The Healing Power of Presence: Respite From the Fear of Abandonment

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We can make our minds so like still waters that beings gather about us that they may see, it may be, their own images, and so live for a moment with a clearer, perhaps even with a fiercer life because of our quiet.

—W.B. Yeats, 1883

Presence has received significant attention in the nursing literature over the past several decades, but it remains difficult to translate into a meaningful paradigm for clinicians. Presence has been described as invisible and indivisible (Gilje, 1992), existential in scope (Doona, Haggerty, & Chase, 1997), "a moment of encounter that requires a lifetime of preparation" (Younger, 1995, p. 66), the most demanding aspect of caring (Davis, 1981), and having the power to "create order out of chaos" (McKivergin & Day, 1998, p. 96). Oncology practitioners understand that presence is essential to meaningful care (Block, 2001; King, 2001; Stanley, 2000). Patients with cancer recognize and value nursing presence across the illness continuum, but its significance increases as patients encounter the limits of treatment, face the realities of dying, and seek meaning in their lived experiences. If oncology nurses are to communicate the value of presence to healthcare systems that increasingly limit nursing time with patients, its meaning and worth must be understood. The purpose of this lecture is to review basic assumptions regarding the paradigm of nursing presence so that nurses may improve clinical practice and enhance patients' experiences at the end of life.

As members of the Oncology Nursing Society, we should take great pride in the fact that we are addressing nursing presence. The selection of this topic for the Mara Mogensen Flaherty Memorial Lecture validates its significance and consequence. It emphasizes that nurses value the individual often found trembling behind this illness called cancer and reminds us that nurses will search for and within the person until he or she is found, validated, and comforted. Today, we will briefly examine the meaning of suffering as it relates to the cancer experience, review some basic assumptions regarding the paradigm of nursing presence, and consider narratives that illustrate the experience of nursing presence.

Suffering and the Cancer Experience

The Nature of Suffering

Suffering has been described as the perception of impending destruction that extends beyond the physical and is connected to an experience that threatens a person's sense of wholeness (Cassell, 1982). It has been further portrayed as an amendment of the self, a loss of one's personhood and central purpose, and disclosure of an existence that no longer lays claim to control (Cassell; Ferrell, 1998; Stanley, 2000; Stollerman, 1997; Younger, 1995). Suffering can devastate one's ability to communicate when words that give meaning to experiences cannot be found. This silence broadens the chasm between those who suffer and those who do not know how or are afraid to enter that experience.

A Diagnosis of Cancer

Cancer amends peoples' perspectives on the past, the present, and the future. Characterized by uncertainty and fear, patients describe feelings of anxiety, anger, depression, loss of control, helplessness, vulnerability, shame, qualms regarding dependence on others, and loss of dignity. Remen (1996) described cancer as an isolating experience, one of separation and loneliness.

The Progression of Illness

If cancer is unresponsive to treatment or recurs, a patient's sense of an intact persona diminishes and distress (i.e., feelings of hopelessness or fatalism, futility, meaninglessness, sense of loss, unresolved grief, and fear of death) assumes an increasingly existential perspective. These inescapable feelings trigger attempts to integrate one's personal world into a larger whole that provides meaning and solace.

Abandonment

People with a terminal illness frequently are allowed to fade from the line of vision of family members, friends, and society. The Western world has a high regard for youth and health, and these values separate the well from the sick. A curative medical model that negates hope when cure is impossible compounds this isolation. Physicians may abandon patients when no further curative treatment is available or when patients refuse further treatment, decline entrance into clinical trials, or choose alternative therapies. Remen (1996) likened these healthcare professionals to those who sit in the front row of life

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with their eyes closed. Abandonment does not have to mean turning patients' care over to other practitioners. Abandonment can be subtle. Suffering patients' increased feelings of vulnerability, isolation, loneliness, and alienation can trigger a profound sense of unease in those who provide medical care. Fewer visits, less eye contact, and increasingly meaningless conversations reflect emotional abandonment; community is denied. Suffering is devaluing and causes people to retreat from dehumanizing experiences. Patients' resultant dilemmas are a struggle between the need to give voice to their anguish and the fear of rejection from those who cannot tolerate the emotional pain of discovery.

