Evaluating the Self-Care Agency of Patients Receiving Outpatient Chemotherapy

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Dramatic advances have been made in cancer treatment in recent years, enabling patients to leave the hospital more quickly and stay home while still undergoing treatment. As a result, the percentage of outpatients has been on the rise. Healthcare providers engaged in actual outpatient treatment, however, spend so much energy implementing daily procedures safely that they have little time remaining to provide patient education or carry out any other systematic patient support programs. Although self-care generally is believed to be what people do to help themselves, differences exist between Western countries and Japan in the interpretation of self-care. In Japan, obtaining necessary support from the family and friends that one relies on also is viewed as essential. Patients’ self-care agency must be assessed if nurses are to make the most of patients’ abilities; however, evaluation criteria for that purpose have yet to be established. Development of a method for evaluating the self-care agency of patients receiving chemotherapy on an outpatient basis is needed to ensure further advancement in this area of nursing.

Some studies concerning patients’ self-care use Orem’s theory, which revolves around a person-centered model in which the nurse identifies the patient’s self-care needs and then works as collaboratively as possible with that patient to meet those needs, to clarify the links between patients’ self-care behavior and their health conditions (Orem, 1991). A questionnaire concerning patients’ self-care agency and health conditions, prepared by Honjo (2000) on the basis of Orem’s theory, targeted middle-aged patients suffering from chronic illnesses and revealed links between patients’ self-care agency and their health conditions. Although the questionnaire was not designed specifically for outpatient chemotherapy, the factor most strongly related to self-care agency was a sense of fulfillment. That suggests a need to incorporate a sense of fulfillment in patients’ self-care actions to ensure continuous health management. Education programs also are available that encourage patients to take self-care actions in response to side effects of chemotherapy. For instance, a care package is available that provides patients with basic knowledge and information concerning the side effects of chemotherapy and techniques to cope with them, in addition to providing a nurses’ telephone counseling service (Larson et al., 1998). In Larson et al. (1998), mouth inflammation and other side effects showed signs of improvement with use of such education programs.

In Western countries, several questionnaires have been formulated to assess patients’ self-care agency, including the Perceived Self-Care Agency Questionnaire (Hanson & Bickel, 1985), Denyes Self-Care Agency Instrument (Denyes, 1982), Appraisal of Self-Care Agency (Evers, Isenberg, Philipsen, Senten, ...
Japan also has seen the development of several criteria designed to evaluate patients’ self-care agency, including a questionnaire to assess the self-care agency of patients suffering from chronic illnesses (Honjo, 1997, 2001). Honjo (2001) indicated that the criteria nurses tend to refer to when evaluating patients’ self-care agency include the patients’ words expressing their willingness to take care of themselves, their ability to track changes in their physical condition, and their ability to use effective support programs.

Chen (1996), among other earlier studies on self-care, illustrated that a relatively strong relationship exists between patient self-care agency and well-being. In addition, according to Anson et al. (1996), a weak link exists between self-care agency and health. On one hand, these articles suggest that, in leading a normal daily life while receiving outpatient chemotherapy, patients need to be able to manage their condition by making the most of their self-care agency. On the other hand, the research also indicates that sufficient studies have yet to be conducted with respect to the criteria nurses can use to assess the self-care agency of patients receiving chemotherapy on an outpatient basis.

**Methods**

**Participants**

Seventeen nurses involved in outpatient chemotherapy who agreed to participate in the study were interviewed in three focus groups. The nurses in two interview focus groups were working in a cancer center in Japan, whereas the nurses in the other focus group were working in an academic medical center in Japan from July 2004 to October 2004 (see Table 1). The study was conducted with the consent of the Academic Ethics Committee in the College of Nursing Art and Science at Hyogo University in Japan.

