Understanding the Experience of Caregivers: A Focus on Transitions

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Objectives: *To review the current knowledge on the challenges and benefits of informal family caregiving; and propose two conceptual frameworks for studying transitions common to patients with cancer and their family caregivers through the trajectory of the disease process leading to better, more focused, individualized interventions;*

Data Sources: *A review of current and classic literature on patients with cancer and their caregivers.*

Conclusion: *Caregivers often take on burdens that they are not prepared for. As they become overwhelmed with the work, they often neglect themselves, leading to physical and emotional illnesses. Not all caregivers perceive the same amount of burden. Careful assessment of each caregiver/cared-for dyad to individualize their support is critical to supporting them along the journey of a cancer diagnosis.*

Implications for Nursing Practice: *Operationalizing conceptual frameworks can accelerate nurses' understanding of patient and caregiver transitions, leading to more focused interventions and allocation of resources to assist them in these transitions.*

Key Words: *Caregivers, transitions, cancer, caregiver assessment.*

ACCORDING TO THE American Cancer Society,[1] almost 11.5 million people in the United States were living with cancer in January 2006. It is estimated that more than 1.5 million new cancer diagnoses will be made in 2010 and more than half a million will die of the disease. One of every four deaths is a result of cancer. Many will be debilitated or otherwise affected by the disease, the treatment, or the combination of cancer and comorbidities

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to the point where they need regular assistance with even the most basic activities of daily living. Informal caregivers, usually a family member, will provide that caring assistance.

FAMILY CAREGIVERS

The concept of family is in constant evolution.[2] Family has cultural, legal, and sociologic definitions, and it may also be individually defined. Traditional definitions of family include what is referred to as a nuclear family – father, mother and one or more children – or the extended family that adds grandparents, aunts, uncles, and cousins. In the past, family members lived in close physical proximity and counted on each other for help. Usually, someone, or more than one family member, was available to help with the care of children or older family members. Caregiving was viewed as a feminine quality, so the caregiver was usually a wife, mother, grandmother, or other female family member. After World War II, more and more women moved into the workforce, and a new child care industry emerged. Social forces such as job mobility, air travel, increased divorce rate, and an increase in cohabitation instead of marriage that accelerated during the 1960s and 1970s influenced the definition of family as well as the availability of family members to help each other.[2]

At the same time, advances in health care extended longevity and increased the number of people living with chronic disease. Many of these chronic diseases had no treatment and were unheard of when the early definitions of family were valid. Often living longer meant suffering longer. The evolution of hospitals meant that many more people who would have died at home in the past were dying in the hospital surrounded by paid caregivers. The family caregivers were often shut out by the rigid visiting hours, clinical language they did not understand, and a sense that their toil was not adequate to the task. Death was moved away from everyday life and became mysterious. The evolution of hospice and palliative care has begun to reverse this "death mystery" with an emphasis on the relief of suffering. Emergence of the patient/caregiver dyad as the focus of palliative care has shined a light on the poor preparation of caregivers for the demands they face.

Myths about the family have persisted in the approach nurses and other health care providers take to patients and families.[2] The first myth is that family members always have the best interests of the patient in mind. This assumption persists in the face of reports of domestic violence, elder and child abuse, neglect, and abandonment. The second myth is the belief that children, especially female children, have an obligation to care for chronically ill or impaired family members, especially elders. This expectation is shared by family, medical providers, and cultural norms irrespective of the burden this places on that person in addition to other family and work responsibilities.

Definitions of Family

A simple definition of a family is two or more people who have come together for a self-defined common purpose.[2] That purpose may be procreation or it may be simple companionship, but the persons involved view themselves as family with the bonds and responsibilities one expects from a family of origin or blood relationship. The caregiver and the cared-for are an irreducible whole. If one is cut, the other bleeds. It is a unique and awesome adventure in commitment.

The number of family caregivers in America is staggering.[3] Family caregiver is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for a person with a chronic or disabling condition.[2] These persons may be primary or secondary caregivers and live with or separately from the person receiving care. An estimated 44 million adults aged 18 years and older are family caregivers to those with serious, life-threatening illness. Family caregivers provide most of the care to seriously ill adults with no evidence of reduction in other family responsibilities. More than one-half of caregivers are older than 75 years themselves.[3]

Demands of Caregiving

Family caregivers are suffering. They provide extraordinary uncompensated care that is physically, emotionally, socially, and financially demanding and results in the neglect of their own needs.[4] The burdens of family caregiving include time and logistics, physical tasks, financial costs, emotional burdens, mental health, and

other health risks.[5] The physical stress of caregiving can lead to significant physiologic changes and medical illness with a greater risk of mortality. In turn, health risks and serious illness require increasing utilization of health care resources and lead to escalated health care costs as caregivers experience heart disease, hypertension, and impaired immune function, placing them at greater risk of cancers, HIV/AIDS, and other infections.[3] Emotionally, caregivers experience symptoms of anger, depression, and anxiety which are often part of a cascading process in which they become demoralized and exhausted.[6] As a vulnerable population, many caregivers of patients with advanced cancer either meet criteria from the *Diagnostic and Statistical Manual of Mental Disorders* fourth edition (*DSM-IV*) for, or are being treated for, psychiatric problems,[7] and they show impaired cognitive functioning.[8] Caregiving demands result in lost wages or even leaving the workforce entirely, both of which have severe economic implications, and personal, social, and institutional effects. As leisure, religious, and social activities are abandoned, there is heightened marital and family stress, with long-term consequences for the health and the stability of the family.[9] On the basis of high levels of burden, depression and sense of abandonment in family caregivers, Given et al[10] suggested that interventions be targeted at caregivers of patients with multiple symptoms, as is the case in patients with cancer.

