

Individual Empowerment Among Chinese Cancer Patients in Hong Kong

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Among the various chronic diseases, cancer is the leading cause of death in Hong Kong. This article presents the process of how cancer patients are being enabled and strengthened to overcome powerlessness based on the interview findings of 12 participants. Interviews were analyzed using constant comparison. The basic social process of empowerment included finding meaning in life, seeking mastery over illness, and acceptance of illness. This study's unique findings suggest that the process of empowering cancer patients consists of more than giving patients control, choice, or resources, such as knowledge and skills. Nurses have an important role in facilitating patients to find meaning in life, as well as in the transformation of thoughts and attitudes. Nurses' personal qualities and skills embedded in the nurse-patient relationship constitute an important source of empowerment for patients.

Keywords: *empowerment process; Hong Kong; cancer; power resources; spirituality*

Among chronic diseases, cancer has become the leading cause of death in Hong Kong, accounting for 24.8% of deaths in 1980, rising to 31.3% in 1998 (Hong Kong Cancer Registry, 2000). The diagnosis and treatment of cancer are associated with a substantial social and psychological morbidity (Derogatis et al., 1983; Greer, 1985; Ma, 1996). Powerlessness is regarded as a central psychosocial issue in health research, particularly among researchers interested in predicting or facilitating positive outcomes among persons with cancer (Miller, 1992). Enabling patients to cope with cancer is paramount, as patients have to cope with the inevitable uncertainty associated

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with possible illness progression or recurrence, difficult treatment side effects and complications, social and vocational discrimination, and financial burden (Gray & Doan, 1990). In spite of such adversity, one often sees patients who show indescribable strength in overcoming their powerlessness. It is important to understand how patients are being empowered in the process.

Patient empowerment has been seen as a new philosophy in patient care in recent years (Falk-Rafael, 2001; Malin & Teasdale, 1991). Some examples of areas that have been studied include empowerment of citizens (Keiffer, 1984; Swift & Lewin, 1987), nursing students (Hokanson Hawks, 1992), employees (Laschinger, Wong, McMahon, & Kaufmann, 1999; Thomas & Velthouse, 1990), parents of children with cancer (Chesney & Chesler, 1993), and mothers of children with chronic illness (Gibson, 1995). Barrett (1990) emphasized that power is the capacity for action, energy, and accomplishment, and not control over means and others. Power was described as an affective feeling of strength, a volitional and cognitive recognition of choices and behavioral activities (Barrett, 1990). If nurses are to be able to facilitate patients to have strength, they have to be able to describe how they know when it is present, how a person becomes empowered, and how they can help individuals to maintain it. By understanding patients' meaning of being empowered and by focusing on coping resources rather than health deficit, health care professionals can more effectively influence a patient's state of powerlessness.

Miller (1992) used a power resources model as a framework to examine causes and interventions for patients with chronic illness. The model places strong emphasis on maximizing patients' power resources to help them cope with cancer. Individuals with cancer may have deficits in power resources including physical strength and energy. In cases of deteriorating health, it may be difficult to mobilize individuals with such deficits. Other power components, such as knowledge of the disease and updated information on alternate treatments, may need to be developed. Varied power resources need to be drawn on to compensate for deficient resources to prevent or overcome powerlessness.

Empowerment is defined as making someone stronger and more confident, especially in controlling their life and claiming their rights (Pearsall & Hanks, 1998). In the nursing literature, the concept of empowerment is used to explicate the strengthening process in the discourse of various health disciplines. Although a theoretical understanding of empowerment may generalize easily across disciplines, its integration into practice changes with the

focus of the discipline and practice setting. Gray and Doan (1990) identified strategies to empower persons with cancer, including provision of optimal care, enhancement of individual patient power, and development of a strong consumer voice in policy-making processes. The empowerment model assumes that individuals typically understand their own needs better than others do, and it is optimal for individuals to have the greatest possible control in determining various aspects of their lives. However, little is known about how patients perceive the process of how they are being empowered in cancer practice. We need to have a better understanding of the basic operating mechanisms of the process to facilitate cancer patients to cope with their illness.