**Procedure**

The researchers spoke with 3–9 nurses in each interview using an interview guide. The authors conducted the interviews on the unit of three hospitals. Interviews lasted an average of 60–90 minutes and were tape-recorded and transcribed verbatim. Examples of question topics included cases that indicated high self-care agency on the part of patients receiving chemotherapy, cases that indicated limited self-care agency, factors that the interviewees believed were related to self-care agency, and matters on which the interviewees placed importance when providing day-to-day nursing care to patients receiving chemotherapy on an outpatient basis. The authors interviewed each nurse about one or two cases where the nurse had evaluated a patient’s self-care agency to be high or low.

**Data Analysis Strategies**

Data obtained from the focus groups were analyzed in five stages by using the constant comparative method (Glaser & Strauss, 1967) and naturalistic inquiry (Lincoln & Guba, 1985). The five stages were (a) identifying basic information, (b) classifying information into units, (c) organizing information units into categories, (d) defining categories, and (e) identifying themes and applying relevant theories. In the third stage, by paying close attention to the intentions of comments and implications of remarks made by nurses in evaluating patient self-care agency, the researchers identified several interrelated factors and named these categories. In stage four, those identified factors were organized into the categories and the components of the criteria for evaluating self-care agency were defined. With the aim of enhancing the validity of the results of the current study, several cancer experts were involved in the interviews and analyses to minimize prejudice or preconception.

**Results**

**Participants**

The average number of years of experience of the nurses at the three hospitals was 15.8 (SD = 4.8, range = 7–26). The nurses had been involved in chemotherapy for an average of 8.4 years (SD = 5.5, range = 1–21).

As a result of qualitative analysis of the interview results, 3 domains, 10 categories, and 53 subcategories were extracted (see Table 2). The three domains were “basis of self-care” (Domain 1), “directly relating to self-care behavior” (Domain 2), and “ability to put one’s knowledge into action” (Domain 3). Figure 1 shows a tentatively structured image of the self-care agency of patients receiving chemotherapy on an outpatient basis classified into those domains. In Domain 1, nurses assess self-care agency based on the patient’s physical condition and the social support networks available to the patient. In Domain 2, self-care agencies are evaluated on the basis of the patient’s cognitive ability and coping styles. In Domain 3, self-care agency is determined through the observation of patients’ ability to develop relations with healthcare providers, accommodate the environment to their needs and conditions, and make use of information.

**Basis of Self-Care**

At first, nurses assessed self-care agency based on patients’ physical conditions and the social support networks available to the patients. Basis of self-care was classified as engagement in social activities, physical condition, and family relationship.

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**Table 1. Characteristics of Cooperating Hospitals**

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>HOSPITAL</th>
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<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Total beds</td>
<td>400</td>
</tr>
<tr>
<td>Daily average outpatients</td>
<td>730</td>
</tr>
<tr>
<td>Daily average outpatients on chemotherapy</td>
<td>35</td>
</tr>
<tr>
<td>Nurses in entire hospital</td>
<td>364</td>
</tr>
<tr>
<td>Nurses in outpatient chemotherapy unit</td>
<td>• Full-time</td>
</tr>
<tr>
<td></td>
<td>• Part-time</td>
</tr>
</tbody>
</table>

Note. The establishing entities for hospitals A and C were cancer hospitals; hospital B was a university hospital.
Table 2. Criteria for Evaluating Self-Care Agency of the Three Domains

<table>
<thead>
<tr>
<th>DOMAIN AND CATEGORY</th>
<th>SUBCATEGORY</th>
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<tbody>
<tr>
<td>Basis of self-care</td>
<td>• Engagement in social activities</td>
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<tr>
<td></td>
<td>• Physical condition</td>
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<td></td>
<td>• Family relationship</td>
</tr>
<tr>
<td>Directly relating to self-care behavior</td>
<td>• Ability to monitor and control one’s body</td>
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<td></td>
<td>• Ability to understand</td>
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<tr>
<td></td>
<td>• Communication skills</td>
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<tr>
<td>Ability to put one’s knowledge into action</td>
<td>• Ability to develop patient-nurse relationship</td>
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<td></td>
<td>• Ability to coordinate treatment and personal life</td>
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<td>• Ability to use information</td>
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**Engagement in social activities:** Data were collected concerning patients’ participation in society through jobs and hobbies. From the data obtained, two subcategories (have social role and have one’s own lifestyle) were extracted. The findings indicated that changes in social roles affect self-care agency and, therefore, serve as an important criterion in assessing patients’ ability to care for themselves. Having a job, however, does not always mean that the patient has strong self-care agency. More important in evaluating the patient’s self-care agency is whether the patient is coordinating work and life appropriately, or is experiencing any major transition in his or her social role, such as retirement from work or a job change. Nurses also felt the self-care agency of patients with individual lifestyles were high. They believed that patients with their own lifestyles were better able to express their wishes relating to various changes that might occur in the process of treatment.

