#### 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.

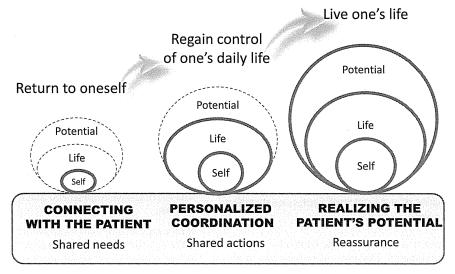


Fig. 1. The power of nursing: Guiding patients across the cancer trajectory.

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'etre* 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' 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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#### \* RESEARCH PAPER \*

# Are we ready for personalized cancer risk management? The view from breast-care providers

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Are we ready for personalized cancer risk management? The view from breast-care providers

Personalized medicine, the tailoring of prevention and treatment, is the future of routine clinical practice. This approach has started to appear in genetic testing for predisposition to hereditary breast and ovarian cancer (HBOC). We explored how breast-care providers perceived HBOC risk management, using grounded theory. This study found that the frontline healthcare providers perceived HBOC risk management as still being neglected in breast cancer care. Emerging challenges included treatment priority, hesitancy to deal with sensitive issues, easily missed risks, genetic data not being shared among multidisciplinary professionals, and patients being lost to follow-up. Oncology nurses are ideally placed to facilitate communication and utilization of genetic information among multidisciplinary professionals. Specialized outpatient clinics need to be established to follow up individuals at high risk. There is a need to create a system to meet the future demands of personalized medicine in nursing practice.

**Key words:** health-care team, hereditary breast and ovarian cancer syndrome, personal genetic information, personalized medicine, risk management.

#### INTRODUCTION

The next generation of care, particularly in cancer, is personalized medicine. The ultimate goal of personalized medicine is to identify individuals at risk for a disease and to tailor prevention strategies including diet, exercise, pharmacological management and frequent screening, as well as treatment based on each patient's genetic

information.<sup>1</sup> This paradigm shift from the traditional 'one-size-fits-all' therapy concept to personalized medicine is having an effect on current health-care systems. Genetics is no longer a specialist field,<sup>2</sup> and it influences nursing practice.<sup>3</sup> All health-care disciplines need to be prepared for the integration of genetics into routine care.<sup>4</sup>

This personalized approach has already started in certain areas, such as genetic testing for predisposition to common and uncommon diseases and pharmacogenomic testing for response to a given therapy. The most common such test is for the *BRCA1* and *BRCA2* mutation genes, which indicate a predisposition to hereditary breast and ovarian cancer (HBOC); this test has been available

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since 1996.<sup>6</sup> There are several options to manage cancer risks, including surveillance, prophylactic surgery and chemoprevention.<sup>7-9</sup>

Despite a small number of mutation-positive patients in Japan, genetic testing for HBOC is increasingly performed. Genetic testing has the potential to reduce cancer morbidity and mortality through targeted surveillance and management. Health-care providers need to respond to emerging demands for HBOC risk management by guiding recommendations for screening in consideration of psychological, social and ethical effects, helping the individual to understand the results of genetic testing and providing preventive care or early management of cancer based on individual values and preference. These efforts prevent, detect or manage cancer in its early stages, leading to better survival.

The need of HBOC risk management reflects concern over whether health-care systems are keeping pace with the speed of the changing demands derived from genetic testing. In general, there is a decade's delay in adaptation of new technologies to clinical practice. An underutilization of genetic testing and counselling services has been reported, and the integration of genetic testing into clinical practice is underresearched. Little is known about how health-care providers perceive cancer risk management based on genetic information.

In this study, we aimed to explore the recognition, implementation, and challenges of HBOC risk assessment and management from the perspective of breast-care providers and to explore the readiness for personalized cancer risk management at the level of clinical practice.

## METHODS Design

As organizational culture is created through interactions of individuals, symbolic interactionism proves a useful framework for analysing organizational culture because it focuses on individuals in social interactions.<sup>13</sup> In the present study, we employed grounded theory<sup>14</sup> using symbolic interactionism as a theoretical basis and conducted a focus group interview to understand the reality in personalized cancer risk management from the perspectives of health-care providers.

#### Recruitment

Multidisciplinary breast team members who were experienced in providing treatment and care to HBOC patients and who had attended meetings at breast centers of two

institutions (one general hospital and one university hospital) in Japan were invited to participate in this study. A letter of participation was given to those who agreed to participate in the study, and a signed consent form was returned by hand or fax to the investigator.