The purpose of this article is to identify, through an empirical study based on in-depth interviews of 12 cancer patients, how Hong Kong Chinese cancer patients are being empowered and strengthened, and how they are moving forward.

METHOD

A qualitative grounded theory method (Polit & Hungler, 1997) was used to conduct this study. A semistructured interview guide was used to facilitate the patients to describe their experiences of empowerment in coping with the illness. Examples of the interview questions are as follows:

1. What does the term *empowerment* mean to you in relation to your illness?
2. What do you do personally that gives you a feeling of strength in relation to your illness?
3. What do others do that influences you and gives you strength in relation to your illness?
4. How would you describe the outcomes of empowerment in coping with the illness?

Subsequent probing questioning, aimed at gaining further clarification and insight into the informant's experience of the illness, was guided by the informant's responses. The qualitative approach focused on the patients' realities, and they were encouraged to describe their feelings, experiences, and actions freely (Polit & Hungler, 1997). This allowed the researcher to gather in-depth information and insight into Chinese cancer patients' feelings and meaning of empowerment in coping with cancer.

Sample

Purposive sampling was used, and patients were deliberately selected according to research needs. For inclusion, patients had to meet two criteria. First, participants needed to be suffering from cancer. Second, nurses had to consider the patient to have faced up to the illness instead of giving up. These patients were perceived to be carrying on, having the strength to fight the illness. Individual interviews were conducted with patients who were referred by nurses from outpatient departments of an oncology unit in a large acute care hospital. We continued to collect data until we achieved saturation, which refers to the completeness of all levels of codes when no new conceptual information is available to indicate new codes or the expansion of existing ones (Strauss & Corbin, 1998). A total of 12 patients participated in the study. Interviews took place in a private meeting room in the outpatient department. Each interview lasted from 45 min to 2 hr, and patients were interviewed only once.

Patients included eight women and four men, ranging in age from 28 to 76 years (mean age = 58 years). All were married except one who was a widow. Four had received elementary education, and five had secondary school education. Three had no formal education. Six patients had breast cancer, four had colon cancer, and two had nasopharyngeal carcinoma. In terms of religion, three indicated they were Buddhist, two indicated they were Christian, and the rest did not claim to have any religious beliefs.

Patients were informed that participation in the study was voluntary and that they could withdraw at any time. Written informed consent was obtained before starting the interview. Approval to conduct the study was obtained by the Ethics Committees of the University and the Hospital.

Data Analysis

The interviews were audiotaped in Chinese, and verbatim transcriptions were made. By doing this, semantic meaning is preserved, and misinterpretation of data due to translation into English is minimized. Only those texts quoted for discussion for the purpose of reporting were translated into English. Data analysis was conducted using the constant comparative methods described by Strauss and Corbin (1998). Data coding procedures were as follows:

1. Open coding involved reading the entire transcript and labeling each piece that might contain ideas, actions, events, or incidents. Codes were derived from the

actual words of the participants to avoid premature categorization and distortion of meaning.

2. Categories were then created from interpretation of codes. Categorization moved the analysis toward a higher level of abstraction and provided working concepts that facilitated further comparison.
3. Categories were connected with each other. The contexts, attributes of the phenomena, conditions, and consequences of the categories were examined (Strauss & Corbin, 1998).

Although each participant's experience was unique, there were remarkably consistent patterns. The influencing factors, processes, and outcomes of the strengthening process were considered in relation to the categories.

To address issues related to the trustworthiness and rigor of the study findings, a method was used in which the interviews were read and coded by two members of the research team. Discrepancies in coding were discussed until consensus was achieved. Credibility of the study findings was addressed by sharing emerging conceptualizations with the participants by telephone. An audit trail, consisting of notes and memos compiled during analysis sessions, documented researchers' responses to the data.

