Experiencing existential changes: the lived experience of having cancer


This phenomenological study was designed to explore the lived experience of having cancer, as perceived by people who have been diagnosed and treated for cancer. The aim of the study was to add to the knowledge and understanding of this complex human phenomenon. Data were collected through in-depth interviews with nine people who were in the remission or recovery phase of cancer. The interviews were tape-recorded and transcribed verbatim for each participant. Through intersubjective interactions and thematic analysis, the essential description of the lived experience of having cancer was constructed. The overriding theme of the lived experience of having cancer is “experiencing existential changes.” Five basic subthemes were identified in the participants accounts, all of which are part of the existential changes involved in the lived experience of having cancer. These are: uncertainty, vulnerability, isolation, discomfort, and redefinition. The study can increase the understanding of what it is like to have cancer.

Key Words: Cancer patients—Patient perceptions—Qualitative studies—Phenomenology—Interviews—Psychosocial factors.

EMOTIONAL LABOR IN NURSING AND HEALTH CARE

Nurses are socialized to be caretakers. They are supposed to be able to handle human feelings and complex human situations, and yet especially newcomers in nursing sometimes feel that they have not been prepared well enough to do just that. Phenomenological nursing research, through the findings, can help nurses in their endeavors to understand human feelings and people’s unique situations, such as the lived experience of having cancer. Informants can tell us what it feels like to experience caring and uncaring encounters with health professionals in those situations. If health professionals get a better feeling for what it feels like to go through the varied human situations, they will be more able to confront pain, shame, and human hurt. Nurses are the ones who can legitimize people, as patients and as persons. They are the ones who can assure another that his or her feelings are normal in their situation. They are
the ones who can lend a shoulder to the one who is crying, if they are not afraid of feelings. Nurses are the ones who should be able to hear about the hurt and the pain, of body and soul.

This is what Patricia Benner and others have called "emotional labor" (1). She has pointed out that there has been a shift in nursing from analytic rule-based thinking to intuition, a movement from detachment to engage participation—of being open to experience. This new way of being in nursing requires the skill of involvement, a fusion of thought, feeling, and action, a skill of seeing and hearing with the temporal focus being the immediate present, which means having to be open and receptive, sensitive to questions, making ourselves existentially available. It means focusing on the other, not so much on oneself; listening, not only to what is important to us but what is important to the other as well. It means staying attuned to the other and staying attuned to the moment. It means seeing the context, seeing the world that is there, seeing the reality that is being shared. If we develop this new mode of being in nursing, we are constantly learning new things about human phenomena in the world. However, there is more to human phenomena then we are able to see. There is more to what people experience and know, than what they are able to express and we are able to hear. What we need in nursing practice is, therefore, "sensitive listening" or sympathetic emotional attunement.

We see it as one of the missions of nurse researchers to aid nurses in helping people to verbalize their experience, so that they can reflect on it and understand it more fully, to move on beyond it; to give people who are sick, or who are going through major transitions in life, words to express their experience: to make conscious what is unconscious, to make visible what is invisible, to make tangible what is intangible. We need words to reflect on our experience and to express it to others.

CANCER AS A LIFE EXPERIENCE

Cancer is a disease, but it is also a series of experiences that profoundly affect the person who has the cancer and those who share the experiences (2). O'Connor et al. point out that it is amazing how little has been studied about the lived experience of having cancer (3). It is known that cancer causes stress because the individual is facing loss, pain, suffering, anxiety, financial difficulties, and sometimes also fear of death (4–6). Most often it seems to be a great shock to be diagnosed with cancer, even more of a shock than to be diagnosed with another serious disease (7). People who are diagnosed with cancer seem to go through an existential crisis for ~100 days, in which everything revolves around life, the disease, and death (3). Often the role of health care professionals is to help people with cancer live a life that is as good as possible (8–10). To do that, health care professionals need information about the lived experience of having cancer to enable them to offer support and caring that has meaning for the person with cancer. This is especially important for newcomers in cancer care. Finally, students of health care professions need this information as part of their studies. Therefore, the study was designed to explore the lived experience of having cancer, as perceived by people who have been diagnosed and treated for cancer. The aim of the study was to add to the knowledge and understanding of this complex human phenomenon. The study was conducted by the first author.

METHODOLOGY

The research question directed the researcher to design a study that explored the lived experience of having cancer. Because the phenomenological research approach exists for this expressed purpose (11), it was the design chosen for this study.

Selection of Participants

In accordance with a phenomenological research perspective, the researcher used theoretical or purposeful sampling, in which the researcher selects a participant according to the needs of the study (12). The criteria for selecting participants included: non-hospitalized people >20 years of age who had experienced the diagnosis and treatment of cancer and were now in the posttreatment phase of cancer, and who were able and willing to communicate their perception regarding the cancer experience. The underlying assumption when selecting participants was that people who have experienced cancer are the source of knowledge for the understanding of this phenomenon.