## **Participants**

Of the 20 health-care providers invited to participate, 17 (85%) agreed to be interviewed. One physician and two pharmacologists declined because of time constraints. Fifteen participants attended the first focus group interview. In keeping with grounded theory, a further theoretical sample of six participants was interviewed with aims to expand on existing data and to test the integrity and credibility of the developing analysis. We performed three focus group interviews with a total of 17 participants comprising seven breast specialists (oncologists/surgeons), five staff physicians, four nurses and one genetic counsellor. Of the 17 participants, four (three breast specialists and one nurse) were reinterviewed. The mean age of participants was 39.6 years.

#### Data collection

The study took place between October 2009 and December 2011. HK, one of the nurse researchers, took on the role of facilitator and conducted semistructured focus group interviews using an interview guide (Table 1). Questions addressed broad areas including the recognition, implementation and challenges of genetic testing, counselling and risk management. The duration of the focus groups ranged from 60 to 70 min. All interviews were audiotaped and transcribed verbatim. The facilitator recorded field notes from each interview.

## Data analysis

Constant comparison analysis was used to interpret the data. Open coding was achieved by deconstructing each interview sentence by sentence to generate the initial concepts. Data collection and analyses were interactive around the exploration of emergent categories. The concepts identified were reintegrated into categories. KY, one of the nurse researchers, performed all analyses. To assess the rigour of the study, KY discussed with HK the interpretation and modifiability of data and the theoretical saturation.

#### **Ethical considerations**

The study was approved by the Ethics Committee of St. Luke's College of Nursing prior to initiating the study

#### Table 1 Interview guide

- 1. How do health-care providers understand genetic testing and HBOC risk management, and provide treatment and care to individuals at risk based on genetic information?
- 2. What are the challenges in treatment and nursing for individuals at risk?
- 3. How does the system work in implementation, record keeping and data management of genetic testing and genetic counselling?
- 4. How are individuals at risk followed up based on genetic information/diagnosis in different treatment policies?
- 5. What are contextual factors in acceptance of and response to genetic testing/diagnosis and treatment/follow-up based on genetic information? How do these factors influence the individual and providers?

(No. 09-039). All participants were informed of the voluntary nature of the study and their right to decline to participate. Written informed consent for study participation was obtained accordingly.

#### **RESULTS**

The analysis presented a core finding that HBOC risk management is still neglected in breast cancer care. It comprised five challenges, supported by extracts from interviews drawn from the data set.

# Core finding: HBOC risk management is still neglected in breast cancer care

Despite the recognition of the benefits of genetic testing, breast-care providers perceived HBOC risk management as still being neglected in breast cancer care. Although genetic testing can provide critical clues to cancer prevention and control, such preventive or early management opportunities might be missed under the current system. The following challenges were identified.

Breast cancer treatment as the first priority
Although health-care providers perceived the importance of HBOC risk management, they concentrated on breast cancer treatment as the first priority because of limited available time and resources. Systemic barriers also emerged to the delivery of comprehensive personalized cancer risk management, and the participants perceived the need of a new system for individuals at risk for HBOC. Under the current health-care system in Japan, genetic counselling and testing for individuals with HBOC risk are conducted in genetics departments, but after disclosure of the results of genetic testing, risk management is conducted at the breast center. Although BRCA1 or BRCA2 mutation carriers and their families should be regularly screened for cancer prevention, health-care providers at

breast centers are too busy treating the disease, and there is little time left for HBOC risk management.

What we can do is use limited available time effectively (Participant C, breast specialist).

For us, treatment of breast cancer is the first priority. Even though we know that follow-up of individuals at high risk is important, it is a lower priority because of limited resources (Participant B, breast specialist).

We should have a specialized outpatient clinic for mutation-positive patients separate from the [routine breast cancer] follow-up system and take the patient's family history every time she visits. For example, if the patient's daughter reaches a certain age, we should provide her [genetic testing-based] advice at an outpatient clinic, for a while, at least if she is mutation-positive. But deciding who, where, when and how often is very difficult (Participant C, breast specialist).

Hesitancy to deal with sensitive issues
Owing to the complexity of HBOC genetic information,
health-care providers are hesitant to deal with sensitive
issues, and might not want the additional task of providing
gene-related advice.

If we find a mutation in one of our patients, we want her relatives to take the test as soon as possible. But it is a very sensitive issue because each family's situation is different (Participant R, genetic counselor).