RESULTS

The process of empowerment for cancer patients was described as a motivational process, a process of seeking mastery over illness, and a process of using transformational thoughts to actively develop new perspectives by reframing and reinterpreting their illness. The process was embedded in a relational context, which was described as connection with others, including family, friends, and health care professionals, and those in the patients' cultural, religious, and personal belief systems (see Figure 1).

A Motivational Process

Table 1 shows the strengthening process consisted of three main intertwining processes. The first is the motivational process, in which conditions that motivate the individual can be identified. The motivational process is defined as a process through which patients derive meanings for surviving illness and enduring the intolerable side effects of treatments. It includes commitments, responsibilities, concerns, and the hopes that motivate patients to strengthen themselves and move forward.

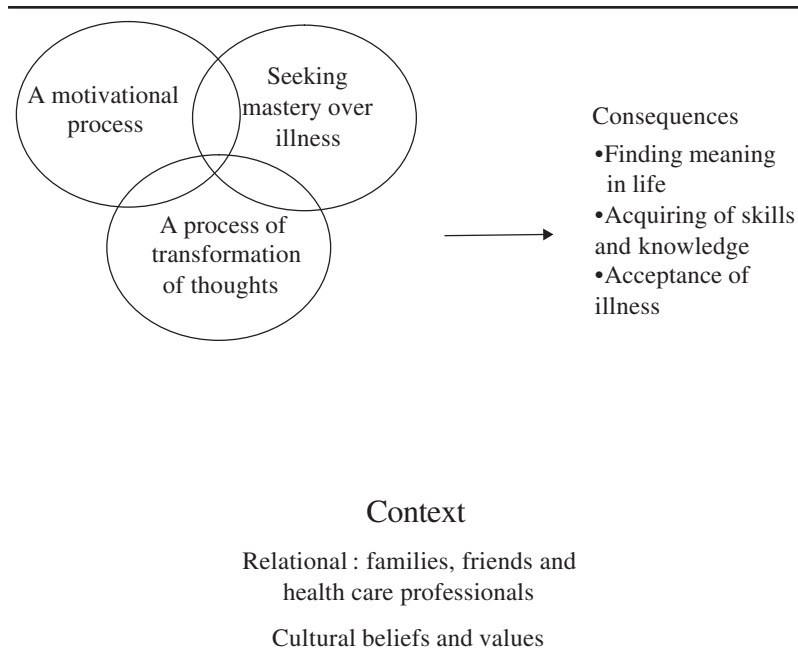


Figure 1: Individual empowerment among Chinese cancer patients.

Commitment, responsibility, and obligation to the family. Because of commitment and responsibility toward their families, patients have gained a sense of purpose and meaning in life. This results in their being more motivated to go on living and not give up. More important than their individual personal concerns were the patients' strong commitment and sense of responsibility toward their families and their future. A husband and father of two children said: "During my illness, my wife had to work to support the family. If I pass away, who is going to look after the family? Who is going to look after the children? I have the responsibility to support my family."

Hope still exists. Another area that gave meaning to the patients' lives was their hope for "a better tomorrow." Patients need to know that potential existed for cure and that there might be a medical treatment breakthrough. In some situations, as when a cure is unlikely, patients were reassured that they would not be left alone, and that health professionals were making every attempt to help them, thus they found the strength to go on. After a patient was told that his or her type of cancer was incurable, it was difficult for the patient to undergo intensive chemotherapy and face the future. The choice

TABLE 1: Empowering Process of Cancer Patients

<i>Major Processes</i>	<i>Strategies</i>	<i>Consequences</i>
A motivational process	Commitment and obligation to the family Hope still exists Religious or cultural beliefs	Finding meaning of life
Seeking mastery over illness	Related to illness, treatment, side effects Alternative medicine Dietary therapy Confidence and trust in the health care professionals Made informed choices in their treatment	Acquiring skills and knowledge
A process of transformational thoughts	Accept the unchangeable Letting go Goal for each day Positive thinking Living in the moment Believing that suffering has an end and a limit Looking at life from the whole perspective Setting alternate goals Downward comparison	Acceptance of illness Perceiving harmony in self and with the illness Peace at heart

and focus of words affects how a patient perceives the illness and whether they are empowered or disempowered:

My doctor told me that some cancers can be cured nowadays, and that the therapies they use hold promise for providing a long lasting remission and, possibly a cure. If needed, they would use newer treatments that are available. They said we would not be left alone and that they would make every effort to help us.

