



## The Power of nursing: Guiding patients through a journey of uncertainty



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### A B S T R A C T

#### Keywords:

Nursing care  
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Care coordination  
Nurse–patient relation  
Patient counseling  
Cancer trajectory

**Purpose:** The objective of this qualitative study was to understand the experiences of oncology nurses in patient counseling and support services in the ambulatory care setting.

**Methods and sample:** A qualitative study was conducted using grounded theory methods. Data were generated through four focus group interviews with 21 oncology nurses currently providing counseling and support services for cancer patients in Japan. The content was analyzed based on a constant comparison approach.

**Results:** The power of nursing was identified through three themes: connecting with the patient (shared needs); personalized coordination (shared action); and realizing the patient's potential (reassurance). Oncology nurses should guide patients through the uncertain cancer trajectory by identifying patients' true needs based on an established relationship, providing personalized coordination, and developing their potential. Patient-centered care can be provided in non-physical care settings such as counseling and support services.

**Conclusions:** Our study describes the uniqueness and significance of nursing, and provides insights into realizing the full potential of nurses. This conceptual model can be used as a guide for practice and an educational tool to build professional identity of nurses. Oncology nurses can take a leadership role in enhancing the visibility of the nurses in multidisciplinary environments.

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### Introduction

Cancer patients take a long journey from diagnosis to treatment and beyond. Since cancer affects not only the body but also the psychological and social status of the patient (Markides, 2011) in myriad ways, there is no single path taken by all cancer patients. The journey is shared between the patient and healthcare professionals, and nurses can provide both care and support to patients throughout their journey (Legg, 2011).

Modern healthcare systems are shifting toward a more patient-centered approach (Pelzang et al., 2010; Jayadevappa and Chhatre, 2011), which is organized around the patient's needs, values, and preferences. In the patient-centered approach, patients are actively involved in their care (Barry and Edgman-Levitan, 2012). The

concept of nursing demands that nurses understand the fundamental needs of patients so that nurses can help their patients make their lives as normal and productive as possible (Henderson, 2006). The patient–nurse relationship forms the basis for nursing practice, and non-technical skills or affective aspects of care are important, as well as technical skills and the physical aspects of nursing care (Zamanzadeh et al., 2010). A partnership in nursing care is an essential part of patient-centered care, in which patients and nurses work together on decisions about daily life and care (Kvåle and Bondevik, 2008).

Despite the importance of nursing, the nursing presence is increasingly invisible to the patients and to other disciplines (Yagasaki and Komatsu, 2013). The complexity of healthcare systems increases the distance between patients and nurses. In addition, the importance of the oncology nurse's role in multidisciplinary teams is waning (Boyle, 2010). There are discrepancies of multidisciplinary awareness of other healthcare professionals' roles, and the nurse's role is consistently “unseen” among other health professionals (Jenkins et al., 2001).

In Japan, while a greater weight has been placed on diagnosis and treatment in oncology, little psychosocial support is offered

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in routine practice. Accredited cancer treatment facilities (397 accredited cancer treatment facilities as of January 2013) are required to provide patient counseling and support services by trained professionals including nurses and social workers (Ministry of Health, Labour and Welfare, 2008). There is great variation in the psychosocial support of patients in practice in Japan, and assistance in decision-making, psychosocial support and care coordination are commonly provided by exclusive staff separately from routine clinical practice.

With the expansion of these support services to various clinical settings including outpatient clinics and ambulatory chemotherapy centers, a question was posed for oncology nurses: What would be the significance of having oncology nurses provide patient counseling and support services rather than having other healthcare professionals do so? To address this question by making the significance of nursing explicit, we conducted a qualitative study to understand the experiences of oncology nurses in counseling and support services for cancer patients.

## Methods

### Design

A qualitative study design was used to understand the experiences of oncology nurses in counseling and support services for cancer patients in ambulatory settings. Using a grounded theory approach, we conducted focus group interviews. The grounded theory approach is focused on social processes and generates a theory that is grounded in the realities of the participants' daily-life experiences (Strauss and Cobin, 1990).