**Physical condition:** Physical condition affects matters relating to specific symptoms and the stage of illness in three subcategories: symptoms controlled, have physical strength, and illness condition stable. The nurses viewed patients’ physical condition, represented by such objective factors as symptoms, disease stage, and physical strength, as effective criteria for evaluating patients’ self-care agency.

**Family relationship:** With regard to family relationship, interviewees’ comments concerning family members’ presence, intentions, and level of understanding were recorded. Five subcategories were identified: family is interested in patient, family is not defensive, family supports patient, family is understanding, and family takes care of patient. Those subcategories indicate that, when checking the patient’s self-care agency through the family relationship, nurses must pay attention to whether family members look after the patient or show interest in the patient’s illness. Those factors are believed to affect patients’ self-care agency. Moderate family intervention also is important; nurses, therefore, judge patients’ self-care agency after ensuring that such agency is not undermined by family intervention. Nurses must examine the patient’s self-care agency by making sure that the family is not preventing the patient from exerting self-care agency and that the family understands what is necessary to support the patient’s self-care behavior and act on it. In any case, nurses tend to evaluate the agency of the patient and family simultaneously, and regard the agency of the patient and family collectively as the patient’s self-care agency.

**Directly Relating to Self-Care Behavior**

Second, nurses assessed self-care agency based on the patient’s cognitive and coping abilities. Categories directly relating to self-care behavior were classified as attitude toward the illness, ability to monitor and control one’s body, ability to understand, and communication skills.

**Attitude toward the illness:** This category is based on observations relating to how the patient handles the illness and emotional changes and how the patient faces reality. Eight subcategories were extracted: have something to live for, fight the illness to live up to the expectations of...
those around, have will, able to face changes in one’s feelings, able to confront reality, emotionally stable, have a willingness to fight the illness, and ready to accept the illness. In those subcategories, nurses referred to the patient’s reactions to the illness and its development as a means of evaluating the self-care agency. In particular, “fight the illness to live up to the expectations of those around” reflects cases in which the patients themselves are not very willing to continue treatment because of severe side effects, but agree to receive treatment so as to accommodate their families’ wishes to have them live as long as possible. One respondent commented, “I had a patient who told me, when his family was not around, ‘I really don’t want to have any treatment at all, but I think I should do so for the sake of my family.’" In that case, the strong wish of the family encouraged the patient to continue receiving treatment. In response to that patient, the nurse confirmed the intention of the patient and his family regarding the continuation of chemotherapy, and facilitated their communication with the doctor. The process revealed that patients who are able to take their families’ wishes and desires into consideration have high self-care agency.

**Ability to monitor and control one’s body:** This category contains matters relating to how interested patients are in their bodies and how able they are to monitor and control its physical condition while on chemotherapy. Eight subcategories were identified: able to follow instructions, able to monitor one’s body, able to pay attention to one’s body, work creatively to keep records, continue treatment, make proper judgment, associate physical condition with daily life, and grasp the conditions of one’s illness. Those subcategories constitute a set of criteria to which nurses refer when assessing patients’ self-care agency.

