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Self-Transcendence in Stem Cell Transplantation Recipients: A Phenomenologic Inquiry

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atients who undergo stem cell transplantation (SCT) face multiple challenges that affect major aspects of their lives. They have been diagnosed with a life-threatening illness such as leukemia or lymphoma and, although transplantation is a potential cure for many of the underlying diseases, the process is complex and arduous. In the acute phase, most patients experience painful side effects from high doses of chemotherapy and radiation and also are at risk for many types of infection. Although survival rates after transplantation have improved since the 1980s, complications are a significant cause of mortality. Beyond the acute phase, the recurrence of disease is a major factor contributing to mortality (Keller, 2007; Rimkus, 2009). Depression and psychological distress, strain in family and social relationships, and financial distress are not uncommon (Cooke, Gemmill, Kravits, & Grant, 2009; Kettmann & Altmaier, 2008; McQuellen et al., 1998; Syrjala et al., 2004).

Many patients are not only resilient and creative in managing the challenges, but grow personally during the process. That observation by the author served as the foundation for this research study, the purpose of which was to understand the meaning of self-transcendence for patients who have undergone SCT.

Self-transcendence has been identified as a valuable inner resource. The human capacity to be directed beyond the self is one way to find meaning in adverse circumstances and, thereby, to reduce the suffering that may accompany such circumstances (Block, 2001; Cassel, 1982; Frankl, 1959, 1978; Reed, 1991b; Teixeira, 2008).

Building on works from transpersonal psychology (Frankl, 1959, 1978; Jung, 1933, 1971) and lifespan development theory (Erikson, 1950), a mid-range theory of self-transcendence was formulated by Reed (1983, 1986, 1991a, 1991b, 1996). She reconceptualized the developmental resource of self-transcendence as a nonlinear (rather than a linear) concept. Therefore, self-transcendence can be triggered in any situation in which

Purpose/Objectives: To understand the meaning of self-transcendence, or the ability to go beyond the self, for patients who have had a stem cell transplantation.

Research Approach: A phenomenologic investigation guided by the interpretive philosophy of Heidegger.

Setting: A cancer center in a major urban academic medical center.

Participants: 4 men and 4 women ages 45–63 who had received a stem cell transplantation in the previous year.

Methodologic Approach: Two or three unstructured, openended interviews were conducted with each participant. Data were extracted, analyzed, and interpreted according to the Colaizzi method.

Main Research Variables: Self-transcendence.

Findings: Self-transcendence emerged as a process that was triggered by the suffering the participants experienced as they lived through the physical effects of the treatment, faced death, drew strength from within themselves, and perceived a spiritually influenced turning point. The experience of a human connection lessened their feelings of vulnerability in the process. As the participants recovered, they described being transformed both physically and personally.

Conclusions: The findings from this study highlight the power inherent in patients to not only meet the challenges they face, but to grow from their experiences. The findings also highlight patients' deep need for a human connection and the power that nurses and other healthcare professionals have to provide that connection.

Interpretation: The caring connections established by health-care professionals can ease the ability of patients to access the inner resource of self-transcendence and reduce their feelings of vulnerability.

a person feels vulnerable. Aging and life-threatening illness are two such situations. Former ways of thinking and being are transcended when they are not useful for coping with present circumstances. That orients an individual toward broadened life perspectives and purposes (Reed, 1986, 1989). Reed (2008) defined self-transcendence as the expansion of personal boundaries

"interpersonally (toward greater awareness of one's philosophy, values, and dreams), interpersonally (to relate to others and one's environment), temporally (to integrate one's past and future in a way that has meaning for the present), and transpersonally (to connect with dimensions beyond the typically discernible world)" (p. 107).

Researchers have explored self-transcendence in empirical studies involving people with life-threatening illnesses. In women with breast cancer, self-transcendence was correlated with greater emotional well-being (Coward, 1991; Matthews & Cook, 2009), greater optimism (Matthews & Cook, 2009), greater quality of life (Farren, 2010), less illness distress (Coward, 1991), and less suffering (Kamienski, 1997). In liver transplantation recipients, self-transcendence was associated with greater quality of life and less illness distress (Bean & Wagner, 2006). Stevens (1999) found a correlation between spirituality and self-transcendence in people with HIV and AIDS.

