed and difficult to engage. After the transplant, she enjoyed a brief state of remission and felt hopeful about regaining a normal life, but she began to be continuously fatigued, and along with this came the fear that she would never feel better. She relapsed within 3 months and was offered a second transplant, but a slim chance for prolonged survival.

"She refused the transplant and chose to live her precious last days as positively as she could, surrounded by family and friends, even giving herself a going-away party," Ms. Cammarata and colleagues reported. "Her hope trajectory completely mirrored her disease and, surprisingly, the curve even rose as she approached death and treatments failed."

► Patient No. 3 expressed "endless hope," in spite of a poor prognosis, the death of a friend who also had leukemia, and ultimately his debilitating graft-vs.-host disease. "He had a tremendous amount of optimism from the time of diagnosis," the authors wrote in the poster. "He felt the transplant made him a better person, and he became closer than ever with his family." In this case, the trajectory of hope was higher than one would expect, and remained high even in the face of life-threatening complications.

Multiple aspects of hope can be fostered, the investigators suggested, not only for the patient but for the medical team and family. These can influence the already complex and confusing role that hope plays in the mind of a bone marrow transplant patient.

Go Carefully With Informed Consent

Dr. Carl G. Kardinal of the University of Missouri in Columbia suggested that Phase II trials offer patients with advanced disease hope that might not otherwise be available. He and his colleagues evaluated the hope trajectory of 50 consecutive patients who consented to participate in phase II cooperative trials. Patients were interviewed by a psychiatric social worker who was not directly involved in their care.

All 50 patients stated that hope of therapeutic benefit, however small, was their primary motivation to join the trial. Other motivating factors were altruism (29), avoidance of regret that later they should have participated (19), lack of other treatment alternatives (14), and trust that their oncologist thinks this trial might help (10), Dr. Kardinal reported.

He pointed out that this is a vulnerable patient population for whom "truly informed consent" might not be possible. He further maintained that the current informed-consent process is too cumbersome and should be simplified.

"Hope of a treatment response is the overwhelming motivation of cancer patients to participate in phase II trials. This places an even greater responsibility on the physician-investigator to protect these human subjects," he said. ■

Physicians Can Create a Space for Hope

Health care providers can foster hope in the following ways:

► Even in cancers of poor prognosis, patients can survive. When physicians deliver the diagnosis, they can create a space for hope.

► "What can I control?" is an important question for patients. Assess what level of information the patient wants, and communicate accordingly. For patients who believe that a healthy lifestyle might make a difference, foster this behavior.

► Psychosocial and support resources might have a positive impact. Inform patients about support resources and peer support programs. Connecting with other patients might help survivors find meaning.

► Cancer is an existential crisis. Some patients search for the meaning of it while their faith, spirituality, and personal beliefs might be challenged. If the patient uses faith or spirituality to gain hope, find ways to support this tool. If the patient's questioning of his or her faith results in a loss of hope, consider helping the patient connect with a spiritual community or adviser.

Source: Ms. Pearson

MY TAKE

Seeing the Future as Half Full

A diagnosis like cancer calls the future into question and causes us to peer anxiously ahead. Hope is a way of seeing our future as half full, rather than half empty. Unrealistic hope can be a form of denial, and many cancer patients find themselves caught in the "prison of positive thinking," urged to be upbeat and positive no matter how bad their prognosis. On the other hand, hopelessness is a symptom of depression, and a uniformly downbeat view is demoralizing to patient, family, and medical staff. The real question is: Hope for what?" Even a very short future can be more than half full.

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