Quill (2001) identified partnership and nonabandonment as primary elements of a healing relationship. If other healthcare professionals walk away when treatments have failed, nurses are still there. Recognition of and attention to suffering is essential across the illness continuum but seems to be thrown into bold relief as patients near the end of life. Nursing's professional and personal ethics insist that we acknowledge and honor suffering as appropriate to the illness experience and assist in the translation of what is heard, seen, and lived (Stanley, 2000).

As the suffering quotient increases, we may see patients who are terrorized by the idea of further suffering and whose needs seem overwhelming. Nurses who choose to work with the dying do so without denial, avoidance, or resentment. Patients expect nurses to be available to them, and we are, in both conscious and unconscious ways. Nursing presence is the bridge to patients' existential worlds. While we may have no easy answers to the dilemmas we encounter, patients are never abandoned.

The Paradigm of Nursing Presence

Overview

Emerging in the nursing literature in the 1960s, presence was conceptualized as a philosophical model derived from the existentialism of Gabriel Marcel and Martin Heidegger. Paterson and Zderad (1976) introduced the concept of presence as a "gift of self" characterized by availability and openness. The paradigm was expanded to include verbal communication (listening and exchange), valuing (positive regard), connecting, inner understanding or intuition, and remembrance or reflection (Cassell, 1982; Doona et al., 1997; Gardner, 1992; Hines, 1992; McPhee & Rabow, 1997; Nortvedt, 1998). Presence has been characterized as an ethical obligation (Nortvedt), one of eight nursing competencies within expert nurses' helping roles (Benner, 1984), the nucleus of the nurse-patient relationship (Gardner) that affirms both as persons (Doona et al.), a nursing intervention (Gardner) that is "inextricably linked" to nursing judgment (Doona et al.), and a subjective experience that cannot be taught but can be cultivated (Doona et al.).

Whereas "presence" has been used to characterize nurses' physical presence, Osterman and Schwartz-Barcott (1996) enlarged the paradigm to include nurses' psychological and spiritual attention. Doona et al. (1997) provided a working definition.

> [Presence is] an intersubjective encounter between a nurse and a patient in which the nurse encounters the patient as a unique human being in a unique situation and chooses to spend her/himself on the patient's behalf. (p. 3)

Barriers

Time has become a scarce commodity in today's healthcare systems. A profit-oriented, business model demands shortened hospital stays and challenging staffing patterns across sites of care. Use of rotating or registry staff disrupts the continuity of care and can produce a stream of unfamiliar caregivers across the illness trajectory. Reduced time with patients confounds nurses' ability to know patients and results in missed opportunities to be sensitive to needs. Finally, because of the pressures of change in the workplace, nurses may have difficulty finding the emotional energy necessary for restorative relationships with patients.

Assumptions

The lived experience of a terminal illness is unfamiliar and frightening to patients and their families. Healthcare professionals who are most comfortable with the curative model of care may find themselves discomfited in the presence of the dying. But something in the essence of these patients beseeches us to be present; and when we are moved by suffering, taking our leave is difficult, if not impossible. Those who remain to care for dying patients "lend strength when people lose parts of themselves; they are sustained by the personhood of others until their own recovers" (Cassell, 1982, p. 644). While nurses are "existential messengers" (Stanley, 2000), the paradigm of nursing presence demands a larger role—that of existential activist. Presence is not a passive concept; it is powerful, requiring strength, courage, and doing. By reviewing basic assumptions regarding nursing presence, the scope and depth of practice can be illuminated.

Presence is a Mode of Being

Being is commonly defined as "existence" or "one's fundamental nature" (*Merriam-Webster's Collegiate Dictionary*, 2000). Thus, presence can be known immediately by a look, gesture, comment, or the tone of someone's voice. Presence is subjective and intersubjective, an experience that only can be known from within. Dossey (1995) described a "capacity competently to absorb, process, do, or simply be in the unknowing" (p. 69). When people are present, we experience their whole being (McPhee & Rabow, 1997) and multidimensional personality. We know we are with someone qualitatively different (Harper, 1991) and remember and cherish the experience.

> Mark, an old friend and colleague, developed metastases from the primary adenocarcinoma of the lung. I had known him for years as an administrator and for months as a patient. I entered his room to discuss the incriminating test results. When he saw me, he said, "So, you'll be the one." "The one?" I replied. He looked away and then directly into my eyes. "I mean the one who is. Thank God."