Targeting Caregivers' Needs

Yet, despite these negatives, other caregivers report great life satisfaction and sense of reward even when care is demanding.[11] Having sufficient resources, receiving acknowledgement of the burden, and remaining active in social roles are associated with more positive perspectives on caregiving, as well as less depression and sense of distress. Given the documented general lack of preparation for informal caregiving described by the Family Caregiver Alliance,[3] it would seem reasonable that more and better resources, including financial, legal, and emotional support, might mitigate some of the negative outcomes for the caregiver.

During the course of medical treatments, family caregivers provide physical and emotional support and care to their loved ones as they face devastating losses that negatively influence the quality of life of both patients and caregivers.[3] Family caregivers must be recognized as "care recipients" in their own right. Family caregivers have a right to their own support and an assessment of their own needs. Family members' experiences should be evaluated as their own and not as an accessory to the patient's experience.[12] Having a holistic understanding of the caregiver's view and desired outcomes enables limited resources to be targeted appropriately and interventions to be improved. Recognizing caregivers as separate persons with their own needs has been shown to have a positive effect for both caregivers and patients.[13] Caregivers' existing psychosocial resources, stage of development, and relationship with the patient may indicate their vulnerability to the challenges of caregiving and may inform interventions that reduce caregiver stress and increase a sense of mastery in the caregiving role.[14] Barack Obama declared November 2009 as National Family Caregivers Month, stating that caregiver support is at the heart of caring for America's families; he further recognized that a variety of programs and services are needed to offer help and encouragement to family caregivers who are the foundation of our health care system.[15]

Family Caregivers for Patients with Cancer

Caregivers for persons with cancer encounter additional burdens. Cultural and societal beliefs about cancer have a significant effect on both patients and caregivers.[16-21] Belief that screening, diagnosis, and treatment are unimportant or futile because of a fatalistic or deterministic view of disease generally, and cancer specifically, can lead to inaction. Inaction plays a role in late diagnosis, poor prognosis, and poorer symptom management, especially pain management. Belief in the inevitability of death once a cancer diagnosis is made can lead to a withdrawal from life before death is imminent. A sense that the loved one is giving up despite the caregiver's efforts leads to anger and resentment. The person who has fatalistic beliefs about his or her cancer may feel guilt over the way life has been lived and see the cancer as punishment. There may be anger at one whose personal behaviors such as smoking, drinking alcohol, or other unapproved social behaviors played a role in the development of the cancer. Religion can be either a source of great comfort or a source of condemnation. These strong emotions integrated with the sense of grief

and loss and the physical demands placed on the caregiver can lead to overwhelming physical and emotional stress.

Health professionals remain blind to the situation of caregivers and do not intervene in ways that take into account their well-being.[13] Family caregivers are a vulnerable and at-risk population that remains neglected by the health care system.[3] Despite the National Consensus Guidelines for Quality Palliative Care,[22] which emphasize that both the patient and family should be viewed as the unit of care, caregivers' needs are not adequately addressed, and resources to assist them are extremely limited, fragmented, and discontinuous. Careful assessment and reassessment of caregiver experiences is vital to ensure caregivers are able to meet their caregiving commitments without being defeated by the burdens inherent in caregiving.[23] To address the unmet needs of family caregivers, the mission and strategic plan of the National Institute of Nursing Research[24] seeks to support research that will 1) identify factors that improve the transition from one care setting to another, 2) evaluate factors that effect the health and quality of life of informal caregivers, and 3) develop interventions to improve the quality of caregiving.

Patient and Caregiver Quality of Life

Patients' quality of care and quality of life depend on the well-being of family caregivers. Achieving quality of care for people with chronic, serious, and progressive illness depends on embracing a family-centered perspective. Without the assistance of the family caregiver, not only is the societal cost of end-of-life care significantly greater, but even the survival rates of patients will be dramatically lower.[25] An assessment of the caregiver's needs and strengths provides the foundation for providing quality care for patients.[26,27] The goal of caregiver assessment and the identification of interventions are aimed at keeping caregivers providing care, protecting patients from abuse and neglect by caregivers who are overwhelmed by their obligations and circumstances, helping caregivers respond to caregiving demands, and providing them with support.[28]

Negative health outcomes for caregivers result in higher public expenditures related to institutionalization of patients.[3] The well-being of the caregiver is often the key determinant of whether the care recipient can remain at home or must turn to a more costly hospital or nursing home setting. Care-related strain increases the likelihood that caregivers will place their relative in a nursing home. There is a need to bridge the gap between research and practice by understanding the caregiving situation, including needs, problems, and risks for caregivers, and to develop interventions that support caregivers in their roles.[3]

CAREGIVER TRANSITIONS

Knowledge is lacking about the transitions experienced by family caregivers of patients with cancer across the cancer illness trajectory. Transitions have been defined as a response to change, especially disruptive change such as cancer.[29] According to Schumacher and Meleis,[30] transitions are both a process and an outcome of complex person-environment interactions that create a sense of disconnectedness, loss of familiar reference points of significant objects or subjects, and periods in which new needs arise, old needs are not met in a familiar way, and old sets of expectations are no longer congruent with changing situations.[30]