A focus group interview helps research participants explore the issues of importance to them in their own vocabulary. Interactions between participants help to identify group norms and cultural values, and group dynamics often address themes that the researchers may not have anticipated (Kitzinger, 1995).

### Ethical considerations

This study was approved by the Internal Review Board of Keio University (No.205).

### Participants

Eligible participants were certified nurses (palliative care, pain care, chemotherapy, radiation oncology, and breast cancer care) and master-level certified nurse specialists; having nursing counseling and support service experience; and living in the greater Tokyo area.

### Recruitment

We conducted a purposive sampling from a list of certified oncology nurses in the Japanese Nursing Association between March 1, 2013 and April 19, 2013. We sent a letter explaining the research purpose, method, and interview venue and date, and a consent form to the eligible oncology nurses. Those who wished to participate in the study responded by a letter or e-mail. We ensured that participation was voluntary, that confidentiality was protected, and that there would be no consequences for refusing to take part in the study. Two focus group interviews were held, but we did not reach theoretical saturation, and we therefore recruited more nurses using the snowball technique. We obtained written informed consent from all participants.

### Data collection

A total of four focus group interviews were conducted in a rental meeting room in Tokyo from March to April, 2013. Each group consisted of four to five nurses. The lead author (HK) facilitated all focus group interviews using a semi-structured interview guide which was developed by the authors and covered areas of the participants' experience of counseling for cancer patients. The interview began with general questions about the nurses' background. Then, open-ended questions about their experiences with counseling and support services for all types of cancer patients and their perceived role were covered, and finally questions about the nurses' values and beliefs in nursing care were presented. Another author (KY) took field notes during the interview. The interview guide was adjusted to cover all the interest areas after the first focus group interview.

After two initial focus group interviews, the data did not reach saturation. We used theoretical sampling, and conducted two more interviews. Finally all researchers confirmed that the data reached saturation. The durations of the focus group interviews ranged from 90 to 110 min. All interviews were conducted in Japanese, tape-recorded, and transcribed verbatim. A professional translator translated the themes and quotations to English after the completion of identification of themes and quotations to support themes.

### Data analysis

The data were analyzed using grounded theory techniques (Strauss and Cobin, 1990). The focus group interviews were recorded, and transcribed verbatim. The data were analyzed in the following process. Line-by-line coding was conducted with a focus on the purpose of the research: What would be the significance of having oncology nurses provide patient counseling and support services. The data were reread, and the constant comparison method was used along properties and dimensions of categories, and then the meanings were labeled. Subcategories were derived from axial coding, and relating these subcategories led to categories. Categories were identified by relating subcategories. Finally, a core category was derived from relating all categories and subcategories as a selective coding. Regular meetings were held among the research team members to discuss the emerging categories and subcategories, and interpretation.

### Rigor

The rigor of the study was confirmed by credibility, dependability, confirmability, and transferability (Guba and Lincoln, 1994). For credibility and dependability, two researchers reviewed the data to determine whether they agreed with the codes and themes identified. We confirmed the data saturation after the fourth group interview. For confirmability, one of the researchers performed an analysis according to the Grounded Theory procedure (Strauss and Cobin, 1990), and another researcher confirmed the results. For transferability, we reviewed whether the results would be applicable to others in similar situations among the researchers.

## Findings

Of 30 nurses we approached for the first recruitment, 16 nurses agreed to participate in the study. We obtained data from five more nurses for the second interview by theoretical sampling. A total of 21 oncology nurses who worked for cancer centers, university hospitals or general hospitals participated in the study. The mean number of years of working experience at a counseling or support center was five years.