Some patients do not want their families to know about their conditions. It is not easy to give the family members a telephone call (Participant F, breast specialist).

We should not put pressure on patients to undergo genetic testing. (Participant B, breast specialist).

Also, breast-care providers perceived difficulties in telling patients the diagnosis of breast cancer and warning about inherited disease predisposition genes at the same time.

[When I tell a patient the diagnosis of breast cancer] Because it [diagnosis of breast cancer] is a very serious issue, I may feel that it's better to tell her about it [genetic testing] after she has calmed down (Participant B, breast specialist).

#### Easily missed risks

Health-care providers perceived that mutation-positive patients would be easily missed in busy clinical practice.

Because physicians are too busy, some physicians may not have time to talk about it [HBOC] to the patient (Participant C, breast specialist).

We are preoccupied with day-to-day clinical demands (Participant C, breast specialist).

We don't know when mutation-positive patients will next come to the clinic (Participant N, nurse).

We can provide a genetic counselling service to individuals at risk, but when they return to routine [breast cancer] care, they become one of many patients (Participant O, nurse).

# Genetic data not being shared among multidisciplinary professionals

Owing to strict management of personal genetic information in terms of confidentiality, important results of genetic tests are often not shared among multidisciplinary professionals. Such information is limited to only a few professionals and is not conveyed to laboratory or healthcare providers in other departments such as gynaecology; thus, the patient is seen as a cancer patient without a hereditary predisposition.

It is up to the patient to decide whether to inform her relatives of the results of the genetic test. (Participant B, breast specialist).

If the result of the genetic test is not stated in the patient's medical record, that patient is seen as an ordinary cancer patient (Participant A, breast specialist).

If genetic information is included in a patient's electronic medical record, we are concerned over potential information leakage (Participant B, breast specialist).

Careful handling of genetic information is embedded in our practice (Participant C, breast specialist).

#### Patients being lost to follow-up

Appropriate follow-up of mutation-positive patients requires not only an improvement in breast cancer care or patient self-management but also a systematic change in which all relevant professionals should be involved in the follow-up.

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We do not have any MRI screening program, and establishing such a system will be the first step. For screening for ovarian cancer, we need to involve professionals in the department of gynaecology. We have to build it from scratch (Participant O, nurse).

We provide genetic testing to our patients, but we are not following them up. (Participant C, breast specialist).

We don't know whether we should follow up patients by telephone or not (Participant D, breast specialist).

We don't know how to follow up those who do not undergo genetic testing (Participant C, breast specialist).

Those who refuse to undergo genetic testing never call back (Participant O, nurse).

#### **DISCUSSION**

The findings revealed that breast-care providers' readiness for personalized cancer risk management was less than optimal. They perceived breast cancer care as being still behind the curve on HBOC risk management. They were hesitant to get involved in sensitive genetic issues because of their complex nature. They were concerned that risks would be easily missed in a busy clinical practice.

We identified the challenges currently faced by breast-care providers seeking to manage individuals at risk of HBOC. Barriers identified in previous physicians' studies include a lack of clinical guidelines, limited knowledge, lack of confidence and lack of evidence-based clinical information. 5,15,16 In the present study, the clinical thinking of health-care providers, ambiguity over responsibilities in multidisciplinary care, and fragmented communication systems affected the risk management.

Clinical thinking, referring to the process of decision-making in clinical practice, is based on knowledge and experience. The breast team felt comfortable about their breast care, but they were concerned about their knowledge and experience in terms of HBOC. Faced with limited resources and multiple problems, health-care providers often adopt additive-sequential decision making, which deals with problems in order of priority. <sup>17</sup> All respondents mentioned limited available time and resources. Consequently, they concentrated on breast cancer treatment, and HBOC risk management was put in second place.

Their clinical thinking process often resulted in their hesitation to get involved in sensitive issues. HBOC genetic information is relevant to both those who undergo

genetic testing and their relatives. <sup>18</sup> As information obtained by women through genetic testing could have a significant impact on their relatives, health-care providers need to bear in mind the scope of family care. <sup>19</sup>

The breast-care providers were also juggling the dual role of telling their patients their breast cancer diagnoses and informing them about genetic testing at the same time. As the diagnosis of breast cancer is a life crisis event for the patient, health-care providers wondered whether additional unwelcome news about genetic testing would harm the patient. In addition, there are no evidence-based standard management procedures with long-term clinical data. This ambivalent view of health-care providers disrupts the timing of communication with the patient.