Caregiver transitions encompass both the patient's phases of illness and the daily adjustments made by families in response to the patient's life-threatening illness, associated deficits, high physical and emotional needs, and symptoms.[31] Much of the literature about the experience of family caregivers is derived from clinical impressions rather than from research examining the caregiving experience.[9] Health professionals recognize physical, emotional, social, spiritual, and financial transitions at the end of life,[31] as well as transitions associated with the health care system, including lack of continuity of care by multiple care providers and multiple physical locations of care.[32] The literature also indicates that family members experience role transitions, stress, and ultimately bereavement as their loved one traverses life's continuum.[9,33,34] However, no studies have examined transitions as experienced by the family caregivers across the patient's illness trajectory. Characterizing the progression of the multidimensional experience of both patients and caregivers is crucial to improving end-of-life care.[11] Not all transitions at the end of life are

avoidable. Knowledge and advanced identification of transitions may allow caregivers and their health care provider partners an opportunity to anticipate problems and consider interventions or strategies to minimize their occurrence.[35]

BENEFITS OF CAREGIVING

Little attention has been focused on the benefits of the caregiving experience and possible gains. The possible benefits of a traumatic experience, such as the caregiving experience, are often ignored or downplayed. The positive aspects associated with the caregiving experience may act as a buffer against overwhelming burden and traumatic grief.[36] Using the Stress Process Model,[37] Haley et al[11] examined caregiver depression and caregiver life satisfaction in spousal caregivers of hospice patients. Caregivers found meaning and subjective benefits of caregiving through counseling. It was suggested that future research identify caregivers at risk and protective factors, thereby providing conceptual and empirical support for interventions for family caregivers. Hudson[38] and Gaugler et al,[39] based on samples of cancer caregivers, proposed that further research was necessary to move beyond the negative focus of caregiving to a focus on the positive aspects of caregiving. They affirmed that caregiver mastery is a particularly strong buffer of stress and should be considered when developing and implementing interventions to meet the diverse needs of family caregivers. Higginson and Gao[12] also emphasized the importance of positivity related to caregiving in designing caregiver intervention programs, because positivity may be an important motivation in maintaining the caregiving role. Furthermore, studies that address posttraumatic growth are almost nonexistent.[40]

Certainly, internal factors of the caregivers' lives have the greatest effect on how they view the demands of caregiving. Competing demands for their attention may well exceed their capacity to meet them, leading to increased stress and its manifestations. Professional caregivers need to examine how their own views of the burden of caregiving may be communicated to family caregivers, adding to the burden rather than alleviating some of it. Honest assessment of strengths and resources, both internal and community resources, and help in recruiting those resources may support and develop those more positive

caregiver experiences. It is critical to help the informal caregivers have realistic expectations that the burden and the satisfaction of caregiving is a dynamic experience with the balance changing day to day. Being positive and reinforcing the individual motivations of the caregivers may benefit them in ways that cannot be detailed or quantified. Understanding that mastery, a sense of accomplishment and success in some aspects of caregiving, is a strong force for mitigation of the burdens of caregiving. This understanding can open a dialog between the family caregiver and the nurse and starts to build the therapeutic relationship necessary for true support.

CONCEPTUAL FRAMEWORKS RELATED TO CANCER CAREGIVING

A need exists for the use of conceptual frameworks in palliative care when caring for patients with cancer and their families. Although some researchers use conceptual frameworks in their research related to family caregivers of patients with advanced cancer,[10] a gap persists in the ability of nurses in practice to explain the relationships among stress, burden, and caregivers' health outcomes from the perspective of the caregiver. The nature and course of these relationships and their evolution or transition have not been studied.[41] Progress in palliative care for patients with cancer and their caregivers can be accelerated through the use of theories and conceptual models.

Conceptual frameworks are a helpful and systematic means to study and intervene to promote creative and supportive relationships in which both the patient and the caregiver benefit. A number of frameworks have been proposed to study and support the caregiver/cared-for dyad.[42-45] Nurses in practice rarely consciously use conceptual models or theories in their everyday practice if at all. However, every time nurses make a decision about how to respond to a person or a need, how or whether to intervene, or what intervention to use, they use a conceptual model or way of looking at the situation. Making a deliberate effort to look at a complex practice situation with a clearly defined model is much like using a map to travel to a destination one has not traveled to before. In the case of caregiving for patients with cancer, it is perhaps a roadmap to find a more efficient or better route to a known destination, in this case,

optimization of care for patients with cancer and their caregivers.

Grey et al[44] developed a theoretical model of self-management and family management of chronic conditions. The model is a Structure/Process/Outcome type model that defines structural elements of health status, individual factors, family factors, and environmental context that characterize the burdens and resources that influence both family processes and individual activities that are directed at management of chronic conditions. These management processes result in outcomes that correspond to the structures in that they include the same categories, namely health status, individual outcomes, family outcomes, and environmental context.