Religious beliefs. For patients who indicated having a religion, their religious beliefs gave them strength to endure suffering. They felt assured that things were not happening by chance, and that there was meaning to life and a reason for their illness based on their faith in God. They believed that God makes correct decisions about life, and that they did not need to worry because their lives were in God's hands.

I am a Christian, I believe God will lead my life and help me with whatever I will be. I know there are a lot of brothers and sisters praying for me. I will be in God's hands. Even if I die, I know where I am going. I will accept whatever

happens. My Lord helps me to face cancer; I don't need to be afraid. I know where I am going even if I die.

As portrayed by the participants in this study, the transition from powerlessness to having strength was first characterized as a motivational process, in which patients found reasons for living and areas of life that were important to them. By contrast, those who could not find areas of life that mattered to them were not motivated in the process. The cultural value of commitment to family, having hope, and having religious beliefs provide meaning to patients' lives and help them through chaotic, threatening situations.

Seeking Mastery Over Illness

Patients found that acquiring skills and knowledge related to their illness and treatment was important in anticipating the illness process and coping with it. In this study, patients had information related to the disease and its treatment, alternative medicine, and diet therapy.

Disease and treatment. Patients expressed that knowledge and skills related to the disease had prepared them for treatments and the management of treatment side effects, which helped them to control the psychological impacts of the disease.

Since getting the illness, I've read a lot of books related to cancer. When I understood the illness, my feelings of powerlessness were reduced. At the least, I was able to understand what phase I was in, what would happen if the situation got worse. With this knowledge, I had a sense of being able to anticipate what would happen. I was more competent in adapting to the illness. If I'd known nothing about the illness, I'd live in fear and helplessness from day to night. I knew of some friends who were in that situation.

Alternative medicine. Patients believed that alternative medicine could help with symptom relief. Participants were aware that Western medicine offered no cure for their disease. Alternative medicine gave them the ability to exert influence over their treatment, for example, in symptom relief. Although study participants did not see themselves as having more control over the course of their illness, they did feel they were more comfortable in their adaptation to their illness.

Initially I didn't believe in alternative medicine, for example, "grass tea." But as humans, we need a lifesaver to hold on to when we are in the sea. Having the

grass tea makes me feel better. I have better mastery over the illness. Moreover, the grass tea was given to me by my friends. I don't need to pay for it. After I take the grass tea, I feel better and more comfortable.

Diet. Patients in the study believed that they could promote their health by changing their diets: "After I learned about the disease, I was better prepared for the illness. I knew what I should and should not eat."

Several patients commented that health care professionals were their main source of information. They expected health professionals to give them information, because they regarded them as experts who could ensure that information was accurate and reliable. Only three participants commented that they had received helpful information from other sources besides health care professionals, for example, books and pamphlets. In seeking mastery over their illness, participants see themselves in control of their lives. Such control has been linked closely to participation in getting better, changing diet, and exercise patterns.

Participants also believed that by changing their diet and exercise habits, they could improve their health:

In order to promote health, I exercise everyday. I've changed my diet to improve my health. I'm confident that I'll get better if I follow these health habits. It's very important that we exercise however tired we are. Exercising speeds up our recovery.

