Reaching to the depths of the soul: Understanding and exploring meaning in illness

Excerpts of this paper were used to present the 1997 Helene Hudson Memorial Lecture. Sponsored by Amgen Canada, Inc. at Toronto, Canada, November 1997.

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Abstract

The nurse who hopes to respond to the experience of individuals and their families with a diagnosis of cancer must understand and explore meaning in illness. Meaning has been described as a fundamental dimension of personhood (Cassel, 1982). There can be little understanding of the person’s behaviour and responses to cancer without understanding the meaning of illness in their lives. The meaning ascribed to a situation can have a profound impact on the individual and family’s coping and adjustment and may influence their relationships with the health care team. Meaning in illness may be influenced by cultural beliefs, religion, values, life philosophy and past experience. Meaning goes beyond the surface reactions of the individual to the very depths of the person’s soul and can be a source of despair and suffering. Meanings evolve throughout the illness trajectory and can have a profound influence on the person’s lived experience. The skills required to understand meaning and the lived experience of illness for the individual are extensive. It is only through true presence, mutual understanding and a sharing of the life of the other that nurses are able to understand and co-construct meaning. It is a respect and understanding of the individual within the whole context of their personhood and the meanings assigned to their experience of cancer which allows the nurse to practice beyond the surface, to touch the person’s soul.

Introduction

Having cancer changes everything, including your perceptions of your world and life (Eick-Swigart, 1995). As described in this statement, a diagnosis of cancer is a life-changing experience that can threaten personal identity, belief systems, roles and relationships and one’s sense of the future. Cancer removes individuals from their social roles and activities influencing one’s sense of self (Lupton, 1994). The limitations in functional roles are particularly relevant to life’s meaning, because loss of such roles can diminish a person’s perceived purpose in the world (Cassel, 1982). As Koestenbaum (1976) states, “being useful to others rather than a hindrance is one of the most meaningful aspects of life”.

The meaning of a cancer diagnosis and the devastating impact of the illness on people’s lives are captured in the following patient statements: “It was like having the world blown out from underneath me”; “My world dropped out. You know “cancer”, it’s a death word— the worst thing you can hear” (Furman, 1993). As a result of cancer, individuals may need to redefine relationships, question the direction of their lives and confront their own mortality for the first time. As Colyer (1996) states, “an awareness of death wreaks havoc with human integrity”. This initial diagnostic period has been described as a time of “existential plight”, when existential concerns having to do with meaning of life, illness and thoughts and fears of death predominate (Weisman, Worden, 1976).

Meaning of cancer

The meaning of cancer can have a profound effect on the person’s emotional responses and may influence the way they will respond to the “existential plight” of cancer. Meaning has been described as a fundamental dimension of personhood (Cassel, 1982) and there can be little understanding of the person’s responses to cancer without understanding the meaning of illness in their lives. Individuals may have two reasons for their symptom or illness experience, the medical reason and their own private version. For instance, cancer might be perceived as punishment (Barkwell, 1991; Luker, Beaver, Leinster, Owens, 1996) or cancer pain might be perceived as God’s will (Kumasaki, 1966). Ferrel and Dean (1995) found that existential or spiritual meanings were assigned to pain and for many patients cancer pain was a test for purification, a sign that the illness was progressing and signified impending death.

Meaning in illness may be influenced by cultural beliefs, religion, values, life philosophy and past experiences. A person’s cultural background provides a model for understanding and responding to experiences. Culture may provide the person with an organized response to changes in bodily appearance, bodily function, mental status or behaviour, functions of body parts, or in

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bodily emissions (Donnelly, 1995). Religious beliefs may influence the meaning of an experience, changing the person’s perception of the meaning of an event. Meanings may vary for both the individual and for the clinician trying to make sense out of the illness. The meanings assigned to an illness are unique to the individual and these subjective illness meanings may be difficult to assess. 

Kleinman (1988) introduced an explanatory model as a way of understanding the meaning attached to an illness experience. The explanatory model includes a lay view of the etiology, onset, pathophysiology and desired or expected treatment. Liposki (1970) defines meaning as the subjective significance of all disease-related information that impinges upon the patient. He conceptualized several categories of meanings assigned to illness, namely; challenge, enemy, punishment, weakness, relief, strategy, irreparable loss and value.