Phenomenologic studies yielded additional information about the process of self-transcendence. People with HIV and AIDS were able to overcome their fear of stigma and rejection to reach out to others, to accept their circumstances, and to find meaning in life (Coward, 1995; Coward and Lewis, 1993; Mellors, Erlen, Coontz, & Lucke, 2001). Women with breast cancer were able to give and receive support, find greater self-acceptance, and find meaning in suffering (Chiu, 2000; Coward 1990; Coward & Kahn, 2005).

Despite the life-threatening nature of SCT, self-transcendence has not been explored in patients who have received the treatment. Therefore, a phenomenologic study was conducted to answer the research question "What is the meaning of self-transcendence for patients who have undergone SCT?"

Methods

The interpretive philosophy of Heidegger guided the study. For Heidegger (1962), phenomenon means "that which shows itself, the manifest" (p. 51). Depending on the perspective from which a phenomenon is viewed, certain aspects are apparent whereas others are hidden. To apply the philosophical principle to the interpretive research method, the researcher attempts to uncover the hidden aspects that underlie the more apparent expressions of a phenomenon; the researcher goes beyond the data to discover the meaning embedded in, but not readily apparent from, the data (Maggs-Rapport, 2001).

Sample

Participants were recruited from the outpatient cancer center of a major academic medical center once they were discharged from the inpatient unit or alternate lodging. That process was formulated to avoid burdening the patient when he or she was acutely ill. Because self-transcendence is not a term used in everyday conversation, it was described for participants as the experience of exceeding what they thought was their ability to manage the challenge of a SCT. Eligible patients were English speaking, older than age 18, had a SCT in the past year, and had the experience of self-transcendence. The study was approved by the institutional review boards of both New York University and the institution at which the study was conducted.

Data Collection

Tape-recorded, unstructured interviews using openended questions were conducted at the location of the participants' choice. The interview guide is presented in Figure 1. Data were transcribed verbatim by a transcriptionist. Field notes were written after each interview and described the researcher's feelings and observations about the interview. Analytic memos about the data were recorded between interviews to identify emergent themes and patterns (Hoskins & Mariano, 2004).

Data Analysis

Colaizzi's (1978) method was used to analyze the interviews. Colaizzi emphasized that the researcher must view the participant "in the full richness of the person" (p. 64). One is attentive to the nuances of speech and gestures that give meaning to words and then engages in "imaginative listening" (p. 64). After extracting significant statements from the transcribed interviews, the researcher used creative insight to formulate meanings from the statements. That raises the data from what the participant said to what he or she actually means. Creative insight is used again to raise the formulated meanings into a cluster of themes. The steps of analysis used in the current study are outlined in Figure 2. Trustworthiness of the findings was ensured by having another researcher independently analyze the data, by returning to the participants to validate the findings, and by creating an audit trail that was examined by a researcher not connected to the study.

Findings and Interpretation

Eight people were interviewed during a period of six months; one participant received an autologous

Interviewer questions were flexible and adaptable to patient responses. The probing questions clarified responses, expanded on those responses, and explicated meaning.

- Tell me about having a stem cell transplantation. What was it like?
- What was the most difficult experience for you?
- How did you get through it?
- What, if anything, has changed for you since the transplantation?
- What does self-transcendence mean to you?

Figure 1. Interview Guide

- Each interview was read while listening to the recording to correct for mistakes and hear voice tone, quality, pauses, and inflections
- Words, phrases, and patterns that stood out were noted as significant statements.
- For each significant statement, creative insight was used to formulate meanings embedded in the statements.
- Once several interviews were analyzed, a cluster of similar meanings were aggregated into themes.
- Themes were referred back to the original data to validate them.
 Whether themes were not reflective of the previous data, they were changed to better reflect the data.
- The process continued until a pattern of relationships among the themes evolved and was integrated into a comprehensive description of the meaning of self-transcendence.
- The participants were presented with the findings to ascertain
 if they were true to their experiences. Relevant new data were
 included in the final description.

Figure 2. Procedural Steps in Data Analysis

Note. Based on information from Colaizzi, 1978.

transplantation and seven received allogeneic transplantations. Data saturation was the gauge used for sample size. Details about the participants are summarized in Table 1.