A Process of Transformational Thoughts

The process of empowerment is not only an active participatory process of acquiring skills and knowledge but also a process of transformation of thoughts. As a result, participants found they had to accept their illness. Participants said that they had reappraised life and were in better harmony with themselves, the illness, and the world. In the process, patients became aware of their situation. For aspects of their illness beyond their influence, patients had to accept their situation, develop alternate goals, and put themselves into the hands of their doctor.

Accept the unchangeable. Participants first identified the controllability of events. In the cancer situation, removing external conditions is not always possible. When it is impossible to change the course of the illness, patients accepted their situation and adjusted to their changed environment. An awareness of their reality helped participants to relinquish their hopeless

expectations and free themselves from longing for what was lost. They accepted what could not be changed and made a conscious decision to move forward. One participant said:

We have to accept that illness is part of the life process. We have to *ting tien you ming* (let everything come from heaven and destiny). Birth, ageing, sickness, and death are the processes of life. Although we don't want to depart from our dearest relatives, none of us can avoid it. All we can do is to try our best to relieve the suffering. It doesn't help the situation to resist against it, escape from it, or cry everyday.

A 38-year-old woman who had recurrent breast cancer gave the following account:

For the last 3 years I have learnt more about cancer. I have learnt how to live with cancer. Suffering is not a punishment, death is not a failure, and living is not necessarily a gift. Each one of us has to go through death. We need to learn how to face illness and to finish works that need to be completed. Since my illness, I've spent 3 years reading books related to life and death, and I've met friends who are in a similar situation. I've learnt to share my happiness and sorrows with others.

The transition to accepting the illness is influenced by the Chinese cultural beliefs of letting go and harmony with the Universe, which are derived from Buddhism and Taoism. Buddhism asserts that holding on to relationships, material, and wealth is the source of our pain and suffering. Letting go helps to relieve this suffering, that is to say, dealing with things as they are, not as one would like them to be:

We can't escape from the illness. It is a fact. We can't escape from it, but luckily I have a family who supports me. They encourage me and help me. It's changed my perspective on seeing things. I have to let go of impossible things. Since I didn't bring anything to this world, I have to be positive about the future. I feel confident of the future.

Patients practiced cognitive/behavioral activities that promoted concentration on neutral or positive thoughts and conditions. These strategies helped them to accept their illness. Patients purposefully moved away from the continuous awareness of threatening conditions, by intentionally distracting themselves with other, more positive thoughts or activities. Next are examples of the patients' use of cognitive strategies that enabled them to cope with the illness.

Positive thinking.

Having cancer doesn't mean death. I have a friend who's had bone cancer for 22 years and is still surviving. Although the wound still gives him pain, nevertheless, he can live independently. Cancer is a trial in my life, but I am sure there is a way out. I like to share my experience with patients and friends who also have positive attitudes towards the illness. I've learnt to accept reality, even though my cancer can't be cured. As long as I can maintain my quality of life and be with people I love, I feel less pain than yesterday, and I'm grateful.

Living in the moment.

I keep myself busy everyday. When I wake up in the morning, I go for a morning walk so I can be near nature, the flowers, and the trees, and to have some fresh air. In the afternoon, I usually go home to do some paperwork. I'm thankful for each day I have.

Believing that suffering has an end and a limit.

If I can take a step forward from suffering, then it will be a step to hope. Though I am still suffering, it's not endless suffering. It has an end. It has its time limit and also the amount of suffering is limited.

Looking at life from the whole life perspective.

I'm already very satisfied with what I have; I have a nice family with three good children. My job has given me a lot of satisfaction, and I'm happy with what I have achieved.

Setting alternate goals. When patients found it would be difficult to influence the course of the illness, they became concerned with having better health and fewer day-to-day problems: "What I'm most concerned about are my children. I'm looking forward to my son's graduation and his return home from overseas."

Downward comparison. Participants make downward comparisons with patients who have similar disease situations. By comparing themselves with others who are worse off than they are, they diminish their feelings of victimization and enhance their self-esteem and sense of protection. One participant said: "I already feel that I'm very lucky. I have relatives who accompany me to see the doctors. Some of my patient friends have conditions that are worse than mine."