For instance, assessment of the health status of the caregiver, including strengths such as self-care activities of exercise, good eating habits, routine screening, and attention to known health problems, identify areas of concern that can lead to encouragement/coaching, identification of respite resources, as well as community resources to strengthen positive behaviors and improve those that may increase caregiving burden. Because much of the self-neglect of primary caregivers is related to competing demands and a shortage of resources, this assessment is important at the beginning and throughout the course of the illness. Clarification of caregiver goals and desired outcomes of the caregiving help to set limits on expectations and provide benchmarks for assessment of mastery or success in caregiving. A clearer picture of the caregiver and family outcome expectations are helpful for the same reasons. Unrealistic expectations are a common source of stress and burden.[3] Ongoing assessment of the environment in which care is provided will help to identify the time when care may no longer be possible at home. This assessment could contribute to a plan that reduces the likelihood that the provider experiences overwhelming guilt or sense of failure that they could no longer meet the caregiving responsibilities.

Family caregiving and informal caregiving in general are complex and the relationships are dynamic. They evolve and change in both predictable and in unintended ways. People and their relationships change and involve family history, social evolution, legal challenges, and medical advancement in ways that make decision making a challenge. Although these models have been useful in some aspects of caregiving, they do not address the evolution or transition that occurs over time.

Schumacher and Meleis[30] assert that transitions are both a process and an outcome. The Theory of Experiencing Transitions (TET)[46] acknowledges the evolution and revolution in one's life and includes challenges and resources from within and in the greater context of relationships, institutions, and society. Some transitions are predictable and have predictable courses and consequences. Other transitions are just the journey the caregiver/cared-for dyad embarks on at the time of the caregiver's commitment to care. This journey is fraught with uncertainty and potential danger. Unexplored beliefs, expectations, and resources, as well as family dynamics, affect the challenges and successes of the journey. The nurse in cancer practice may have more experience with this journey either personally, through study, or through the vicarious experience of other patients and families. When this experience and expertise are brought to bear on any caregiver/cared-for journey, the nurse becomes the guide. Multiple maps or conceptual frameworks will be helpful for this nurse/guide because no two journeys are identical although they share many points in common.

Two promising conceptual frameworks are discussed here in more detail as they relate to caregiver transitions – the Theory of Experiencing Transitions[46] and the Stress Process Model.[37]

APPLYING THE THEORY OF EXPERIENCING TRANSITIONS TO CAREGIVERS OF INDIVIDUALS WITH CANCER

Nature of Transitions

Three concepts with multiple descriptors contribute to the Nature of Transitions (Figure 1). First, there are four types of transitions: developmental, situational, health/illness, and organizational. Identifying the types and patterns of transition in adults with cancer is intuitive and confirmed by mostly qualitative studies.[9,16,21,47] The addition of a cancer diagnosis to these other somewhat expected transitions can be overwhelming. This is true for both the caregiver and the cared-for. Because they are entwined, and their futures are entwined, they experience much of the same transition, but they experience it in different ways with different strategies, resources,
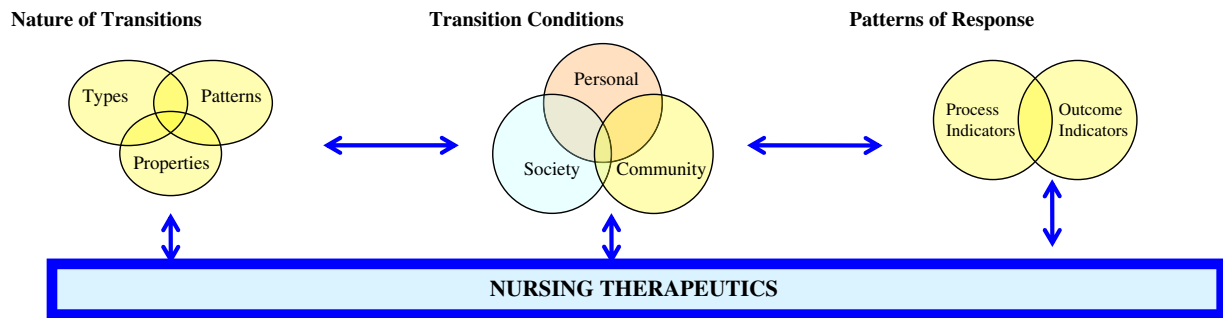
FIGURE 1. Experiencing transitions. (Adapted and reprinted with permission.[46])

and outcomes. Often the uncertainty of the future contributes to the intensity of the transition and makes the process more difficult. Without doubt, the diagnosis is a health/illness transition for both. As the caregiving becomes more demanding, the caregiver often neglects his or her own health, transitioning from health to illness.[2] As the household is changed to accommodate the cared-for, changes in the organization of the family occur in relation to priority setting, financial planning, and even physical structure changes in the home. The cared-for becomes the priority, and other lives, not just the caregiver's life, may be changed as the commitment to the care for the person with cancer evolves. By assessing and reassessing the Nature of Transitions, the nurse in cancer care is able to coach the caregiver and the patient through difficult times.

The TET also describes six patterns of the Nature of Transitions: single, multiple, sequential, simultaneous, related, or unrelated. Any or all of the transition patterns in the TET can be present at any particular time in the process. Transitions within the dyad are rarely single and more often are multiple, related, and simultaneous. The sheer volume and pace can be overwhelming. Living with the reality of remission and exacerbation makes much of the transition process sequential. The list of unrelated and unanticipated patterns is also large.