The power of nursing

The themes were developed, constructed, and emerged from the analysis of the data. The Fig. 1 describes a conceptual model of the power of nursing to guide patients across the cancer trajectory emerged as three phases: (1) connecting with the patient (shared needs); (2) personalized coordination (shared action); and (3) realizing the patient's potential (reassurance). These nurses' efforts had goals in the different phases. In the first phase, the nurses took special care of her patients to return to oneself. In the second phase, the nurses focused on the patient's life to empower the patient to regain control of his or her daily life. Finally, the nurses gave a particular attention to the patient's potential in the third phase that the patient would live his or her life. The oncology nurses established relationships with their patients and cared about what really mattered to the patients from the patients' perspectives. The nurses tailored their care to individual patients, and reassured them to move forward.

Connecting with the patient (shared needs)

The nurses made considerable efforts to connect with their patients in order to understand them. This typically began by oncology nurses' adoption of a "We care about you" attitude to show acceptance of their patients.

*First, I thank my patients for coming to me. I admire their strength to face their problems. I try to fully accept the patient, and share his or her suffering (Nurse 8).*

The participants said that cancer patients are often overwhelmed by their diagnoses or confused by the complexities of the health care system.

*Patients often say that they do not know what they should talk about, and they are overwhelmed (by the diagnosis of cancer) (Nurse 10).*

*Patients do not know where the best place for consultation is. In our hospital system, it is not easy for patients to use consultation services. So we try to accept any patients who have unmet needs and to coordinate care among disciplines (Nurse 11).*

Furthermore, it is not easy for patients to address their concerns to health care providers; thus, oncology nurses need to invest time in building a trusting relationship with their patients.

*If the patient is very confused, how to spend time together is important or sometimes I leave the patient alone by saying 'Could you stay here alone for just 20 or 30 seconds?'. (Nurse 11).*

*It is true that there are some patients whose minds become a complete blank. I tell them what the physician said but still they are very confused...I help them review the today's conversation with the physician and clarify their problems to tell (the physician) next time (Nurse 12).*

*I say, 'Take it easy. I will make time to talk to you.' I send them a message that I am prepared for (dealing with your problem). I can wait. I welcome you. If the patient is crying, I simply wait until the patient stops crying (Nurse 10).*

Other nurses emphasized the importance of the nurse's empathetic presence during difficult times.

*The patient may acknowledge 'Oh, the nurse is here for me.' I believe that sharing the same moment together is also important (Nurse 8).*

The nurses also tried to establish a professional distance between their patients and themselves. Some nurses said that it was like a psychological distance.

*I wonder about the current situation of my patient. I enter into the patient's world, but I don't drown in his or her emotional world. I maintain my objectivity. It does not sound like scientific at all, but I know there should be a comfortable distance between the patient and me. I may decide 'this distance is comfortable for this patient' based on the patient's response (Nurse 16).*

The oncology nurses not only listened to their patients, but also made an assessment to discover and share their patients' needs. The nurses heeded patients' values and wishes. Moreover, they insisted that attentive listening would not be sufficient to help their patients.

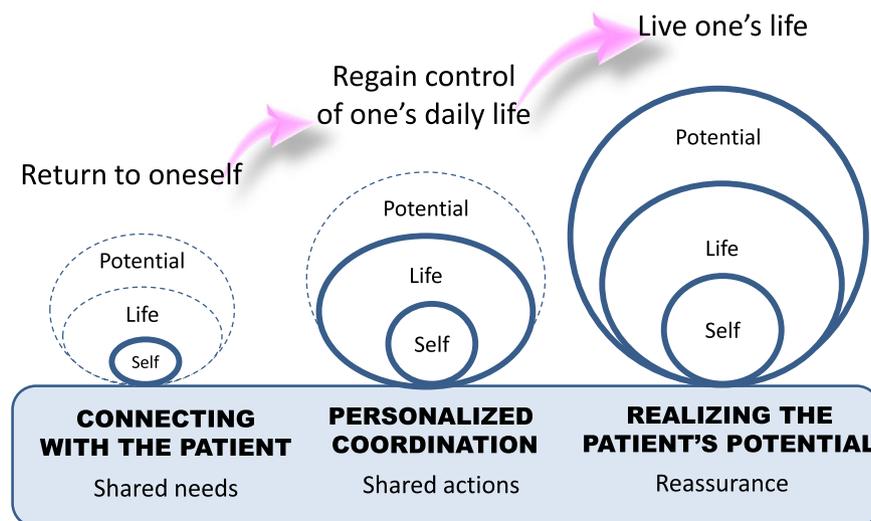


Fig. 1. The power of nursing: Guiding patients across the cancer trajectory.