Presence Requires Knowing and Being Comfortable With Oneself

Self-awareness requires moving beyond the superficial and naming what is discovered. Only then can a life that is valued and valuable be lived.

> As soon as we feel at home in our own house, discover the dark corners as well as the light spots, the closed doors as well as the drafty rooms, our confusion will evaporate, our

anxiety will diminish, and we will become capable of creative work. (Nouwen, 1972, p. 38)

Presence reflects the sum of lived experiences, an acquaintance with life. We learn and grow as we review our experiences. The tape may be rewound countless times in such ways that the significance and richness of our experiences are woven more tightly into our understanding and, subsequently, into the fabric of the present moment. Terminal illnesses expand our understanding of the human journey by placing us in a position to share the lived experience of others. Their experiences provide insight into who we are and what we should be doing.

Margaret was dying of metastatic ovarian carcinoma and assigned to an inpatient unit that was not accustomed to caring for the dying. As I spent more time with her, she noted that I seemed uncomfortable at times and that it surprised her. I had not realized what was happening, but in that moment I understood the reason. "There are times when you especially remind me of my grandmother," I said, "and I still miss her. I wasn't allowed to go to the hospital before she died, and I never had a chance to say good-bye." She smiled and said, "Aren't grandmothers the best?" What a glorious response . . . and how kind of her to allow me that moment of self-knowledge in the midst of her story.

Presence Requires Knowing the Other Person

Kagawa-Singer and Blackhall (2001) quoted a wise patient who described the importance of knowing.

Because if you don't know a person, you got to find out his identity, go where he lives, where he goes, where he was born, who's in his family. And he's got to open up, and tell you these things. Because the more you know about this person, his family, then that'll make you know more about you. (p. 2993)

Working within the experience of the terminally ill is like walking in a world of "light and shadow" (Stanley, 2000) and requires more than a review of the medical data. Suffering can make a stranger of oneself, and that stranger may be too difficult or too painful to see in the bright light of anguish. And so, to know the whole person, nurses must welcome the dark. We start at the outer orbits of personhood and gently work our way toward the patterned and nuanced shadows of the lived experience. As we encounter patients' personal agony, our presence permits the unspeakable to be spoken and we are able to see the "less visible meanings that are part of the dying person's experience" (Boston, Towers, & Barnard, 2001, p. 251). At times it may seem like reading Braille, for we cannot know unless we use our senses, our sensitivities, and other peoples' knowing. Presence requires a willingness to participate in a story that has not been written. Fully understanding the experience of people who are dying may not be possible, but we must continue the dialogue so that we might deepen our capacity to know.

Gertrude was hard to know. Her difficult childhood and immigration to the United States had made her "prickly." Our best attempts to know and understand her went unheeded. As the illness progressed, she was admitted to hospice and I began visiting her at home. I met her husband for the first time, never having seen him at the hospital. I saw her meticulously decorated home with her "treasures" spread out around her. She seemed to cherish them so. I remarked one day about a particular figurine. "That is all I have left of my grandmother," she said, "and I am going to give it to my granddaughter." "I didn't know you had grandchildren," I said. "I don't, so I have to stay alive long enough to see her." I replied, "That might not be possible." She began to cry, and we began that very day identifying what **was** possible.

Presence Requires Connection

Presence never is a solitary experience. An authentic relationship between two people requires an interpersonal alignment that is permitted to make a difference. This relationship necessitates an intentional decision to invest ourselves and our time in an extraordinary way and to increase the depth of the relationship in situations "where the elemental need for connectedness with another person transcends theoretical considerations" (Drew, 1997, p. 412). This kind of connectedness symbolizes caring, commitment, and wisdom. Presence "leads the patient from the silence of alienation to the voice of connection" (Younger, 1995, p. 71).

Will had been practicing medicine in my institution for many years; the news of his extensive malignancy flew like wildfire through the hospital. He intimidated the majority of staff who worked with him. They did not know what to do or say, and they stayed away. His children, who lived in another state, continued to work, as he had instructed them to do. I usually found him alone. One day he was standing by the window and seemed to be looking at something. "What do you see?" I said. "I don't see anything. I'm looking for something." "What are you looking for?" I asked. His shoulders slumped. "I'm looking for a friend." I stepped in front of him and said, "I'd like to be that friend." And so began a remarkable friendship. I discovered we had many interests in common, had read many of the same books, and liked the same kind of foreign films. Early one morning, he looked especially frail. "How goes it?" I asked. "I'm dying, you know." "I know." "I mean I'm dying!" he shouted. "What can I do?" I replied. "Well, you didn't leave, that's a start."