The most popular meanings assigned by women with breast cancer to their illness were challenge and value (Luker, Beaver, Leinster, Owens, 1996). These women went through a process of reevaluating their lives in an attempt to determine what contributed to continuing meaning in their lives and served as a means of helping them to reestablish priorities. The illness was perceived as contributing to the women’s renewed growth. As a meaning, when value is attached to an illness the following changed perception of the disease is possible:

“I have this sense of being alive and embracing life. The spirit is the energy that drives the whole vehicle, it is the lust for life, wanting to get there, that’s the energy, that’s the spirit, that drives me, the zest of energy...I can live life to the fullest, even if I have no physical ability. I can still live life to the fullest because where I am living is from within”

Women who perceived their illness as an enemy experienced more difficulty getting on with living, stating, “it’s like being on death row waiting for your turn to die”.

An individual’s personal meanings and the context in which the person lives affect the meaning that a serious illness will have in their lives. Illness is always an interruption and the meaning or significance of that interruption will depend on where that person is in their own life journey (Benner, 1989). The following story demonstrates the meaning derived from a cancer diagnosis for a young, athletic man:

This young man with bone cancer, who raged throughout the early days of his diagnosis and treatment, drew a picture depicting the meaning of cancer in his life. He drew a crude sketch of a vase with a crack running through it. Eventually this young man redefined his purpose in life and began a kind of ministry of helping other patients. As a result of this new-found meaning he asked to complete his earlier drawing. He drew yellow lines radiating from the crack to the very edges of the paper, and pointing to the yellow coming out of the crack stated, “This is where the light comes through” (Remen, 1996).

In contrast, a veteran railroad worker regarded his cancer solely as an annoyance, as something not to be thought about but eliminated (Ryder, 1993). In an effort to adapt to these interruptions and changes, individuals reformatulate their way of being in the world (Carter, 1990) and attempt to develop a sense of the meaning of the illness (Steeves, 1992; Barkwell, 1991).

Searching for meaning

Persons with cancer search for ways of explaining their sickness experiences in an attempt to make sense out of the chaos. By giving meaning to their experiences, individuals define and give purpose to their cancer experience and their lives (O’Connor, Wicker, Germino, 1990). Frankl (1959) identified the search for meaning as the primary force in life and believed that each person’s meaning is unique and specific and must be fulfilled by him alone. Only then does it achieve a significance that satisfies his own “will to meaning”.

The person searching for meaning may enter an initial search attempting to find an answer to their symptoms, the meaning of tests and finally the meaning of life in light of the illness (Barnard, 1995). It has been proposed (Thompson, 1991) that the search for meaning could involve looking for: causal attributions (Why do events happen?), selective incidence attributions (Why did this happen to me as opposed to someone else?), and responsibility attributes (questions of personal responsibility for the event). Unfortunately, self-blame may be one of the potential outcomes of searching for meaning in cancer.

Meanings might also evolve out of seeking an understanding of the personal significance of the cancer diagnosis (O’Connor, Wicker, Germino, 1990). Finding meaning in an illness experience may require a change in values and priorities in life. Many individuals are able to rework and redefine meaning in their lives by embarking on a process of restructuring values and their attitudes towards self, life and others. Women experiencing uncertainty from breast cancer embarked on an exploration to find meaning in their lives to help them live with multiple possible outcomes in their uncertainty (Nelson, 1996). These women struggled with what their lives had meant and what their futures might hold and had to learn a new way of being in the world. New meanings surfaced for these women through helping others.

The human spirit searches for goals that have personal meaning and enhance life (Frankl, 1959). Meaning can be found in three categories: creative (accomplishments), experiential (witnessing a sunset) and attitudinal (adopting a positive attitude toward a fate that cannot be changed). Frankl (1959) states, “when called upon to deal with life’s challenges, the spirit’s defiant power is activated in tenacious determination; it responds with irresistible stirrings including the urge to live, to be free, to understand, to enjoy, to create, to connect and to transcend”. Those who are able to attribute meaning to their cancer experience can be led to a creative, self-actualizing experience (Granstrom, 1985).