Five women and four men participated in the study and were seen as coresearchers (13). The participants represented a variety of professions, their socioeconomic situations were heterogeneous, and the style of living varied markedly within the sample. The ages of the participants ranged from 38 to 69 at the time of the study. Most of the participants had
experienced multiple hospitalizations. Seven of the participants were employed at the time of the study. Two participants were in the terminal phase of cancer; the other seven participants considered themselves free of cancer at the time of the study. The participants had been treated for six different types of cancer, e.g., breast cancer, cancer of ovary, cancer of cervix, prostate cancer, skin cancer, and cancer of intestines. Three of the participants had experienced recurrent episodes of cancer and cancer treatment, for up to a 20-year period. Seven of the participants have been dealing with cancer within a 2-year time. Two participants were dealing with cancer 4 and 6 years ago, respectively. The rights of the participants were safeguarded through informed consent and confidentiality. Because Icelanders are so few in number, it is very difficult to provide contextual information about each participant because confidentiality might be severely threatened by that.

Data Collection and Data Analysis

Data were collected through in-depth interviews, one to three interviews with each participant. At least 2 weeks elapsed between interviews. The interviews were 1–3 h long. They were tape-recorded and transcribed verbatim. In qualitative research the researcher’s analytic and observational activities run concurrently, because there is temporal overlapping of observational and analytic work (14). Data collection and analysis in this study reflected an evolving dialogue between the researcher and the participants, adhering to Strasser’s ideas of true dialogues (15). The researcher approached the participants with a very broad question that concentrated on the description of the lived experience of cancer, i.e., Can you tell me of your personal experience of having cancer? In the first interview the participants were allowed to tell their stories. During the dialogue or interaction with the participants in subsequent interviews the researcher asked questions that were in direct response to the participants’ descriptions to arrive at a deeper level of understanding, to reflect and to validate. It was through this intersubjective interaction or dialogue that the participants and the researcher constructed the essential description of the lived experience of having cancer. The data analysis was greatly influenced by Colaizzi’s variation of the phenomenological method (16).

FINDINGS

The overriding theme of the lived experience of having cancer is “experiencing existential changes.” Five basic subthemes were identified in the participants’ accounts regarding their lived experience of having cancer, all of which are part of the experience of existential changes involved in the lived experience of having cancer. These are: uncertainty, vulnerability, isolation, discomfort, and redefinition. These will be described with quotations from participants.

Uncertainty

All the participants experienced uncertainty in all the stages of cancer: The diagnostic phase (is it cancer?), the treatment phase (will the treatment work?), during the posttreatment phase (will I get cancer again?), and in the terminal phase (will I die?). There are also many other uncertainties and lack of control the person with cancer experiences. One man in the terminal phase of cancer commented:

I wanted more definite answers about what the situation was like and I didn’t get it, and that was the most negative thing of all, not being able to follow up on how the disease was progressing, at which level it was … what I could expect … what was the prognosis, what the chances are.

Getting rid of uncertainty means that sometimes the diagnosis of cancer is welcomed after a long period of uncertainty. One man vividly recalled:

He took a sample and after a week I had an appointment with him again, and then he told me that it was malignant, that it was cancer. And to tell you the truth, I was very comfortable with it. He told me exactly how it was. And he told me exactly how it was progressing and even if this is a disease that people don’t like very much, I was very content to finally know what was wrong with me. Having been like this for a few years, I was always getting lower, and lower. I was worse and worse all the time. I almost cheered up just to know what it was. … You have been fighting some ghost that you don’t know what is, nothing. That was absolutely the worst thing about the whole thing, at least in my case.

Twenty years ago it was common that people were not told that they had cancer. Living in uncertainty, not knowing what was wrong, was described by one woman:

I started to become sick when I was 19, and I wasn’t told that I had cancer. I had five operations before they told me. I was terribly scared. I wasn’t told anything.

One man had a similar experience in the past, but fortunately things seem to be better today:

I was full of anxiety. I always suspected that something was wrong. But they didn’t talk to you about anything. Nothing. The operation was just done. And this is very
thinking then that I didn’t want to become old...I am a very happy man...and I think it is just good to die happy...I think for me that is the main thing.

Redefinition also includes redefining your place in society and how society redefines you. Sometimes this redefinition is unwanted and causes anger. One woman explained:

There was a life insurance company that was supposed to be open to everybody, but then when you started to read more closely you saw that it was not for those who had had cancer, no matter how long ago. That really made me angry.

**DISCUSSION**

Experiencing existential changes is the overriding theme of the lived experience of having cancer, as constructed from the participants’ descriptions in the present study. Supporting a person with cancer would, from that perspective, involve the emotional labor (1) of “sensitive listening” or sympathetic emotional attenuation, as well as existential guidance to the person on the often tumultuous journey through a cancer experience.