Included in the Nature of Transitions are five properties that characterize transitions. These properties include awareness of the transition, engagement in the transition, change and difference without which there would be no transition, transition time span, and critical points and events along the way that mark the path of the transition. Little is known about description or measurement of the properties of transitions generally or specifically for persons with cancer

and their caregivers. Awareness is the person's recognition of the transition. Awareness would seem to be critical to the work of transition and critical to the successful fluid integrative identities outcome indicators. Meleis et al[46] do allow that awareness is not necessary for the transition to begin and that awareness may be raised by a nurse or other person who recognizes the transition.

Not all change results in transition, but all transition involves some change, acute or gradual. A frame of reference is required to differentiate change and difference, identify transition time span, or mark critical points and events. Time span as a property of transition refers to the period of time from beginning of the transition until a period of stability. Not all transitions are marked by critical points and events. Nothing in the description of the Nature of Transitions implies or asserts that the transition is linear and unidirectional. In fact, the model allows for variation in type, pattern, and properties of transitions over time. Not all transitions will reach a point of mastery or resolution. Transition is a process that uses personal, family, community, and social resources to move toward a successful transitional response however that may be defined.

A complete discussion of the properties of transition in the care of caregiver/cared-for dyads is mostly philosophical at this point and beyond the scope of this discussion. It is a fertile area for research into those properties as points of intervention such as coaching, counseling, and referral, but they are not well developed at this time. It is impossible to do more than speculate as to their value.

The utility of this portion of the TET may seem a bit abstract at this point. The real value from a nursing practice perspective is this. The nurses' understanding of the bigger picture of transition

and the foreseeable challenges in that transition for caregivers and patients with cancer is critical to confidently guiding the patient and caregiver through the experience. The nurse cannot raise the awareness of the caregiver without a personal awareness of the transition process the caregiver faces. The confidence that the patient and caregiver have in the nurse/guide is enhanced and nurtured by the competency of that nurse/guide in using the map or conceptual model. Furthermore, the use of the model helps in characterizing specific barriers and facilitators of the transition applicable individually to each caregiver/cared-for dyad. A case scenario appears below. Table 1 that follows exemplifies the use of the Theory of Experiencing Transitions in assessing a patient with a cancer diagnosis and his wife/caregiver.

Case Scenario

Adam is a 38-year-old man who experienced a grand mal seizure at his brokerage office and was admitted through the Emergency Department after a computed tomographic scan showed multiple masses consistent with glioblastoma. He was able to return to work, but 3 months later, he began experiencing right-sided motor weakness and slurred speech that left him unable to work. His wife, Jane, has remained home to care for their three children ages 8 years, 3 years, and 6 months. They have extended family in the area and his parents are frequent baby sitters. They have a large group of friends and a much larger group of acquaintances. They live in an affluent suburb and have a large home with an equally large mortgage. They have been careful to live within their means, but without Adam's income they are facing the exhaustion of all their savings. Adam has excellent insurance, including disability, but it only provides about two-thirds of his current salary. Jane has a degree in early-childhood development but has never worked.

Adam still believes he will defeat the cancer. He has always been competitive and successful in everything he has attempted. Jane is more pragmatic and realizes that he will likely not be able to return to his old job, but neither is able to acknowledge that his survival is not likely, given the natural course of the disease. They do not have a will, a durable power of attorney, or a plan for living on a reduced income. They are becoming more and more focused on Adam and his inability to play with the children, drive, and attend social events. They have become progressively less involved in family and social activities and rarely leave the house.

Jane has become more and more angry at Adam and now is also impatient with the children when they are loud or spill food or other things she had not noticed before. She is not sleeping well because Adam does not sleep for days and then sleeps 24-36 hours at a time. Jane has expressed concerns that she is not able to keep up with Adam's medical needs and appointments and the children too. She cries and says she never wanted to be a "nurse." Adam is becoming more and more passive and unengaged in any aspect of the children's lives and barely speaks to Jane unless he needs something.

At the most recent visit to the oncologist, neither Adam nor Jane were able to talk about end-of-life issues, although the oncologist made it clear that the disease process was progressing rapidly and there was no further treatment available.

Transition Conditions

Transition conditions are the facilitators and inhibitors of the transition process. Meanings attached to a cancer diagnosis, as well as meanings attached to the transition and the experience of caring itself, can have enormous effects on diagnosis, prognosis, treatment, and survival of patients and caregivers. Meanings are individual and cultural. Meanings are learned from our families, our peers, media, and religious beliefs. Meanings are learned but are often integrated unconsciously into our sense of self. Richer and Ezor[48] differentiate meaning and belief. Although the two concepts are linked, they are different. Beliefs are convictions that one's view of the world is correct and true. Beliefs organize the world in such a way that we perceive patterns, label right and wrong, judge behavior, and sense and think about our environment. Meaning is more of a search for purpose. The search for meaning in our experiences includes a search for meaning in a cancer diagnosis for both patients and caregivers. Beliefs about cancer can direct our search for meaning in cancer to specific places consistent with our view of the world and lead us away from other places that might help if they could be perceived. Fatalism[16,18,19,21,49] as a belief system can lead to punishment or helplessness as the meaning attached to cancer and ultimately can affect the success of a transition and even survival.