Finding meaning in suffering

Illness has been described as both a soul and body experience and it is within the soul where meanings may surface. “Meaning is one of the most powerful of all intrinsic rewards and it sings to the soul” (Frankl, 1959). Secretan (1997) states, “a person’s mind and emotions are windows to the soul and the soul is the spirit, inner self or the essence of the person, which is tied to a greater sense of self-awareness, a higher degree of consciousness, an inner strength and a power than can expand human capacities and allow a person to transcend his or her usual self”. The soul has been described as our essence and the immortal or spiritual part of us that transcends our temporary existence (Secretan, 1997). Psyche is the Greek word for soul. Hippocrates believed that the person’s mind and soul should be inspired before illness could be treated.

Suffering may be a possible outcome of not being able to find meaning in an illness experience or patients may find a way through suffering by finding new sources of meaning. Illness has been described as a manifestation of soul suffering but what is meaningless suffering can be transformed into soul making (Woodman, 1990). Our minds are limited to dealing in possibilities, but our souls are capable of reaching beyond the traditional, to the magical and the richly elaborated dream.
Meaning can be derived through a spiritual connection or through beliefs about God (Shuster, Steeves, Richardson, 1996). The ability to find meaning in suffering has been identified by hospice patients who describe experiences of the whole person that brought them in touch with something greater than or outside themselves (Steeves, Kahn, 1987). As Nietzsche states, “He who has a why to live, can bear almost any how.” Hospice patients were found to impart meaning or purpose to their situation in order to create a sense of control over their environment (Lewis, Haberman, Walligan, 1987). The following nurse’s description poignantly captures the meaning that can be found, even in dying, that allows the person to regain control and transcend the experience:

Mr. Baker was dying. Medicine had nothing left to offer. She entered into his room with a sense of despair, wondering what she could offer in what seemed to be a hopeless situation. Mr. Baker taught her that life continues even for the dying. He still liked his coffee hot, he loved to be positioned so that he could see the sunrise and the sunset. He relished his visits with his wife. A rather elaborate management strategy helped him cope with his colostomy. He wore brilliant green socks, and he made jokes about leprechauns and the touch of the Irish (Benner, 1989).

Significance of meaning in illness

Victor Frankl (1986) states, “to live is to suffer, to survive is to find meaning in the suffering”. The search for meaning is a significant part of the cancer experience and may affect survival, coping and adaptation. Meaning is primarily a cognitive phenomenon that arises in response to specific situations and events, and it is a central factor in the process of social adjustment to everyday existence (Mead, 1934). It is meaning that enables an individual to regain an “inner hold on life” (Frankl, 1986). An important aspect of the coping process is the struggle to maintain a sense of meaning that allows the individual to regain a sense of their self and to maintain a sense of wholeness and personal integrity (Fife, 1995). The meaning that an individual develops concerning their illness may have an impact on their psychological well-being (Lewis, 1989) and may be a significant factor in achieving a positive adaptive response and an ability to cope with their illness experience (Steeves, 1992; Fife, 1994).

It has been postulated that there may be a biology of meaning that affects the healing process (Barash, 1993). Meaning may be able to influence the biochemical processes of the body (Block, 1997). The ability to reframe illness in a different light through the reconstruction of meaning may have an influence on survival. Speigel (1989) found that women who received a support group intervention were able to extract meaning from the tragedy by using their experience to help others. Lack of meaning was found to be a predictor of depression (Thompson, Sobolew-Shubin, Graham, Janigan, 1989), anxiety and a lowered self-esteem (Lewis, 1989). The search for and discovery of meaning was an important aspect of recovery from breast cancer. The meaning ascribed to the cancer diagnosis and treatment seems more destructive than the cancer itself. Recovery from the psychological effects of cancer can continue long after cure has been pronounced (Northouse, 1981).

Responding to meaning in illness

How people experience meaning in their lives is not readily understood or recognized by health care professionals. To achieve understanding, it is necessary to explore the meaning that persons attach to situations. A person’s illness experience may not be related to the external world as much as to the person’s inner world as he or she experiences it. As Cassel (1982) states, “illness and suffering cannot be understood without taking personal meaning into account”. Travelbee (1977) notes that the professional nurse hoping to deal with human responses in the fullest sense of the word “human” must be prepared to assist individuals and families not just in coping with illness and suffering, but in finding meaning in these experiences.