Self-transcendence emerged as a process of "rebirth," a journey from intense suffering to the manifestation of new life. The findings are presented through the metaphor of the seasons (i.e., winter and spring) as they represent rebirth in the natural world and provide a framework for understanding the profound experiences of the participants. Eight themes were generated from the data. A summary of the themes and their meanings is provided in Figure 3.

Private Storm

As participants described the side effects and complications of the treatment that they experienced, it was as though they were living through their own dark, cold, and turbulent winter storm, one that was occurring inside them. The symptoms (e.g., severe mucositis, nausea, vomiting, diarrhea) left them feeling profoundly weak and interfered with eating, sleeping, and breathing. It was a major effort to survive the storm, a "scratching my way back" scenario, as one man described it.

The road back was brutal.... I couldn't eat, I couldn't keep anything down. My whole digestive system was shot to hell, I mean, I couldn't sleep, I couldn't do anything. I had so much phlegm I could hardly breathe half the time. I was a wreck physically, destroyed ... it was just an effort to stay alive ... not, like, to choke to death ... my basic thought was "let's try to survive this, you know, hang on and get through it."

For the participants, self-transcendence was triggered by living through debilitating symptoms and the awareness that, to survive, they needed to think about and make adjustments for performing the most basic of human activities. In the process, several participants perceived a seeming separation of body and mind. One woman shared, "I really think somebody else came in and just took over my body." Another man explained,

You know your body is really taking a rest, it has to take it to heal itself and, so, your body is on vacation and the mind is going somewhere and you have to try to get it back. I wasn't sure (where) it went while the body tried to catch up with me.

Not only did participants need to find ways to survive, they needed to do it with a fractured sense of self—the perception that they were not whole.

Lowest Point

During the winter solstice, the sun is at the lowest point in the sky. Likewise, participants reached their lowest point when they faced the possibility of death, either because their condition indicated that death was a strong possibility or because they did not think they could continue to go on and death became an acceptable alternative. The physical symptoms, profound sense of weakness, and severe complications they experienced led to feelings of helplessness and hopelessness. That was described as a "downward transcendence," "my lowest low," and a "hell that you can't get out of." For some, suicide was a momentary thought.

It was so overbearing . . . that's how people maybe commit suicide, because I was in the state that I wanted to give up. At that one moment, maybe that hour, I just couldn't take it . . . I wanted to jump through that window. I was really down. And, I was thinking, "Gosh, how long does this have to go on?"

For the SCT recipients, self-transcendence was first a descent to despair. They faced the ultimate separation not only from their bodies, but from others and from life

| Table 1. Sample Characteristics | | |
|---|-------------------------|------------------------------|
| Characteristic | $\overline{\mathbf{X}}$ | SD |
| Age (years) Months since transplantation Total number of interviews Hours interviewed | 52 9 2.4 2 | 6.72 2.18 0.52 0.55 |
| Characteristic | n | |
| Gender Male Female Transplantation type Allogeneic Autologous | 4 4 7 1 | |
| N = 8 | | |



Figure 3. Progression of Themes and Meanings

itself. Once hopeful for survival, they now doubted it or questioned their desire for it.

Getting Through

Hibernation in winter is a process of going within to access and use deep inner resources for survival. So too did study participants access their inner strength to survive. Their capacity for imagery was one inner resource commonly used to get through the challenges of transplantation. But participants also drew strength from those in their environment who provided protection and care, just as how, in winter, the earth protects the life within it until the conditions are right to sustain growth. Participants drew strength from the healthcare team, family, and friends.

Imagery: Imagery was used to encourage stem cells to grow, to decrease uncomfortable symptoms, or to alleviate loneliness. Only one individual was actually exposed to and trained in the technique of imagery. Others spontaneously created their own. One woman kept mementos from loved ones in a "box of energy and love." When she felt lonely, she held the items and visualized past memories or future events.

It gave me the strength when I was wondering how I was going to make it through the day. I would pick up the golf ball . . . I would just look at it and I would think of the times that we played golf and it would get my mind away from what I was going through and it would make me laugh or smile or just give me the comfort.

Some participants did not use the process of imagery per se, but had an image or symbol that was inspirational to them. For example, one woman whose transplantation occurred on Good Friday found the symbol of the resurrection particularly meaningful. As she explained, "Jesus was in the tomb and He rose on Easter and it just meant a lot to me that it happened during the holy season."