Because the preservation, fostering, maintenance, and the facilitation of the integrity of all the human needs of the person(s) is the territory of nursing (17), in discussing the findings, an attempt will be made to look at unfulfilled needs that seem to be behind the five major subthemes identified in the study.

Having a cancer seems to involve uncertainties and perceived lack of control, which can be anxiety provoking. The underlying unfulfilled need behind the uncomfortable feeling of uncertainty seems to be the need for security and certainty, the need to know how things really are, and the need to have some sense of control. This is in accordance with studies regarding the stress of contracting cancer and coping with it (7,18–21).

Cancer patients, as are most patients, seem to be vulnerable, and sensitive to and in need of caring, when they are in the hospital. Patient vulnerability and sensitivity within today’s hospital reality has been described in the literature (22). The underlying needs behind the feeling of vulnerability seem to be the need to feel like a normal human being, and the need for respect as a person, and to be understood by another person (22). This need for normalcy is clear in the following account made by a woman who has been diagnosed and treated for cancer more than once in her life: “I have always felt like a normal human being, even if I have had to face some difficulties, then you have just done that and met the challenge.”

All participants in this study experienced withdrawal and isolation at some point in time, which can be self-induced or caused by perceived or actual rejection in the environment. Similar results have been reported in the literature (5–7). Because everyone has the need for connectedness and person-to-person human contact (22–24), this isolation is, for most people, very uncomfortable. Unfortunately, there is some indication that negative attitudes toward cancer and cancer patients affect not only patients with cancer and their attitudes toward the disease, but can also affect the quality of their care (25). Furthermore, findings from several studies indicate that the social context and social support from partner, family, friends, relatives, and health care professionals are important for psychosocial adjustment and survival of cancer patients (26).

All participants in this study experienced discomfort in some way. The cancer patient is dealing with side effects of diagnostic measures, drugs, and other forms of treatment along with many other sources of discomfort, which are a source of suffering. Similar results have been reported in other studies as described by Carnevali and Reiner (2) in an excellent review of the literature on the management of daily living in the different phases of cancer. However, in a qualitative investigation of the experiences of the chronically ill within today’s health care system, Thorne (20) comes to the conclusion that the subjective experience of living with a chronic disease is far more complex than simply feeling fatigued, bearing pain, or living with the physical symptoms that the disease or its treatment might bring on. She claims that it is an entity constructed by the many forces at play in the interaction between ourselves and our social worlds, an interaction that can, and often does, pose discouraging problems for the chronically ill (20). This conclusion is supported by the present study.

All the people who participated in this study seemed to have gone through a redefinition of roles and goals. When this redefinition is under way, many find it uncomfortable because people have the need to have clear roles and clear goals (20). Cancer patients, as do other people, also have the need to be at peace with themselves and with their environment. They have a need for support from family, friends, as well as from health professionals (8–10). Finally, people who have been diagnosed and treated for
cancer have the need to be taken back into "the land of the well" when they have been cured of cancer.

It is concluded that the findings of this study can be of value for nurses and other health professionals in cancer care, as well as for cancer patients and their families. Furthermore, they can be valuable information for nurses and other health professionals in oncology orientation and inservice education, because participant evaluations seem to indicate that incorporating the area of emotional function into staff development programs is an important component in assuring the assimilation and adequate performance of new employees in cancer care (27–29). Therapeutic relationships require care, self-awareness, and awareness of other's emotional needs. In comprehensive cancer care it is, therefore, important to emphasize what the person with cancer is going through—the lived experience of having cancer—to provide quality patient care, enhance professional development, and promote job satisfaction.

LIMITATION OF THE STUDY

The reality constructed within the research encounter is that of participants and is culturally and socially located. This means that the generalizability of findings is limited to the cultural and social groups represented in the study sample. Furthermore, one qualitative study alone will not provide the whole picture of a phenomenon, just as no single quantitative study does (30). Tesch has pointed out that as qualitative descriptions accumulate, they will make it possible for us to gradually "recognize" the phenomenon in the sense of a "second, fuller knowing." That is the goal of qualitative research (30).

CONCLUSION

The lived experience of having cancer seems to involve existential changes that are, for the most part, a burden on the individual. The findings of this study can be of some help in the effort to understand and support cancer patients on their illness trajectory. Because this study provides some descriptions of the lived experience of having cancer, it can be a reading material for students of health care, enabling them to get a better feeling for what it is like to be suffering with cancer. Health professionals must be aware of what the person with cancer is going through to provide support and help that is meaningful to the person coping with cancer. In caring for the person with cancer, the health professionals should try to diminish uncertainty as much as possible and remember cancer patients' vulnerability. They should try to help the person with cancer in combating tendencies to withdrawal and isolation, decrease the physical discomfort as much as possible, and be open to patient description of discomfort; and finally, health professionals should try to be of help to the cancer patient during the often painful process of redefinition.

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REFERENCES