Responsiveness within the context of the nurse-patient relationship means a willingness to accept a patient’s invitation to be a close traveling companion on an uncertain journey. Experiences of intense pain, abandonment, and fear of living and dying are shared in an effort to construct the meaning of seemingly meaningless experiences (Parker, 1990). The coconstruction of meaning is a dynamic process that necessitates engaged listening and exploration, understanding and true presence, with the nurse acting as catalyst to facilitate the discovery of meaning and having the courage to bear witness.

Exploration of meaning

Nurses have a unique opportunity to bring compassion and support to people who develop cancer, the kind of support that touches and transforms human life far beyond the level of curing illness. Responding to the illness experience of the person defines a crucial domain for nurses (Dougherty, Tripp-Reimer, 1990). This means being involved in the life, not just the disease of the patient. As nurses we must move beyond the use of conceptual models that divide a person into parts to be fixed and treated (Bennett, 1993). Being able to see the meaning of dying, to nurse the whole patient we must have knowledge of the whole spectrum of the patient’s experience. It is the nurse’s duty and responsibility to help patients in their search for meaning (Stark, 1992).

The personal meaning of an illness may be largely invisible. The nurse can create an environment in which reflection on and redefinition of meaning in life by the patient is supported. Nurses can help the patient to determine the personal meaning of cancer in patient’s lives through exploring with the individual, “What does this illness mean to your life”?, “What has changed”? Cassel (1982) concluded that the only way to know if suffering is present is to ask the sufferer. Using questions such as: “Can you tell me what it is like?” “Can you help me to understand what it is like to be in your place?” In exploring with the patient their illness experience nurses can arrive at understanding and shared meaning, giving voice to the language of suffering. Transformational care involves listening to the person’s description of their illness to discover the meaning the illness holds for the individual. The meaning of survival or the meaning of dying can be known only to the person, and nurses - through gentle presence and listening - will be able to hear meaning. As Hallsdorssottir and Hamrin (1996) state, “the nurse must at times assist the person to find the words to express their experience, make conscious what is unconscious, make visible what is invisible, make tangible what is intangible”. Nurses should be able to hear about suffering and loss of meaning. As Kubler-Ross (1977) states, “if you do not use your head and your heart and your soul, you are not going to help a single human being” (p. 13).

Understanding meaning

Moore (1991) states, “There is a quality to our understanding that promotes healing of body and mind and moments of deep understanding can transform suffering”. The following excerpt provides insight into a moment of deep understanding:
To feel understood is to experience the fact that one’s personal meaning is shared by another person. The very nature of nursing practice necessitates hearing and understanding the language of other. Shared understanding may not be possible through verbal communication only. “When I insist that my clients provide increasingly verbal definitions to describe feelings, I may not be dancing well with them” (Moore, 1991). A more important dance may be occurring outside our awareness, which contains the stuff of healing. Patients may not be able to provide the language and much of the way they communicate meaning may be through story, symbolic language and metaphors.

Through story, human beings communicate their dreams, hopes and sufferings (Collins, 1996), allowing us to enter their world, to see the illness through their eyes, to understand how they perceive, understand and feel the illness experience (Kleinman, 1988). Entering the patient world and seeing the world from their perspective is described in the following excerpt from the author’s clinical practice:

Ellen was a young woman who had a promising career in a public domain and was enjoying life to the fullest when a squamous cell cancer of the palate of her mouth required extensive surgical removal, involving enucleation of the eye. The only patch that could be made to hide what she perceived as the “nightmare” left by the surgery involved the use of a patch that covered most of one side of her face with a fake eye painted on it. When she came to see me for counselling her head was bowed, her humiliation would not allow her to face me. She had been trying to get through and reinvest in life with little success and was now unable to leave her house, not even to the mailbox. In exploring what life was like for her right now she described how “she felt like a monster” and some teenagers at the mall had verified her beliefs. The real unconscious source of her distress was found to be that when she was a little girl she was taught that you were not a good person unless you always had a dress on and shoes shined and face made up when you left the house. Ellen’s entire personhood was in jeopardy and she felt worthless. Her entire meaning in life had been destroyed.