Self-transcendence, therefore, involved the use of imaging and was the means by which participants were comforted, felt less alone, and were able to continue in their struggle to survive when they doubted their ability to do so.

Support: Support from others helped participants to move forward in some way. For some, it was assistance they received with activities such as walking, eating, and showering; simple activities that now seemed overwhelming. For others, it was communication that provided inspiration and confidence or practical suggestions for getting through the day.

Care was considered supportive when it was delivered in a manner that was personal and provided a human connection. And participants were aware when this connection was not present. One woman, when told that her chances of surviving an SCT were less than 50%, needed to know that the physician who was delivering the news was personally concerned for her.

They aren't great odds; you don't go into it thinking "I've got a good bet here." But, it was my only option. I need(ed) somebody to be a little more human. And, unfortunately, I think that they can't be sometimes. I can understand (them) wanting to not connect because it's difficult, but the more human, for me, that worked and for the doctors that weren't, I had a problem with that. I was more anxious.

For that individual, being more human meant "Talking to me like a person, not a patient." A caring approach by a nurse gave one man a reason to live when he no longer felt that he could go on.

She (the nurse) came into the room and, the way she spoke to me, I felt cared for. My pain . . . it didn't go away, but it just felt like comfort. She held my hand and she said, "I don't know how you feel, but can I get you something? Can I do this for you? Can I do that for you?" She rubbed my shoulder. And, I was really down . . . she made my day . . . she made me feel like I have something to live for.

When participants were vulnerable, they were able to continue in their effort to survive through support and caring. It was important that they perceived a connection to others into whose care they were entrusted. When they did not feel this connection, they were more vulnerable.

Turning Point

The winter solstice, the longest night of the year, is also a turning point because, at its end, the sun begins to gradually return. So too participants experienced a turning point when their suffering lessened and they felt hopeful that they would survive. Either symptoms improved or the individual's outlook changed and he or she could endure the symptoms a little longer. In addition, the turning point was perceived by most as spiritually influenced (i.e., attributed to either divine intervention or to one's own spirit). That occurred regardless of the individual's previous faith, relationship to God, or religious practices.

Somebody wanted me to get through it . . . the Man upstairs . . . because I couldn't do anything anymore. There was no hope, there was no nothing. There was this turning point, and not that it improved much, but it was just a different outlook. There was something that was different, you just got moving. I just went through it.

For some, spirit was associated with uniting body and mind.

It's a case of a spiritual other than physical kind of effort or striving to pull the body through. I mean, the body and the mind aren't two different things. So I think it all works together.

Self-transcendence, then, involved a spiritual influence that lifted participants out of despair and provided a sense of hope when they believed no hope was left. And, for some, through that influence they perceived themselves as whole.

Transformation

Just as the light and warmth of the sun in spring transforms the landscape, so too study participants, as they recovered, were transformed. Most described the change as rebirth. Some participants felt better physically after the transplantation than they did prior to becoming ill. But transformation also took place on a deeper level.

I'm not a religious person but, call it self-realization or transformation, something does happen to you after a transplant. I can't see somebody successfully completing the transplant and going back to the way things were before. . . . I moved to, I think, a higher level because of the success of the transplant.

Change also was articulated as becoming "whole," or becoming "more of who I really am." Some noted that they were more patient, more appreciative, or more forgiving. And priorities changed—things that previously seemed important were now trivial. For one man the change was deeply felt but difficult to grasp.

On one hand, all I really want to do is put it behind me and move on. But, I'm somebody who went through something that should by rights have pretty much finished me off. And so to survive something like that . . . it's got to change you at some level that you probably can't even perceive necessarily.

Self-transcendence, therefore, involved a transformation characterized by a changing sense of self that went beyond the physical to the discovery of deeper dimensions of the self.

New Perspective

Moving to a higher level allowed the individuals to look at life from a new vantage point, one that revealed a pattern and design not previously apparent. They believed that becoming ill did not "just happen." One woman had attempted for years to place her developmentally disabled daughter in a group home, but she was denied because others were more in need. When the woman became ill, she was able to obtain emergency placement for her daughter. Looking back, from a different perspective, she explained, "I honestly believe that's why I got sick." Others were not able to discern the plan but trusted that it existed and that it would be revealed.