Presence Requires Affirmation and Valuing

Existential suffering is characterized by a loss of self and self-respect. It must be like looking at a barren landscape with no sign of life. Nonjudgmental and respectful presence can help to restore self-esteem and dignity. Focused energy and attention validate a willingness to stand and wait for what is to follow. Words do not fill an empty present or future; presence can.

Gene was a difficult person to know. He was unsure of himself, and yet, constantly bragging about his abilities and accomplishments. His family had long ceased to listen to his repetitive stories, and the nursing staff struggled with their negative feelings about him. He seemed to sense that and would talk faster and louder. He had little interest in personal hygiene and refused the nursing aide's assistance. The nursing staff began rotating his home visits. A local newspaper approached us about a story on hospice care and requested that patient interviews be arranged. Because Gene had lived significantly

longer than the hospice staff had anticipated, he had a clear understanding of the hospice model. I visited him in his home and addressed the possibility of an interview, complete with photographs. He was absolutely silent for a time and did not look at me when he did speak. "Why would you want me?" he said in a self-disparaging manner. "I'm not worth the time." The opportunity at that moment was considerable but required a careful choice of words. "Because you've been part of us for a long time, and you could tell our story. We call you our miracle man." He looked at me cautiously, attempting to confirm the sincerity of the invitation. "All right," he said, "I'll be the miracle man." In the few weeks before the interview, he seemed to change before our eyes. He requested the nursing aide's assistance and became involved in a self-care regimen that the nursing staff had all but abandoned. One of the hospice nurses surprised herself and the rest of us and bought him a new shirt for the interview. He cried when she gave it to him. The interview went extremely well, and he had multiple copies of the newspaper everywhere. The weeks preceding his death were better ones for Gene and the staff. Right before he died, he thanked us for that day and said, "It's better to die knowing you've done something good."

Presence Acknowledges Vulnerability

The mystery of dying can trigger profound vulnerability. Loss of control, decreasing independence, uncertainty, a fear beyond knowing, and constantly changing experiences all contribute to an existence of the unimaginable. Vulnerability breeds silence. Nurses' verbal acknowledgment of the unimaginable allows patients to express shame and fear without concern for the consequences.

When I first met David, he had been recently diagnosed with a rare tumor and admitted to the hospital for a rigorous chemotherapy regimen. Unlike most men, he had long blonde hair down to the middle of his back. I mentioned his beautiful hair on many occasions, wondering how he would feel at its loss. He would respond positively about treatment outcomes and ignore my comments about his hair. I continued to worry about his hair loss for reasons I could not explain. One morning I walked in his room and he had a handful of his hair outstretched before him. "You said that chemotherapy kills good cells as well as bad ones; these are good cells! Does this mean I'm going to die?" At that moment David allowed his vulnerability to be seen for the first time. I believe I had given him permission by acknowledging the fact. What started with a handful of hair brought us to an entirely different dimension—that of life itself.

Presence Requires Intuition

Caring for the dying requires more than technical proficiency. It requires an inner understanding of others' essential needs. Intuitive knowing, or "immediately knowing something without use of reason" (Moch, 1990, p. 158), cannot be learned. Intuitive knowing distinguishes the expert from the beginner (Benner, 1984) because of the unquantifiable value of lived experience. Countertransference, or responding to the conscious and unconscious thoughts and feelings of others (Geach & White, 1974), can lead us toward intuitive knowing, an elegant example of unconscious competence. An intuitive understanding of the unspoken validates presence in a remarkable way.

I had spent long hours with Caroline as she completed induction chemotherapy for acute myelogenous leukemia, but we were not able to reach the place where her illness could be discussed. She became increasingly withdrawn during the consolidation phase of treatment and seemed to be disappearing before my eyes. I sat down on the bed one day and inquired how she was feeling. "Fine," she said, not looking at me. "It's hard to say good-bye, isn't it?" I replied. With a startled look, she described holding her newest grandchild and trying to say hello and goodbye at the same time. That moment was a pivotal one in our relationship, and I transitioned from the role of kind stranger to trusted confidante.