The recent model of multidisciplinary care makes it difficult even to integrate genetic data into information sharing, although multidisciplinary efforts would lead to successful cancer risk management.20 In Japan, genetic data given in paper-based medical records at genetics departments are kept in locked cabinets. Personal information is protected, but this means that it is not shared among multiple disciplines. Some genetic information is shared through verbal communication between professionals in breast-care and gynaecology or included in electronic medical records at certain institutions. However, unlike in the United States, the law is not prepared in Japan for electronic data interchange, and concerns about privacy and genetic discrimination remain a deterrent for health-care providers. Even though the results of genetic testing are given to relevant health-care providers, some of them do not understand the value of genetic information because of insufficient knowledge of genetics.

Also, the breast-care providers mentioned that multidisciplinary care obscured where responsibility for HBOC risk management resides. They were preoccupied by daily practice, and responsibility for HBOC risk management was not assigned, so that individuals at risk were likely to be missed in the routine practice in these fragmented communication systems. These barriers need to be identified as common concerns among multidisciplinary care providers, and the communication process should be improved. Multidisciplinary care represents best practice through the enhancement of communication.

The cost of genetic testing for the BRCA1/BRCA2 mutation genes is expensive. It ranges from  $\$250\,000-350\,000$  (about US\$2500-3500; US\$1=\$100), depending on the

institution. There is no insurance coverage for such testing in Japan; thus, individuals pay for it out of pocket. The results of the tests help health-care providers make more informed patient-management decisions and should be used effectively. Not only mutation-positive women but also mutation-negative women might need additional help.<sup>21</sup>

In terms of nursing implications, these findings provide insights that can help nurses manage individuals at risk. As oncology nurses are positioned as a communication bridge between cancer patients and multidisciplinary teams, 22 they are ideally placed to facilitate communication among members of multidisciplinary care teams, utilize genetic information in electronic medical records and hold multidisciplinary meetings on HBOC risk management.

Appropriate clinical thinking comes from confidence in decision-making based on solid knowledge, and therefore, training is essential. Education alone, however, does not necessarily translate into effective adoption of innovative practices, and an organizational culture in which proactively coordinating genetic information leads to cancer prevention and early management needs to be created within the health-care system. <sup>23</sup> It is not genetics providers but oncologists and oncology nurses who see their patients regularly for screening or follow-up. <sup>24</sup> To ensure the follow-up of individuals at high risk and their families, specialized outpatient clinics need to be established for multidisciplinary collaboration and partnership, or the current breast screening services could be used with a more personalized approach.

#### **LIMITATIONS**

The sample in this study might not accurately reflect the full spectrum of characteristics in the target population because we collected data from breast team members who were available for the focus group interviews at two institutions, and therefore, generalizability might be limited. Theoretical sampling allowed for refining of the categories of challenge and added new richness to their description; however, the limitations of the sampling might influence deeper exploration and generation of an emerging theory. Some situations specific to the Japanese health-care system could have hindered some aspects of the focus group conversation. Owing to the nature of focus group interviews, the results might have been influenced by group dynamics. The advantage of this approach is the acquisition of

constructive data, whereas the disadvantage is the influence of the opinions of others.

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#### **CONCLUSION**

In this study, we focused on HBOC risk management based on the *BRCA1/BRCA2* tests, which have more than a decade of history. Despite the fact that these are the most common genetic tests, the breast-care providers perceived HBOC risk management as still being neglected in breast cancer care. The health-care system is failing to keep pace with the speed of development, and health-care providers are not ready for personalized cancer risk management in everyday practice. There is much to be done in nursing practice. Additional research is clearly needed to better understand the barriers to adopting personalized cancer risk management in practice, in order to ensure that the benefits from progress in genetics are passed on to patients.

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# 胸部食道がん術後外来患者に対する看護ケアの分析

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【背景】食道がんの術後は多様な症状・徴候があり、長期的な外来でのケアが重要であり、看護師が行う外来の看護ケアを 明らかにする必要がある.【目的】胸部食道がん根治術後患者に対する外来での看護ケアの実態を明らかにする.【方法】2009 年1月~2010年12月にかけ、外来の看護ケアについて記載された診療録を前向きに調査し、質的記述的分析を行った。 【結果・考察】66 名の対象患者の診療録から、外来の看護ケアに関する記録単位は372 であり、12 カテゴリ、74 コードに 分類された. 看護師は, 患者のもつ形態・機能の変化に伴う症状・徴候をアセスメントするとともに, 患者の主体的なセル フモニタリングを活用していた. 術後回復過程に合った栄養摂取と身体活動の促進のため, 系統的なプログラムを開発する 必要が示された.【結論】今後,胸部食道がん術後回復促進のためのプログラムを考案したい. Palliat Care Res 2014; 9(3): 110-7