*Just listening to the patient does not solve the problem. We need to find out the fundamental aspect of the problem, and clarify what the patient really wants while talking to the patient. That's, I believe, acceptance (Nurse 9).*

Another nurse said,

*I also agree that attentive listening is just the beginning. We need to know what patients want most. Otherwise, we cannot move further. So I ask them what they really want (Nurse 11).*

The nurses emphasized the importance of the assessment of the wholeness. The symptoms are not the entire picture, because the disease affects the patient's everyday life. Patients' needs include issues that extend beyond those directly related to their disease.

*Having a view of wholeness is unique to nursing. Nurses are good at it, and every nurse must do it regardless of their subspecialty. We should look not only at the disease, but also the family or social background, and find out what area we should focus on (Nurse 21).*

The nurses connected relevant information by asking questions about the patient's health, treatment, meals, sleeping, and working.

*I believe it is the nurse's advantage that we can perform a comprehensive assessment and imagine what is happening to the patient and the impacts of their disease and treatment on their personal and social lives (Nurse 16).*

The nurses looked at both the patient's treatment and daily-life activities, and carefully assessed the balance between them.

*Outpatients have everyday lives. Has their disease been disclosed at the workplace? Are they allowed to take sick leave? When they return to work, can they adjust (their schedules for treatment)? The nurse can assess whether this patient maintains a balance in his or her daily-life activities during outpatient treatment. It's the nurse who will think about that aspect. In ambulatory settings, we teach patients how to achieve a balance between treatment and daily-life activities (Nurse 19).*

The nurses also assessed the patient's comprehension in relation to their cultural backgrounds. One of the nurses said that she asked her patients about their values; "I ask the patient, 'What is really important to you?' (Nurse 14)" She added that understanding the patient's values and attitude toward cancer is useful.

*I always think about the patient's values. I try to fill the gaps between the patient's wishes and reality. That is very important (Nurse 6)."*

The nurse described the following perspective:

*The whole picture can emerge by assessment that is based on how the patient and family have lived so far (Nurse 12).*

The nurses acknowledged that it is a challenge to identify the patient's true needs. In fact, they took considerable time and energy to build trust with their patients and used their professional skills to elucidate the patient's needs.

*If the patient's real concern is identified, it is relatively easy to connect it (to possible solutions). However, identifying the real issue is very challenging (Nurse 9).*

*Personalized coordination (shared action)*

The discovery of any problem is the beginning to connect the patient with necessary care.

*The role of the nurse includes care coordination...We sort out the issues and connect one to another (Nurse 12).*

Another nurse said,

*We should focus on patients' real issues and navigate them to the right direction. We decide whether the patient's problem can be solved within our scope of practice or requires the next level of care (Nurse 15).*

Furthermore, the nurse connects the patient to appropriate professionals in a timely manner.

*Because patients live their lives with cancer, they often face various problems. Looking at the whole picture, we decide whether the patient needs advice from a social worker, dietician, or pharmacist at this point in time (Nurse 13).*

Anticipatory guidance is an important skill in nursing. The nurses said that they were able to anticipate what would probably happen to the patient, including the progression of the disease and its effects on family relationships. This skill helped them to prepare to implement the next nursing interventions. Furthermore, they provided advice on how to overcome challenges and they prioritized actions during the process of care, including psychological changes and work adjustments.

*We can predict the progression of the disease and the problems the patient will face in the near future so that we are prepared to intervene. I believe this is the strength of nursing. (Nurse 11).*

The nurses were able to appreciate the limitations of treatment. For example, when active treatment is no longer effective, the nurse coordinates the next step with the patient's perspective in mind using external resources such as home care or palliative care.