Presence Requires Empathy and a Willingness to be Vulnerable

Empathy, the subjective ability to experience and share others' fundamental feelings (Morse, 1991), opens the door to a deeper understanding of patients' perceived worlds at a particularly vulnerable time. "For a compassionate man, nothing human is alien; no joy and no sorrow, no way of living and no way of dying" (Nouwen, 1972, p. 41). Empathy requires participation, not observation; compassion, not pity; humility, not arrogance; spontaneity, not planning; and courage, not cowardice. Empathy demonstrates an ancient idea that the eye of the mind sees concepts, the eye of the body sees objects, and the eye of the heart sees by entering into a caring relationship (Roach, 1998).

This approach does not separate the professional from the personal self, unlike more traditional postures that make a distinction between the objectivity of science and the subjectivity of caring. If we focus on the pathology and ignore the person, we distance ourselves and depersonalize and devalue our patients. A willingness to make an "emotional" investment conveys the value of the investment fund. Entering the world of the dying may be risky, for it requires an acceptance and offering of one's own vulnerabilities (Boston et al., 2001) and reminds us of our own mortality. This shared vulnerability transforms relationships into communal experiences and supports the exploration of unknown or hidden spaces. Presence allows for the journey into the world of suffering, where we may be able to assuage the devastating loneliness and fear.

At our last visit, Charlie had been told the colon cancer had spread to his lungs. We had been treating him for hepatic metastasis, but this was, for him, an unexpected blow. On his next visit (mid-July), he had a gift for me. It was a Christmas ornament—an angel. He remarked that I had been like an angel to him, and he was grateful. I was very touched and wondered why I would be getting a Christmas ornament in midsummer, but I didn't ask. I talked about symptom management and a different kind of chemotherapy, but I didn't focus on Charlie. That was the last time I saw him alive. He shot himself the next day. What had I been thinking? I relived that day over and over again in my mind for clues, for some intimation of what was to come. All I had was the Christmas ornament. That day I learned far more than I would have wished, and with great pain. One of my deepest sorrows was that he died alone.

Presence Requires Being in the Moment

Being fully in the present moment necessitates emptying oneself of personal desires, setting aside thoughts of the past or future, resisting the urge to plan what we will say or do, focusing solely on the person before us, and believing that this moment is the only one possible. The sufferer may have lost the world of the familiar and no longer have a frame of reference for the present. But, visualization happens in the brain, and presence may provide a way to revisualize the reality of the moment. This could mean approaching death as a natural part of the life cycle rather than as an enemy to be fought until the bitter end, assisting someone to regain control by identifying the controllable, or remaining with another as his or her life fades. Presence is "a way of spending time that cannot readily be measured. What can be counted is not all that counts" (Sabatino, 1999, p. 376). These are fragments of time—something momentary is so momentous.

> Brian had a dry sense of humor made even more delightful by his strong British accent. We had instantly liked each other, and I always set aside time to talk despite or in the midst of other care issues. He had expressed his fears of suffocation and dying alone countless times, and so I spoke directly to those issues at each visit. He would always smile and squeeze my hand. It became increasingly difficult for him to speak as the shortness of breath worsened, and the last few visits were punctuated by labored breathing, rather than conversation. His family remained terrified of what was ahead, despite many family conferences with the hospice team. A constant concern was the need to address his fear of dying alone by making sure someone was always with him. His wife called me late one night because she felt he was dying, and she did not know what to do. I hurried over to the house, and she went into the other room, despite my protestations. I sat down on the bed with Brian, and he opened his eyes and motioned for me to come closer. I lifted his frail body so that I might sit next to him and hold him. He whispered, "Scared." I nodded and continued to sit there, without words. Gradually, I felt his body relax. . . . It was as if he were becoming liquid. He died that evening while I was holding him. That was momentous.