TABLE 1.
Using the Theory of Experiencing Transitions to Identify Interventions for Patients with Cancer and Their Caregivers

Assessment	Facilitators	Barriers	Process Indicators	Outcome Indicators	Nursing Therapeutics/ Interventions	Comments
Both Jane and Adam are experiencing developmental, situational, and organizational transitions. Adam is also experiencing a health/illness transition. They are experiencing multiple, sequential, simultaneous and related patterns. Neither Jane nor Adam appear to be aware that this is a transition and not just a temporary inconvenience. Neither is engaged. Their expectations are not realistic and there is no big picture that incorporates the significance of the diagnosis and its effect on their lives. This does not mean that they have not been told the prognosis or discussed the options, only that they are not aware and engaged in the process.	Both are intelligent and educated. They have access to family and community resources.	They are facing significant financial challenge without Adam's income. Jane has little potential to match Adam's income. Although intelligent, Jane feels unprepared to care for Adam.	Although they have friends and family, they are becoming progressively more isolated and unconnected to those friends and family. Adam is withdrawing and is likely depressed because his expectation of return to work is not being met. He copes by shutting his wife and children out. Jane's level of frustration is reflected in her hostility toward the children and her reaction to things she would not have reacted to before the stressors of caregiving.	Jane is not feeling any mastery in her role as caregiver. She is feeling like a failure in many ways and compensates by noting this is not a role she ever wanted.	It does not appear that the difficulties are a matter of information, at least not from the standpoint of the professional providers. Education here is also not the answer to their disengagement. Before any real progress can be made though, the nurse needs a trusting and honest relationship with Jane and Adam. This relationship is critical if they are to engage in the transition process. No awareness can be raised if Adam and Jane cannot hear the nurse. Awareness of the transition is more than an intellectual appreciation of the diagnosis. Once they are aware and engaged, then resources can be identified to approach their issues as they perceive them.	Motivational interviewing is a means of getting patients to talk about what this process means and to learn how their isolation has evolved, as well as clarifying their expectations and perceptions of what is happening. This is critical to help them through this transition. The nurse cannot start with "what is usually true" or "on average these are the things you will be going through." This conversation starts where Adam and Jane *are*, not where they are supposed to be. Simply arranging for resources such as home nursing, etc. will not be effective until they perceive the appropriateness of resources for their situation. This may take awhile, longer than Adam has in terms of life expectancy. This model is not prescriptive. It offers a framework for approaching the work with patients and caregivers. The interventions and resources to meet their needs comes from the knowledge, skill, and communication of the provider in partnership with patients and caregivers.

TABLE 2.
Using the Stress Process Model to Identify Interventions for Patients with Cancer and Their Caregivers

Caregiving context	Primary stressors	Secondary stressors	Resources	Outcomes	Interventions	Comments
Jane and Adam are both young and have a young family. They did not have financial difficulties before Adam's condition was diagnosed. They have family, friends, and many connections to the community. Jane's history of caregiving is related to her children and expresses doubt about her role as "nurse" for Adam. There is no evidence of a history of illness requiring family caregiving. They are comfortable in their home.	Adam: Loss of his role as provider, and his ability to function independently. A desire to return to his previous life of work and family in the face of evidence he will not be able to, leading to depression and abnormal sleep cycles as well as withdrawal from Jane and the children. He may be having cognitive deficits and other symptoms from the cancer. Jane is becoming hostile and angry because she now has total responsibility for the children, the home, caring for Adam, the loss of intimacy and relationship with her husband, isolation from family and friends, and her sense of not being adequate in the role of caregiver. She is feeling trapped. Children: Their world is completely turned upside down, and they are not mature	Income is reduced by at least one-third. Jane has not worked outside her home and will need to after Adam dies. Neither she nor Adam have planned ahead for this kind of event with wills, durable power of attorney. It is not clear whether they have adequate life insurance. They are isolated from family who might offer respite and support. They have not even begun to deal with Adam's impending death or the grief and loss they are already experiencing.	Financially, they do have savings and some income to support them while they plan for the future. Both are intelligent and energetic with a great deal of family and community support. They have insurance, making Adam's treatment, palliative care, and even hospice viable options. Emotional resources are almost exhausted and will require intensive intervention.	Potential positive outcomes could include a deeper and more satisfying intimacy for Adam and Jane, but they are currently moving farther and farther apart and more isolated from each other and other family members. Important end-of-life decisions need to be made, and there is some immediacy to the decisions because his condition is deteriorating. Helping Jane become more satisfied with her performance as caregiver requires instruction, examination of her expectations to make them more realistic, encouragement, and support from the professional providers from and family and friends.	It is clear from this analysis that Adam and Jane have unrealistic expectations of themselves, the situation, and Jane as a caregiver. The nature of those expectations, their source, and the exact approach to helping them reframe their expectations is not as clear. That information must come from conversations based on trust and support that characterizes the therapeutic relationship between the nurse and the couple. Helping Jane develop realistic expectations of herself in caring for Adam involves helping her identify community and family resources to help her. She may not realize that no one expects her to meet all of the children's needs, Adam's needs, and her own without help. That relationship is important as well in helping Jane and Adam to focus in on his impending death.	This model is not prescriptive. It offers a systematic framework for approaching the work with patients with cancer and their caregivers. The precise interventions and appropriate identification of resources to meet their individual needs comes from the knowledge, skill, and communication of the provider in partnership with patients and caregivers.