The empowerment process is a self-empowering process and one that is facilitated by others. When participants found that they could not change their situations, they realized that they still had the choice to change how they perceived their situations, attitudes, and thoughts.

The Relational Context

An essential context of the strengthening process is the relationship patients have with families, other patient friends, and health care professionals. Relational support includes relational qualities of nurturance, reassurance of worth, sense of reliable alliance, and support from a caring person. One patient said:

My siblings, relatives, and friends often rang me up and told me stories of how people had successfully coped with cancer. My wife always expressed her concern by cooking nutritious food for me every day and escorting me to see the doctor. Support and comfort from others is of utmost importance.

Besides families and friends who support the patients, health professionals were also reported as important resources in their coping with cancer. The characteristics of health care professionals that patients perceived as empowering included showing caring attitudes, delivering expert information, demonstrating kindness, being approachable, and being cheerful. Patients' sense of being in control was enhanced when they knew that health professionals were there to help. Health care professionals empowered patients by taking time to talk to them, answering questions, offering helpful information, and listening. Patients wanted to know that health care professionals were doing what they could to help and that they had a genuine interest in them as individuals. As a result, there was mutual trust, respect, genuineness, and open communication between patients and health care professionals. Health care professionals decreased their power by communicating poorly, or being disrespectful, or cold. Patients' sense of power is contingent not simply on their own behavior but on what others did and how others responded.

When I was being treated just like a thing, an object, I was told to do this or do that. I felt I was being treated like a case, a number. When a person is in a depressed state, they are very vulnerable. You feel much better if health professionals show their encouragement and concern, and when they ask you questions related to reactions to the treatment. They told me they were available to help me. On the other hand, when you're just being treated like a case, you feel more depressed and powerless.

Patients in the study commented that doctors were professional people, and that they preferred to comply with treatment. Although they were aware that they had choices, they thought it was best to trust the doctor's decision as being the right one. Patients appreciated being told about changes in the illness, in a collaborative talk between patient and doctor. Seeking mastery over an illness depends not so much on decisional control being made available but rather by allowing the patient to control the degree to which he or she is able to participate in decision making:

The doctor asked me whether I should continue to have chemotherapy. Though he has given me a choice, I listen to his advice, as he is the expert. Nevertheless, I appreciate that he's kept me informed of the treatment and progress.

Patients were empowered by the support that they have received from health care professionals. Information about the disease, treatment plans for care, and future projections were important to them. They felt empowered when they were given choices and were respected as partners in the decision-making process.

Patients' feelings of strength did not operate in a vacuum but instead were facilitated by the caring relationship and the resources they obtained through the environment. Results of this study show that the interpersonal component is of utmost importance to participants. The relationship participants had with others formed a powerful resource and source of strength.

Cultural and Personal Beliefs

Another important feature of empowerment is rooted in individuals' cultural and personal beliefs. Cultural beliefs of Taoism and Buddhism affected the patients' personal beliefs. These were reflected in quotes, such as "Let nature take its course," and "*Tien Yi*," "God has a reason," and "I have to let go." Taoism sees the universe and all living things in it as manifestations of a unifying force called "Dao," which includes virtue, goodness, and moral excellence. Because mankind is an inseparable part of the cosmos, which has its own Dao or cosmic evolutionary course, believers seek to be in harmony with the universe. With these beliefs, patients have an explanation of the illness that it is part of life.

Participants' cultural beliefs helped them to create meaning, including their belief in a power beyond themselves, a life after death, destiny, and the grandness of nature. Acceptance of their illness helped participants to let go

of things they could not control and to set priorities that were within their reach.