God has a plan for you. If you don't see it today, you're going to see it tomorrow, if not tomorrow, next month; but the plan is there and you've got to be patient and you'll see what He wants.

Self-transcendence allowed for a broadened perspective from which participants realized that illness had served a purpose. The pattern of their lives now made sense and new meaning was revealed.

Valuing Self and Valuing Others

Participants experienced an expanded appreciation for themselves and for others as they continued to recover. Several of the women who formerly put others' needs before their own now decided to meet their own needs as well. As one woman remarked, "Instead of everybody else in my life, I live for me a little." Participants also had a deeper appreciation for others: their families, their stem cell donors, those before them who participated in research, and the healthcare professionals who cared for them. One man described the profound impact that doctors and nurses had on him,

I've felt this desire: really it has rocked me I think emotionally more than I really know how to deal with . . . something like this which is so earth shaking, something about people who saved your life, it kind of opens up a new perspective on what human beings can do for each other. I've been awed by the professionals who do this . . . nurses and doctors . . . they are just a level of human being that I really never appreciated before. They seem so selfless. I guess I'm just grateful.

Participants also had a deeper concern for others who are suffering from cancer now or who will suffer from cancer in the future. All were taking part in research studies. Some also offered to counsel others in need of a transplantation. One individual planned to teach children about cancer and to bring physicians to an underserved country to treat the disease. Another planned to advocate for stem cell research.

The deepened capacity to value others who were formerly viewed as different and sometimes less valued was illustrated by one participant, a Black man, who was touched by the kindness extended to him by a Caucasian woman. She visited him and brought him food and "it made me look at life differently, period." He further explained,

Coming from the country I come from, there's a lot of friction with different races. When she befriended me, it made me feel different about the race thing. . . . I used to say to my daughter, "Don't bring no White boys inside here." It made me start thinking, and I came to the conclusion that it doesn't matter who the person is, the thing is love.

Self-transcendence emerged as a deeper connection to self and others; an ever-widening awareness of a shared humanity. And from that connection arose the desire to express gratitude and concern, not only by helping others, but by looking beyond differences to embrace others.

Moments of Darkness

Even in spring, darkness occurs as the sun creates shadows on the thriving landscape. The individuals in the study likewise continued to experience moments of darkness. Despite their transformation, they lived through disappointment and fear as they recovered. They promised to make changes in their lives but were finding that more difficult to accomplish than they thought: the SCT process had taken a toll on their families, who continued to make adjustments, and the participants struggled with ongoing medical problems and

the fear of relapse. However, they put their struggles in perspective and continued to move forward. One woman whose transplantation was not a cure for her disease, but rather a treatment to extend her life, said,

I live every day knowing that my cancer is going to come back. It's a very lonely thing; it's very difficult. Some days you can handle it, some days you can't. But, for the most part, I'm learning to celebrate my life. And I just feel that I've got a lot to live [for] now.

Self-transcendence was the capacity to accept the ongoing challenges following the transplantation while continuing to live life as deeply as possible.

Discussion

Living through an SCT for the participants was a profound experience. Self-transcendence was the process that not only propelled them through very difficult challenges, but also gave their lives meaning, purpose, the discovery of deeper dimensions within themselves, and expanded connectedness with others. The process revealed patterns consistent with Reed's (2008) definition of self-transcendence: Participants expanded their boundaries interpersonally by their capacity to use inner resources and discover deeper meaning, transpersonally by accessing a spiritual source that provided a turning point, and interpersonally through their appreciation and concern for others.

Imagery was a powerful inner resource for participants that provided them with comfort and inspiration so they could continue their effort to survive. That can be explained by the theoretical underpinnings of depth psychology. According to the theory, imaging is a fundamental human activity and the foundation of conscious life (Jung, 1968). All thoughts, understanding, and language arise from images. In addition, imaging has intentional force (i.e., a force that demands a response). A person is moved in some way by an image and is given an instinctive direction (Hillman, 2004). That suggests imagery may be related to self-transcendence by having a strong influence on a person's thoughts, feelings, and actions. Consistent with the theory, a qualitative study by Freeman et al. (2008) using focus group methodology with survivors of breast cancer suggested that imaging changed mood states and facilitated transformation. The study also indicated that when spontaneous images were negative, the purposeful development of more positive images was effective in changing feelings.