One powerful way that meaning can be communicated is through metaphors (Czechmeister, 1994). Metaphor is one way that people think about and interpret their world. Metaphors can provide a window into the person’s reality or lived experience. Metaphors do not add facts to a description but they add depth of meaning. Metaphors are often used to communicate the meaning of a situation, and by asking the patient to tell you about the metaphor, significant insight into meaning of illness is uncovered. The importance of metaphor is captured in the following story:

A young child was deeply disturbed upon hearing her diagnosis of leukemia and was desperate to make paper cranes. It was discovered that a few days prior to her diagnosis her class at school had been told a story about a young Japanese girl with leukemia who would die if she could not make 1000 paper cranes within a certain time frame.

The cultural meaning of cancer can often be communicated through the use of symbolic language. Symbolic language is particularly important in caring for children as it may be their only means of communicating difficult-to-verbalize feelings and the meaning attached to illness. Kubler-Ross (1983) shared the story of a child in an oxygen tent who asked how he would get out if a fire broke out. The first nurse explained that this would never happen, then told the story to another nurse who understood symbolic language. The second nurse went into the room, asked the child to repeat the question and, instead of explaining, took the child in her arms and said “Would this help?” The child began to share his feelings about dying.

As nurses we must learn to acknowledge the patient’s need for meaning in their illness and learn their symbol system and the person’s unique way of communicating their experience. We must also learn the way in which they assign meaning to life events, exploring with them new ways of finding meaning in their experiences.

**Knowing the person**

Knowing has been described as one of the five dimensions of caring and has been defined as striving to understand the meaning an event has in the life of another (Swanson, 1991). Meaning occurs through entering into the world of the person, understanding that world and responding to needs. Knowing the suffering of others requires an exhaustive understanding of what makes persons the individuals that they are and a comprehension of when the suffering person feels whole, threatened and disintegrated (Cassel, 1982). Gadew (1985) states, “knowing the patient limits their vulnerability and preserves their integrity and dignity”.

In coming to know the patient, nurses cannot rely upon theoretical formulations but must instead be willing and open to allowing the person to be themselves and to hearing about who they are. The whole-person (personhood) concept includes personality and character, the person’s past and life experiences, family identity and cultural background, roles, relations with other, political aspects of our being, the body, our secret life, perceived future and a transcendent or spiritual dimension (Starck, 1992). In knowing the patient, the nurse is able to provide compassionate care that is relevant to the life of the other. Compassion is a sensitivity to the pain and brokenness of the other, a quality of presence which allows one to share with and make room for the other (Roach, 1987).

**True presence**

True presence is an experience of genuinely engaging with another, perhaps for only a fleeting moment, perhaps intermittently for an extended time (Liehr, 1995). In moments of genuine meeting and mutuality, we make the other present as a whole and unique being, as the person that he is, a presence by which we are told that there is meaning (Buber, 1965). Human touch and human presence in some way directly or indirectly restore the dignity and affirmation of being. Caregivers participate in the act of being fully present with the patient, within the context defined by that individual patient. Shared understanding emerges through connection with another human being. If the inner world of the individual (the soul) is to thrive, it requires connectedness, communication and love during times of life threatening illness (Murphy,1996). Mutual caring has been identified as the most satisfying of human experiences as well as a source of meaning in life (Koestenbaum, 1976). One woman described this connection in the following way: “she would look right into my eyes which is like looking into my soul. So she looked into my soul to see what I needed” (Watson, 1988).
Another human being’s presence is a therapeutic activity of its own characterized by sensitivity and understanding of the patient’s plight. Leo Buscaglia was asked to judge a contest. The purpose of the contest was to find the most caring child and the winner was a four-year-old child whose neighbor had recently lost his wife. Upon seeing the man cry, the little boy went into the old gentleman’s yard, climbed onto his lap and just sat there. When his mother asked what he had said to the neighbor, the little boy said, “Nothing I just helped him cry” (Canfield, Hansen, Hansen, 1996, p.28). This boy demonstrated that presence and relationship are not about doing, they can be silent and they are more about just being and presence than anything else.