**Ability to understand:** This category is based on comments about how patients undergoing chemotherapy understand information provided by nurses. From this category, seven subcategories were extracted: able to understand what has been said, limits of treatment, purpose of treatment, treatment procedures, treatment priorities, treatment risks, and able to ask necessary questions. In particular, “able to understand treatment risks” refers to a patient who, when told by the nurse, “I’m afraid that chemotherapy with this drug will cause hair loss, so your hair may start falling out from the second round,” responded by saying “That means I’m going to start losing my hair maybe around such-and-such a time.” According to nurses, patients’ responses to nurses’ explanations reveal how well the patients understood the risks of certain treatment and how able they are to take care of themselves. One respondent said,

> I warned a patient about the risk of leakage from the IV tube, but he looked kind of vague and uncertain. I thought maybe I should not give too much information all at once. So I decided to tell him only what is immediately necessary, leaving other things for the next time.

In that way, the nurse told patients about possible side effects in two or three steps at separate times, assessing from their responses the extent to which they had understood her explanations.

**Communication skills:** This category concerns the patient’s ability to respond during conversation at hospital. Four subcategories were extracted: willing to listen, has no communication impairments, able to ask for necessary assistance, and able to answer questions properly. When assessing a patient’s self-care agency, nurses base their judgment not only on whether the patient has sufficient speaking faculties and no communication impairments, but also on whether the patient is able and willing to listen. The patient’s self-care agency also is examined regarding the ability to speak in a coherent and to-the-point manner.

**Ability to Put One’s Knowledge Into Action**

Third, nurses assessed self-care agency based on the more complex ability to put one’s knowledge into action, classified as ability to develop patient-nurse relationship, ability to coordinate treatment and personal life, and ability to use information.

**Ability to develop patient-nurse relationship:** This category is based on observations regarding the patient’s ability to build relations with medical experts. Three subcategories were extracted: able to express oneself, have trust-based relationship with healthcare providers, and able to ask for assistance in a tactful manner. Those subcategories illustrate that outpatient nurses judge patients’ self-care agency by assessing how well they build relationships with healthcare providers. Nurses also determine whether patients can express themselves effectively so that they can develop better relations with the medical staff, and carefully monitor whether that relationship is working well. Patients who are successful in building a firm trust-based relationship with healthcare providers are viewed as being capable of taking care of themselves.

**Ability to coordinate treatment and personal life:** This category concerns matters relating to the kinds of adjustments patients have to make in their personal lives if they are to continue receiving chemotherapy, and their ability to make such adjustments. Eight subcategories were extracted: able to coordinate treatment schedule, able to coordinate work schedule, set goals of treatment, make use of human resources, manage one’s daily life, manage one’s physical condition, ask for necessary care, and incorporate self-care rules into daily life. In particular, “set goals of treatment” represents a story about a patient who predicted when she’d lose her hair based on previous experience with chemotherapy.
Having been told that the same type of drug was going to be used in the upcoming course, the patient refused treatment because she wanted to avoid hair loss at the time of a sports festival at her child’s school. She did not want to attend the festival with a wig on her head.

As that example shows, some patients, based on their past experiences of chemotherapy, can adjust treatment timing with events in daily life. Patients who can set mid-term goals in their treatment plan are regarded by nurses as having high self-care agency.

**Ability to use information:** This category concerns how patients obtain information about chemotherapy and how they digest the information they have acquired. Five subcategories were extracted: put together obtained information, make use of obtained information, exchange information with other patients, obtain information in selective manner, and eager to learn. Those subcategories revealed that patients are regarded as having higher self-care agency not when they have a lot of information, but when they are able to collect and organize necessary information and make use of it in actual situations.