TABLE 2.
Continued

Caregiving context	Primary stressors	Secondary stressors	Resources	Outcomes	Interventions	Comments
	enough to understand what is going on. It would not be unusual for them to act out in different ways to recapture their stay-at-home mother's full attention. All are affected by the uncertainty of the diagnosis, prognosis, and change in roles.				There is great potential for increased intimacy and closeness for both Jane and Adam and for Jane, Adam, and the children. Their past closeness with extended family offers much in the way of support and the opportunity to leave nothing unsaid, unexpressed, or unreconciled.	

Socioeconomic status has been documented as a strong determinant of survival in persons with cancer. Many studies link socioeconomic factors to patient diagnosis, treatment success, and survival.[45,50-52] The cost of care, especially when there is no insurance; the financial hardship of not being able to work; the financial hardship of the primary caregiver working less or not at all outside the home are a perfect storm. Self-actualization is difficult at best when basic needs for food, water, and safety are at risk. These hardships do not prevent transition, yet they are potentially barriers and may even facilitate transition to the integration of a sense of failure or burden. If one believes that transition is always a positive integration, there may be no way to attach meaning to resolution of the transition that results in rage, anger, and hostility.

Preparation and knowledge can shift beliefs and meanings for both the caregiver/cared-for dyad and the nurse who enters the transition process with them. There is much documentation that preparation and knowledge are often ignored or inadequately addressed for caregivers as well as the cared-for with cancer.[3] The convergence of personal meanings, beliefs, and resources with those of the community, however it is defined, and society are important facilitators and can inhibit successful transitions.

Patterns of Response

Two sets of indicators reflect Patterns of Response in resolution of a transition. Process indicators are components of the transition process itself. Indicators that the process is moving along toward a resolution include expressions of feeling connected. The important connections for both patients and caregivers are with each other, with the community of neighbors and friends that make up the extended social group of the dyad. Humans are social creatures, and, when socialization changes to isolation, then depression, emotional distress, hostility, and abuse can develop in the patient caregiver relationship. It is the interaction with others and our environment that nurtures us and nurtures the process of transition. Location and being situated refers to the sense of belonging and the sense of being in the right place to develop confidence even in a context of uncertainty. Coping, adaptation, and adjustment require a degree of safety for the development of trust. Trust is critical

among the caregiver, the cared-for, professional caregivers, and friends and family who are able to provide support and respite. Over time, caregiver will master the tasks, conflicts, symptoms, and uncertainty. Mastery is not an absolute and may be stronger at some times than others.

The other outcome indicator is that of fluid Integrative Identities. A simplistic approach to this indicator would be the integration of the roles of caregiver or cared-for. It is more though and involves surrender of some of what one used to be to embrace what one has become in the transition.[53] It is the surrender of some one's former life for that of a life confronted by the imminence of death perhaps.[54] Surrender is a recognition of the release of the old to embrace the new.

CONCEPTUAL FRAMEWORK: THE STRESS PROCESS MODEL IN A CAREGIVING CONTEXT

The Stress Process Model[37] addresses the stressors as well as the resources and possible gains in the caregiver experience. This model provides structure to identify and explore predictors and characteristics of posttraumatic growth, increase knowledge about the resiliency of caregivers, and identify potential interventions as suggested by Steel et al[40] and Waldrop et al.[31]

The Stress Process Model[37] addresses the experience of caregiving associated with caregiving transitions and transitional events that occur from one phase of the illness trajectory to another. Its five components are *caregiving context* that includes sociodemographic characteristics of the caregiver and patient, history of illness, history of caregiving, and caregiving living arrangements. *Primary stressors* arise directly from the patient's illness and may include the patient's symptoms or impairment, ability to perform activities of daily living, cognitive deficits, and behavioral problems; as well as stressors such as caregiver burden, including the subjective assessment of the degree to which the caregiver perceives each event, including possible role overload (time and energy), role captivity (trapped in the caregiving role), and the loss of relationship (lost intimacy and social exchanges). *Secondary stressors* include tension and conflict in maintaining other roles in one's life such as employment and family relationships; interruptions in other areas of the caregivers' life; and intrapsychic strains that erode a person's self- concept, particularly related to

a sense of caregiver mastery. *Resources* include social, financial, and the internal resources, which increase the ability to manage stressful experiences. Resources also include social support that involves information, material, or financial support and instrumental or emotional support, as well as perceived gains of the caregiving experience, such as personal growth. *Outcomes* include positive and negative health outcomes (both physical and emotional) related to caregivers.

The Stress Process Model explores the same issues as the Experiencing Transitions Theory, but from a different perspective and vantage point. Both are useful, and they are not mutually exclusive. The important aspect of any model is its utility in guiding practice. Table 2 is an example of assessment of the same patient and caregiver dyad with the use of the Stress Process Model.

Both the Theory of Experiencing Transitions and the Stress Process Model offer rich frameworks for exploring the transitions and experiences of caregivers of patients whose condition is diagnosed as cancer. They both allow for a longitudinal and comprehensive view of the complexity and dynamic nature of the caregiver journey. At times when the caregiver or the patient is not fully aware of where they are in the transition, having an aid in the bigger view through these frameworks prompts the nurse to look in specific areas of the relationship that reveal a better course of intervention.