Catalyst to meaning

Meaning is unique to each individual and must be discovered. It cannot be given to another person (Frankl, 1959). Each patient encounter is an opportunity for the nurse and the patient to join in a search for meaning and understanding that is relevant to the patient. The nurse can be a catalyst facilitating the patient’s ability to extract meaning from the experience of illness and death (Jones, 1993). In order to act as a catalyst, nurses need to move from merely understanding meaning to illuminating peoples’ capacity to transform meaning and experience (Hartrick, 1997). Starck (1992) recommends a three-step process to facilitate the discovery of meaning and purpose: assessing the meaning of life in the suffering experience; validating the strength of the human spirit; and freeing the human spirit. Assessment means eliciting information about the suffering experience and the meaning it holds for the patient. Assisting the patient to get in touch with the human spirit can mobilize the forces of healing, allowing the person to choose a new attitude. Frankl (1959) states, “the last of the human freedoms is to choose one’s own attitude”.

Story telling, use of fables or metaphors, and use of parables help persons to find meaning in their experiences, possibly helping to free the spirit (Starck, 1992). The following story demonstrates how a nurse can help to free the human spirit:

Bernadette was a patient I cared for whose suffering was endless and she could not find any reason to live and constantly spoke of her desire to die. Much of the meaning of her suffering was hidden so I decided to use a poem from a book entitled, “The Fall of Freddie the Leaf” to reach her and possibly free her in her struggle. I used this parable because Bernadette described her favourite season as the fall. She would vividly describe how she felt in looking at the changing colours of the leaves. Fall signified for her that new growth would begin. Many days prior to sharing the parable with her I filled a green garbage bag full of fall leaves and dumped them all over her. It was the first time I had seen her smile in months. The parable is about a leaf who does not want to let go of the branch because falling would be like dying. Others provide him support and describe how he will be part of the new forming leaf, and finally at the end of the story he decides to let go.

Courage to bear witness

There comes a time in illness that goes beyond meaning, when the search for and seeking of meaning is no longer relevant. Instead, the caregiver offers a quiet sharing of the experience and helps the person to sustain the burden of suffering (Donnelly, 1995). At this stage of illness the caregiver is needed to witness the patient’s fears, pain, sorrow and dying. Being witness has a peculiar property of being separated from the action, yet at the same time fully engaged. There is sympathy and empathy, resentment and compassion...often the patient’s pain or distress is indirectly felt, transformed, vividly imagined, or distorted by thinking it is much worse than it really is. Witnesses are afraid for the patient and themselves (Horowitz, Lanes, 1992). The following excerpt of a poem written by a student nurse (Ferguson, 1989, p. 131) poignantly captures the fear of being witness to the experience of dying:

The Transfiguration

I was afraid at first
To look at her
Because three days ago
When I looked she was not dying
Three days ago we talked
As she washed her flesh
Protuberant and sagging at the sink
Struggled to wash the suffering from her mind
No use
For it had worked its way
Into the pores of her skin
And into the whites of her eyes
Remembering this I was afraid.

Part of being witness is being able to accept the truth that we are vulnerable in our humanity and having the courage to share our whole person with another in order to help them in finding meaning in the face of death. It requires significant courage to enter into the unknown of someone’s reality, to be open in compassionate ways and to live with the uncertainty of the outcome (Longhurst, 1987; Gadow, 1989). As Frank (1997) states, “having the courage to bear witness means being able to abdicate the power to cure for the power to witness”.

Summary

In summary, meaning is a powerful and significant part of the experience of living with cancer. Meaning may be a significant factor in understanding the patient’s lived experience of illness and their ability to adapt and respond to the chaos wrought by a cancer diagnosis. Nurses play an important role in helping patients in their struggle to find meaning in their circumstances as they attempt to restructure and find new meaning in their lives throughout the illness trajectory. The search for meaning can be a lonely and isolating experience without the presence of another caring and compassionate human being who is willing to become part of the journey. The nurse’s presence can be a significant factor in establishing meaning and can be a powerful source of healing. At the beginning of this presentation I described how cancer changes everything. In closing, I would like to share with you a poem (Canfield, Hansen, Aubrey, Mitchell, 1996) about what cancer cannot do.

What Cancer Cannot Do

Cancer is so limited -
It cannot cripple love
It cannot shatter hope
It cannot corrode faith
It cannot destroy peace
It cannot kill friendship
It cannot suppress memories
It cannot silence courage
It cannot invade the soul
It cannot steal eternal life
It cannot conquer the spirit.

Source Unknown
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