Several participants in the current study experienced a detachment from the body while living through intense symptoms. Similar findings emerged from two phenomenologic studies involving survivors of critical illness (Granberg, Engberg, & Lundberg, 1998; Papathanassoglou & Patiraki, 2003). The concept of

disembodiment explained how that could occur. The unity of mind and body (embodiment) is disrupted in illness and one experiences disembodiment, the feeling of not being connected to one's body as one tries to adjust to extreme bodily changes (Gadow, 1980; Thomas, 2005; van Manen, 1998; Wilde, 1999, 2003). Gadow (1980) theorized that the interaction with and intense concentration on the body presents the opportunity to express the meanings, values, and purposes of the deeper self. Disembodiment, then, can provide an opportunity to reunite the body and the self at a higher level. That view explains how study participants who felt disconnected from their bodies may have found deeper dimensions within and a sense of wholeness as they recovered. Disembodiment during illness, then, may be related to self-transcendence.

The findings from the current study also describe how spirituality may be related to self-transcendence. From participants' descriptions, transcending to a higher level was preceded by descending to a level of despair. Theologic scholars have described the moment as a dark night of the soul (Dombrowski, 1991; Moore 2004). A dark night refers to a time of suffering in which a person is alone, lost, and detached. In that state, a person is receptive to spiritual influence. Suffering forces a person to rely on something beyond human capacity and opens up new possibilities (Dombrowski, 1991; Moore, 2004). That profound experience also was described in previous research involving patients with cancer (Lane, 2005; Perreault & Bourbonnais, 2005). In Lane's (2005) study, participants used various forms of art (drawing, dance, sculpting, and poetry) as a guide through the process.

The participants in the current study were empowered when those who cared for them conveyed an understanding of their suffering. The finding is consistent with Watson's theory of human caring. Caring is the ability to enter into another's frame of reference and to respect the deep spiritual dimension and the interior, subjective world of another—an authentic encounter with another person. Interventions that flow from that connection open new possibilities for healing and human connection at a deeper level. In addition, the process goes far beyond the moment of caring itself and becomes part of a larger, more complex pattern of life, one that continues to open new possibilities in the future (Watson, 1988, 1999, 2005, 2009). Therefore, when participants were recovering, they continued to be open to the possibility of deeper connections with others and they expressed that openness through their gratitude and concern and by seeking ways to help others.

Implications for Nursing Practice

Patients are vulnerable when they go through a SCT, but they also have powerful inner resources that they bring to the experience. They require highly complex, technological care, but also benefit from assistance with basic tasks and strategies for simply getting through the day. Regardless of the level of intervention, however, the need for human connection is clear. Nurses must understand that every interaction with a patient presents the opportunity to provide that connection and ease the patient's ability to continue their struggle. When care is strictly physical or technical, it can hamper the struggle. In addition, when nurses engage in a caring encounter with a patient, they participate in a process of personal growth that continues into the future. Patients continue to experience greater depth, purpose, and interconnection with others as they recover and beyond.

By understanding the process of self-transcendence, nurses can be aware of and assess for feelings of hopelessness that may occur in patients undergoing a SCT. The use of words, gestures, or touch that convey empathy can inspire hope and encouragement when the effort it takes to survive seems overwhelming. Nurses also may better understand how spirituality emerges during serious illness, being mindful that spirituality is not necessarily synonymous with religion. Both, however, can be a source of comfort and relief. Collaborating with spiritual care providers may enhance the experience of spirituality.

Nursing interventions also could include ways to foster the natural tendency for imaging. Implementing a program that includes drawing, sculpting, poetry, and dance (Lane, 2005) may help patients to access and express inner images. A structured imagery program may be beneficial when patients' spontaneous images are not as positive as those described by the current study's participants (Freeman et al., 2008). Finally, the use of a professional practice model (such as the theory of human caring) that conceptualizes the patient as a person who can change and grow through the experience of illness may provide a guiding framework for nurses to enhance patients' experience of self-transcendence.

At the time of the interviews, none of the individuals in the current study had experienced a recurrence of their disease; this fact is important to note when implementing study findings. The meaning of self-transcendence might be different in patients who do experience recurrence. For many in that population, no further treatment may be available. Future research involving those patients may give nurses additional valuable information about self-transcendence.

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