**Discussion**

The authors conducted three focus groups with 17 outpatient chemotherapy nurses to explore the concept of self-care agency in patients with cancer. As a result, 10 aspects of self-care agency were extracted: engagement in social activities, physical condition, family relationship, attitude toward the illness, ability to monitor and control one’s body, ability to understand, communication skills, ability to develop patient-nurse relationship, ability to coordinate treatment and personal life, and ability to use information. Honjo (2001) conducted a study concerning indicators for the evaluation of self-care agency of patients suffering from chronic illnesses. The study identified six components: level of physical functions and level of cognition, interest in health management, ability to choose, ability to coordinate one’s life by taking into consideration one’s strengths and weaknesses, ability to find and follow through with the health management method that matches one’s lifestyle, and ability to effectively use assistance (Honjo, 2001). Comparison of those items with the categories identified in the current study shows that the ability to coordinate the environment is described as “ability to coordinate treatment and personal life” for patients on outpatient chemotherapy and as “ability to coordinate one’s life by taking into consideration one’s strengths and weaknesses” for chronically ill patients. In the case of chronic disease, patients are likely to derive, through their experiences of long-term treatment, their own unique ways of coping with illness and to become stronger from facing a cancer. Major differences are suspected in the nature of experience between chronically ill patients who are able to lead relatively healthy lives by controlling their conditions and patients with cancer who are obliged to coordinate their lifestyles to cope with their physical condition, which can change in a relatively short period of time.

Nurses would like patients receiving chemotherapy on an outpatient basis to practice self-care agency by being sufficiently assertive and proactive to act on their own initiative. Nurses also expect patients, instead of passively following instructions given by healthcare providers, to have self-care agencies of the kind that enable them to develop interactive communication with the medical staff so that they eventually can work out their own ways of caring for themselves. Nurses also regard patients’ ability to face the limitations of their treatments and the conditions of their illnesses as part of their self-care agencies. That demonstrates nurses’ desire to see patients live with the reality of cancer treatment. Because nurses feel that patients’ attitudes toward treatment were affected largely by their way of living, nurses tend to depict, without identifying specific links between the two sets of attributes, patients with high self-care agencies as having a specific role in society or their own distinctive ways of living. Nurses identify those attributes, which do not directly concern treatment per se, as important factors affecting patients’ self-care agencies.

In assessing patients’ self-care agency, nurses also take into account any decline in patients’ physical functions resulting from damages that accompany cancer treatment. That indicates that nurses are strongly aware of the fact that patients need to have a certain level of physical strength and power of concentration, supported by physical well-being and the successful management of symptoms, for them to exercise their self-care agency.

Generally, the pattern of human relations of Western countries and Japan is oriented toward the value notions of “separateness” and “connectedness,” respectively. Western societies make relevant sacrifices to attain “separateness.” On the other hand, the Japanese people sacrifice separation to attain “connectedness” (Colman, 1986). Emphasis is put on the relevance of the family and other individuals in the workplace more so than the individuals’ independence and autonomy. The Japanese people take relations between families seriously, and reductionism divides things so that it may be seen by Western culture in the mind and body dualism, which it tries to understand. Generally, a person should be separated fundamentally from the environment and other human beings.

A healthy family is one where the members stand on their own feet independently. Those points are combined with the bigger system—such as the general idea of positive and negative in Taoism and the recognition to make an original figure—is in the bottom in Japan. As a result, families are regarded as playing a major role in patients’ self-care agency. Even if patients have lower self-care agency, nurses view them as sufficiently capable of self-care as long as their family is interested in and committed to their treatment.

The focus of this research was patient self-care agency; therefore, investigating the influence that family support gives to patients’ self-care agencies is important. In addition, when an evaluation tool of self-care agency is developed, researchers must take into consideration the family’s support.

**Implications for Nursing Practice and Research**

Self-care generally is believed to be what one does to help oneself. However, differences exist between Western countries and Japan in the interpretation of self-care. In Japan, doing everything on one’s own is not the only requirement of self-care; obtaining necessary support from the family and friends that...
one relies on also is viewed as essential. Taking the cultural background unique to the country into consideration, therefore, is important when evaluating patient self-care agency. That also will lead researchers to think about how to take into account the family’s ability when developing self-care agency evaluation tools in the future. When the self-care agency of patients with cancer undergoing chemotherapy is evaluated, nurses must examine the degree of family relationship in cases with Japanese patients. In the future, educators in the field of oncology nursing will make use of that point of view for the cancer nursing education and the development of the self-care agency assessment tool.

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References


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