*We can see what is down the road for the patient. We may suggest home care or palliative care in consideration of the patient's values, family's behavior, place of care, and limitations of treatment. We can inform the patient of the advantages and disadvantages of the care setting options and assist the patient in making decisions (Nurse 15).*

The nurses encouraged the patients by saying: "I will support you while you cannot make up your mind (Nurse 14)." The nurses oversee the entire process, and personalized the coordination of care for individual patients. Based on individual situations, the nurses set goals and offered practical action plans. For example, the dietician's advice was important but the strict instructions often discouraged patients and their families.

*Nurses are more flexible to respond to individual patients (Nurse 18).*

The participants emphasized that it was important not to pursue perfection.

*If they are not confident about what they should do, I tell them, 'Not 100% but 10% may be good enough.' When I propose some actions to the patient, I look for the most practical one among the options (Nurse 18).*

Patients also need to restore a sense of order to their lives but they often lose their confidence. The nurses encouraged the patients' motivation to regain control of their daily lives. There was a general agreement among the participants that they tried to find something the patient could do to regain their strength and confidence.

*When I talk to the patients, I carefully explore what the patient is able to do. Frequently, we identify patients' strength after reviewing them one at a time together. A number of patients lose themselves in fighting against cancer. We review possibilities together; the moment the patients think of themselves as they are, how they can reset it, or what they can do to get back on their feet (Nurse 10).*

The nurses talked about the uniqueness of nursing in care coordination.

*We decide how to explain and provide suggestions to our patients by assessing their comprehension or readiness. Doing this is unique to nursing (Nurse 14).*

The oncology nurses recognize the professional responsibility involved in patient-care coordination, but felt that it was a rewarding assignment.

*We have a significant responsibility that comes along with it. However, it may be that only nurses can do it (Nurse 9).*

#### *Realizing the patient's potential (reassurance)*

The oncology nurses encouraged patients to move forward.

*I encourage the patient to take the next step (Nurse 15).*

The nurses praised patients when the patients told their physicians what they wanted to say, or when they successfully controlled their symptoms.

*I try to highlight the patient's strengths. I tell the patient This is great. You should continue to do it. I hope it gives the patient confidence and stimulates their motivation (Nurse 20).*

Although many patients tend to focus on their problems, the nurses tried to find something positive. The ultimate goal of nursing is to realize the patient's potential.

*My focus is not discovering the problem, but something more positive. I am searching for the patient's potential. I try to look at the same issue from a different perspective. Otherwise, I feel my limitations in cases of supporting terminal patients (Nurse 6).*

*I always try to encourage patients to feel confident about something, even a very small thing. Something positive, you know (Nurse 20).*

The focus may not be the best one, but rather the best possible one. Some patients cannot expect to be cured of cancer, but all the patients can seek ways to make their lives better. Furthermore, the patients may need the nurse's supportive presence to help them affirm their core values.

*As everybody said, patients are not only persons with illness. They want to have lives based on their own values. They want to live their lives fully. We should take this as important, and support them as they continue their treatment journey. I believe that this outlook*

*is central to the importance of our support services. Nurses are able to use resources, including the strengths of patients, family and friends (Nurse 18).*

One of the nurses described a norm of the patient–nurse relationship,

*Together (with the patient)...I follow their process, and I just want to say 'Go!' when the time comes. I wish to have a relationship with patients in which I give them a little supportive push to achieve what they have decided to do (Nurse 10).*

## **Discussion**

We explored the significance of nursing in patient counseling and support services in Japan, and the *raison d'être* of oncology nurses emerged as the power of nursing. We developed the conceptual model of the power of nursing from the results of the present study. In the model, oncology nurses guide cancer patients across the cancer trajectory with a special attention to the patient's self, life, and potential in different phases. The nurse always cares about what is important to the patient that leads to personalized care, and aims to realize the patient's potential because the ultimate goal is that the patients live their lives.