DISCUSSION

These findings indicate that empowerment is contextually specific. Empowerment of cancer patients comprises facilitation by others, as well as self-empowerment. Three main processes of empowerment can be identified as a motivational process, a process of seeking mastery, and a process of transformation of thoughts. The outcomes result in finding meaning in life, having knowledge and skills, as well as accepting the illness. Empowerment of cancer patients is more than giving them control or choice, or giving them resources such as knowledge and skills. The concepts of empowerment that emerged from this study are consistent with other models (Falk-Rafael, 2001; Freire, 1973). Similar concepts include the requirement of active participation by those becoming empowered, the importance of relationships in the process, and focusing on enabling others to increase mastery over their own health.

Illness also prompts patients to find meaning in life, which gives them the power to continue. For nurses, one goal of care is to encourage patients' search for and experience of meaning. The search for meaning is a basic human need (Frankl, 1985). Finding meaning in an illness and in life fosters positive coping and increases patients' hopefulness. Nurses can assist patients and families in finding meaning through identification and modification of short- and long-term goals, which provide hope.

The cultural beliefs of *tien-yi* (God or supernatural has a reason), letting go, and harmony with the universe became an internal resource for participants. Lee (1995) explained that Chinese continual belief in supernatural explanations of life's vicissitudes helps to defend a person's ego, and his or her social network. It provides the individual with ready and convincing answers to all kinds of vicissitudes in life. Whatever happens, he or she can simply attribute it to a reason, which is beyond human understanding. Because an external invisible force beyond people's control is the cause, the individual does not need to blame oneself or others for the occurrence of any unfortunate events. It is also believed the situation will not be forever, that the individual has to look for ways to become better, therefore revealing an

element of activism. It is a combination of self-directed approaches to changing conditions and fatalistic acceptance of the “way things are.”

The belief of “letting go” also helps to dissolve suffering. Another common belief among the participants is harmony with universe. Man follows Nature, and in doing so he is not eliminated, but instead, his nature is fulfilled. Embedded within all these concepts is the idea that although an event such as cancer may appear to be undesirable, it is part of a much larger, meaningful process. By interacting with the event, no matter how destructive the force might seem to be, its energy augments the patients’ own energy and enhances their power in the situation. It is similar to Newman’s (1986) concept that life is an ongoing process of expanding consciousness. Participants tried to accommodate existing realities by changing their self-expectations, wishes, goals, perceptions, attitudes, interpretations, and attributions.

The cornerstone of interventions on the level of transformation of thoughts is remarkably similar to the findings of Falk-Rafael (2001) on the primary importance of increasing awareness. It is important to understand the tenuous nature of confronting the ultimate course of illness. Often, patients must carefully balance the sobering realities of cancer against mitigating the threatening nature of the illness. Transformation of thoughts marks the most significant difference between this model and others. In cancer, when the situation was objectively uncontrollable, patients used different strategies to empower themselves. These included accepting the reality of the illness, setting alternate goals, and reinterpreting the illness, which is explained by Rothbaum, Weisz, and Snyder (1982) as secondary control. Some of the empowerment strategies found in this study support Gray and Doan’s (1990) suggestions, for example, those of meeting patient needs for information and participation in decision making, and using alternative therapies. Because conscious awareness, acceptance of reality, and transformation of thoughts are major dynamics in the empowering process it is important for nurses to match therapeutic interventions to facilitate patients’ empowerment.

Factors that impaired patients’ sense of strength and confidence were isolation, lack of information, and a feeling of being deserted or being a victim of circumstances. Not being recognized as a complete person was viewed as humiliating and increased feelings of loneliness. Empowerment is integral to patients’ daily activities, existence, and growth. More than mere control, empowerment encompasses self-transformation and the transformation of relationships with others.

CONCLUSION

This study adds patients' perspectives of empowerment to other perceptions of the concept of empowerment. Although limited by the small number of participants, their perspectives add richness and existential meaning to abstract conceptualizations. Some Chinese cultural beliefs become important protective resources in the empowering process. Empowerment consists of dimensions of active, participatory processes as well as a process of conscious awareness of accepting and achieving harmony with oneself and the illness.

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