EXPERIENCING TRANSITIONS AT THE END OF LIFE

The ultimate developmental transition for patients and their family caregivers is from life to death.[55] Death is a given and no one escapes the process. Not all of this developmental transition is about dying. Much of it is about surviving after the loved one has died. People rarely get the opportunity for awareness and engagement in the process because for them death comes suddenly and finds them too busy living to think about dying.

Life does not stop while the transition from living to dying proceeds. It is one of many patterns of transition interrelated with the transition to the end of life. Even though aware of the coming change, not all will engage in the transition. The lack of engagement is what we have often referred to as denial. Perhaps it is not truly denial, but an unconscious decision not to engage and thereby somehow cheat death and the process.

TABLE 3.
Teaching, Coaching and Supporting Patients and their Caregivers*

Issues Identified through Application of Theory of Experiencing Transitions or Stress Process Model	Teaching	Coaching	Supporting	Mentoring
Jane is feeling the pressure of caring for Adam and dealing with her grief and trying to care for their children while she feels isolated from her husband and family	Teaching her about glioblastoma will inform her about her husband's disease process, but it will not help her deal with her stress, grief or her transition to widowhood. Teaching her techniques for stress reduction will help her when she is feeling overwhelmed, but it will not help her deal with the increased responsibilities of caregiving.	Providing a phone number where she can contact you when she needs to talk or has a specific question that helps her manage her day to day responsibilities Arranging a regular contact schedule just to check in and see how she is. Encouraging her to see even small successes in her caregiving as reinforcement of her worth and value. Suggest that and encouraging her when she takes steps to meet her own needs for socialization, health care and well-being.	Acknowledge her successes and failures non-judgmentally. Provide a safe place for her to let her defenses down. Encourage her to reach out to family and friends for respite. Help her to clarify her beliefs and meanings associated with her husband's diagnosis and her own sense of burden and grief and to see them as her own, but modifiable.	Help her to begin to see the trajectory of Adam's diagnosis and begin to plan for her and her children's future without him. Help her to discover authentic ways to engage Adam in discussions that will begin to restore their emotional intimacy. Help her to navigate the health care system to optimize benefits for her and her children. Guide her to appropriate support groups, grief counselors, financial advisors and community agencies that will help her to make life decisions.
Adam has withdrawn into an apparent depression that isolates him from his wife, children, extended family and friends	Teaching him about his disease process in isolation from the decisions he needs to make about dying is probably not of any benefit. It is not clear what information he needs at this point and, for him, teaching is about providing information.	Coaching for Adam is about discovering what he wishes to accomplish in the time he has left. Discovering his wishes requires engaging with him in an authentic way that wins his trust and allows him to open up. Some direct conversation about identifying realistic expectations about what he can expect with relation to his diagnosis, end of life decisions, maintaining relationships with his wife and children. Encourage him to explore his beliefs about his role in the family, dying and the meanings this process has for him and for his family	Supporting him means starting where he is in his depression rather than where he should be. Help him to see that he can still be a provider for his wife and children. Rather than provide for their financial needs, he can meet their needs to be with him physically and engaged with him emotionally. Listen if he needs to express anger, rage, disappointment, grief that he will not be there to see his children grow up and to grow old with his wife. Answer his questions about is disease process, prognosis and dying honestly and frankly.	Help him to navigate the path toward a good death by encouraging him to talk to his wife and children about what he is going through. Acknowledging his grief at leaving them. Encourage him to reach out to the people who love him and let them be a part of his life. Identify a counselor or support group that can help him reconnect with the world.

*These are examples and are generalizations related to an incomplete scenario. In a real situation, the nurse would have the opportunity to build a relationship with Jane and Adam and respond authentically to them in specifying real teaching, coaching, support and mentoring activities.

If family caregivers can respond to the challenge of this end-of-life transition by maintaining connections with others, then they would realize that they are not alone in the journey. Ecclesiastes 4:12 says, "Again, if two lie together, then they have heat: but how can one be warm alone?/And if one prevail against him, two shall withstand him; and a threefold cord is not quickly broken." It is the connection to others that gives meaning to the lives and deaths of patients and caregivers.

CONCLUSION

The goal of nursing is congruent with the purposes of palliative care – the relief of suffering and the support of quality of life of patients and their family caregivers. When once upon a time, death was not hidden, and, because it was out in the open, it was not dark and mysterious. People spoke openly of death and it was connected to life.[3] When death moved into the seclusion of intensive care units and social and family connections were replaced with professional caregivers, it gradually moved out of conversation and out of people's lives. The approach of palliative care to end of life has brought it back to the light. Open,

honest conversations about treatment options, pain control, and decision making have empowered patients and their caregivers and helped to develop their confidence in themselves to navigate their own journey with the support and care of those who love them.

Nursing interventions rest in that connection and the mutual process that teaches, coaches, encourages, lifts, and relieves suffering. It is a mutual process because the nurse is transformed in a personal transition. Table 3 suggests activities that one might use to teach, coach, support, and mentor patients and their caregivers at the end of life. Raising awareness of the patient's and caregiver's transitions informs and supports them as they engage in the transition and the journey toward the end of life. The nurse can help both of them to realize their own beliefs and meanings as they evolve. The nurse can help to identify resources that they cannot identify on their own. The nurse who authentically engages in this therapeutic relationship brings knowledge of himself or herself to the science that is artfully applied in the care and nurturing of this dyad or family or community. The nurse, the caregiver, and the cared-for are a "three-fold cord that is not quickly broken."

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