The relationship with the patient is central to the power base of individual nurses (Reid-Ponte et al., 2007), and the quality of the relationship can be therapeutic for the patient (Markides, 2011). It starts from nurses' readiness to connect with their patients by showing openness, acceptance, and a caring attitude. A good communicator can provide comfort to the patient and find connection with the patient in silence. In the present study, the oncology nurses showed their emphatic presence, while they were keeping a professional distance. Establishing a trustful relationship with the patient and identifying the patient's true needs are the most challenging tasks for nurses.

Patients' needs may be beyond those directly related to the illness (Lehto, 2011; Galway et al., 2012). Nursing coordination helps focus on what is important to the patient (Wiederholt et al., 2007), and nurses can play a critical role in influencing a patient's attitude toward cancer (O'Baugh et al., 2008). Nurses assist patients' decision-making for treatment but also help them navigate their everyday lives, because it is the nurses who care about the world the patients live in. Since every patient has his or her own needs, personalized coordination is essential. Individualization is pivotal to the patient-centered approach (Radwin et al., 2009).

Oncology nurses also encourage the patients to experience hope and reconciliation through the development of their potential. Larsson et al. (2007) reported that the encouragement and support given by the nurses motivated the patients to go on. In the present study, the oncology nurses' goals were to help the patients "find their way back," regain some balance in their daily lives, and ultimately realize their potential to live their lives. Sherman et al. (2012) describes "creating a new life" as a final phase in the process of breast cancer survivorship. Nurses encourage patients because they believe that patients can use their strengths even in difficult times.

Cancer patients live with uncertainty. Oncology nurses guide cancer patients on their individual journeys by anticipating the patients' needs, applying their experiences to new contexts, and dealing with uncertainty. In this context, the oncology nurses are considered reflective practitioners, reflecting on their intuitive knowledge in the midst of action to cope with the unique, uncertain, and conflicted situations (reflection-in-action) described

by Schön (1983). Experienced nurses are automatically reflective in practice, using the repertoire of examples, images, and understanding for an action plan and the improvement of skills for future events. Oncology nurses can appreciate the impact of the cancer treatment within the framework of the patient's entire cancer experiences (de Leeuw and Larsson, 2013), and ensure patient comprehension and decision-making, and contribute to patient satisfaction during the whole trajectory of care (Larsson et al., 2007).

The process identified in the present study is consistent with the attributes of patient-centered nursing care: caring attitude, individualizing patient care, and encouraging patient autonomy (Lusk and Fater, 2013). Oncology nurses provide patient-centered care even in non-physical care settings.

### Limitations

Several limitations of the study deserve mention. The participants in the present study were all experienced oncology nurses. This may have limited the extent to which our findings are generalizable to other nurses. Because of the nature of the focus group interview, the results may be influenced by the opinions of others.

### Implications for nursing

Cancer patients continue to need information and support during different phases of the cancer trajectory from treatment to survivorship (Knobf, 2013). The conceptual model of the power of nursing serves as a guide for nursing practice, and helps empower patients to manage consequences of the disease and develop their potential across the cancer trajectory. It also can be used as an educational tool to build the professional identity of competent and caring nurses. Oncology nurses should guide patients through the uncertain cancer trajectory by identifying patients' true needs based on the established relationship, providing personalized coordination, and developing their potential. Patient-centered care can be provided in non-physical care settings such as counseling and support services.

### Conclusions

The power of nursing was demonstrated as the unique abilities of nurses. Nursing should be consistently portrayed as an indispensable body of professional colleagues within cancer care (Boyle, 2010). The findings of the present study provide insights into realizing the full potential of nurses. Oncology nurses can take a leadership role in enhancing the visibility of the nurses in the multidisciplinary environment.

How patients re-establish themselves through relationships with nurses should be further studied. In addition, a future study should identify the effects of consultation and support services by nurses.

### Conflict of interest

None declared.

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