Presence Requires Serenity and Silence

The key to listening is intention. We must quiet our "inner dialogue" so that we may hear more clearly, allow others to tell the whole story, listen without judgment or advice, and bear witness to the experience. Attentive silence is a communicative act in its own right, an act of compassion. It signifies respect, legitimizes what is said, and creates an atmosphere where self-discovery can occur (Lewis & Zahlis, 1997). Listening deeply means fearless travel to an undefined destination. When we listen to narratives of great existential anguish, we may find insufficient words to provide solace, but solace is in the listening. Solace resides in our ability to provide a peaceful and safe haven so that others can pour out their anguish. If we try to soften words, we deny the agony behind those words.

A patient's silence may represent despair, withdrawal, depression, or feelings of alienation, but without confirmation, we cannot know. Nouwen (1972) described a patient "imprisoned in a life where all the words were already spoken" (p. 75). Presence may help others to find a language that gives form to the unspeakable.

> John had promised his wife on their wedding day that he would never leave her. Her first husband had died of cancer, and it seemed the right thing to do at that time. But this was now, and at age 45, he was dying. His wife repeatedly begged him to hang on, to see this crisis through, so that they might resume their life together. He was transferred to the intensive care unit, still receiving chemotherapy, and became increasingly withdrawn and finally, semicomatose. I sat with them and listened to her pleading and watched him somehow hanging on. We left the room for coffee. As we were talking, I mentioned that we might want to sit by his bed quietly and see if we could hear anything. She said, "He isn't talking." "I know, but he might want to say something." We went back to the room and sat down. She took his hand, started to speak, and then sat quietly. We both closed our eyes and listened. It was remarkable. Out of the silence came "I have to go. I cannot stay with you any longer. I'm sorry. I love you, but I have to go." And so we became witnesses in our silence to what had to be spoken.

Presence Can Be Transcendent

Transcendence is arguably the most powerful way in which we can be restored to wholeness after an injury to personhood. When experienced, transcendence takes the sufferer to another place, beyond the here and now, transforms the reality of the present, and integrates the suffering person's existence into a greater whole. It may, but does not have to, involve spiritual or religious values. Transcendent presence has no boundaries or limitations between people but necessitates an energy that exceeds that required for typical interaction (Osterman & Schwartz-Barcott, 1996).

Being in the moment, empathy, sharing one's vulnerability, listening, silence, and speaking to the unspeakable all contribute to the potential for transcendent presence, but **we** rarely are able to leave the here and now.

> Peter wanted to die so very much. The cancer had eaten away part of his face, and he hated for others to see him. But vanity was not the issue; he was ready to die. He had been admitted to the hospital for improved pain management. His daughter and I sat with him that night in the darkened room. She fell asleep; she had been caring for him so long without respite. I heard his breathing, her breathing, and the sound of the infusion pump. He opened his eyes and said, "I want to die . . . please." I replied, "Why don't you let go, Peter, I'll hold your hand." I woke his daughter and explained what we had said. She said to him, "I'll hold your hand too, Dad. It's all right." And so we sat there quietly. After a while, Peter said, "Can you see that? Can you feel that?" We looked and there was this feeling of intense light at the foot of his bed. I could not see it, but I knew it was there. His daughter was quiet, absorbed in her grief. "Good-bye, Peter," I said. "I think you'll be safe." He died just a moment later. His daughter and I were transformed by that experience. She was confident that he was in another and better place, and I had learned that one cannot know nor does one need to know everything that is possible.

Conclusion

Nurses have described experiences of presence as privileged moments and meaningful experiences that are affirming and amending for both themselves and their patients. The dying live beyond the usual and the commonplace; and, so too must we. If we do not understand suffering, we have failed. But if we honor the sanctity of suffering during moments of uncertainty, we have succeeded. Nurses must understand that presence provides meaning; engenders feelings of comfort and peacefulness; diminishes anxiety, loneliness, and vulnerability; and reassures when no words exist.

Presence is compelling work, for we must learn to live beyond the ordinary. Presence is not easily quantified. We will always have extraordinary experiences that lay outside the boundaries of these assumptions, elegant moments that sustain us. We remember and use narratives because they are healing and because they give voice to our understanding of the work that we value. We file every narrative we have ever heard or lived and open that file when we are able. At that moment, the unsuspected meaning becomes available and we are changed. We find that we are not solitary travelers; we are traveling in the company of heroes disguised as ordinary people. We must continue to teach each other about experiences with presence; how it happened, what it meant, and how we were changed. We cannot falter, for we have much to learn. And so we go, with resolve, courage, and tenderness, into moments of profound experience.

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