Key words: 胸部食道がん, 術後外来, 看護ケア, 内容分析

#### はじめに

胸部食道がんの手術は、開胸・開腹による食道亜全摘、胃管 再建、3領域リンパ節郭清が標準とされている.この術式は侵 襲が大きく, 患者には術後多様な症状・徴候が出現する<sup>1)</sup>. 患者 は手術前とは異なった摂食・嚥下機能,消化管の形態・機能に 適応し,多様な症状・徴候に対してセルフマネジメントするこ とが不可欠となる.

イギリス2, スウェーデン3,4)では, 食道がん術後の経過を QOL 尺度を用いて縦断的に評価しており,症状の影響が術後 数カ月から数年にわたり続くことが示されている. 日本では, 食道がんの術後急性期を過ぎ、その後の回復過程を促進するケ アに関し、嚥下障害に対するリハビリテーションに関する研 究5,6,術後の患者の生活上の困難や生活構築過程に関する研 究<sup>7-9</sup>, 術後の食の再獲得に関する研究<sup>10</sup> などが報告されてい る. これらから, 患者が主体性をもって回復過程に効果的なセ ルフケアを実施することが重要であることが示されている.

また, 術後の多様な症状・徴候!) に対して, 異常の早期発見・ 早期治療, 治療後の全身管理・QOL の把握等, 医療者の多様な 視点による診療・ケアの重要性が指摘されている").

看護師による外来に関する研究は, 頭頸部がん術後外来, が ん化学療法外来などで報告されており12,13)、医師の診察と連動 し実施した成果として,医師がより高度で専門的な治療に対応 できるようになったこと, さらに患者の待ち時間減少, 患者の 満足度向上,ケアの継続性確保,看護師の仕事に関する満足感 やキャリアパスの向上などの成果が報告されている.しかし、 食道がん手術後における効果的な看護ケアの実態については 明らかでない.

そこで本研究では、外来における看護ケアの実態を把握する ことを目的として調査を行った.

#### 目的

本研究の目的は,胸部食道がん根治術後患者に対する外来に おける看護ケアの実態を明らかにすることである.

#### 方法

本研究は,前向き観察研究であり,診療録からデータを収集 した

#### 11対象

2009年1月~2010年12月の間に、関東圏のがん専門病院1 施設において胸部食道がん根治的手術を受けた患者に対する 外来における(退院2週目~12カ月目)診療録のうち、今回は 看護ケアの部分のみを対象とした.

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なお,対象患者は,次の要件を満たすものとした.①胸部食道がん根治的手術を受けた,②開腹・開胸,腹腔鏡・胸腔鏡による術式または補助下術式も含む,③再建術式や手術前後の化学療法・放射線療法の有無は問わないこととした.ただし,今回の研究は,胸部食道がんの標準的な根治術を受ける患者を対象とするために,永久気管孔を造設した患者,二期的手術を受けた患者は除外した.

外来において対応した看護師は2名であり,いずれもがん専門病院における看護師経験10年以上であり,摂食・嚥下障害看護認定看護師,がん性疼痛看護認定看護師資格を有していた.

#### ② データ収集方法

食道がん患者の外来における診療録を研究者が閲覧し、①対象属性、術後の症状・徴候・処置を記録するとともに、②外来における看護ケアについてフォローアップ・データシートから抽出した。

本調査に先立ち,意図的な試みとして,患者の相談内容と看護ケアの内容を確実に記録に残すため,医師の外来診察前後に実施した看護ケアの内容を,外来看護師がフォローアップ・データシートに記載した.本シートは,本研究に先立ち文献検討を行い,患者の多様な症状と訴え・相談内容の推移と,看護師によるケアについて詳細に記述する記録用紙である.この記録は,看護師がメモした内容や,ケアの後に実施した内容を振り返って記録した.

また,退院時の指導内容を把握するために,調査施設における胸部食道がん手術患者に用いている,退院指導パンフレットを入手した.

#### ③ データ分析方法

データの分析は、内容分析の手法<sup>(4)</sup>を参考に、以下の手順で分析した。①フォローアップ・データシートに記載されている胸部食道がん術後患者に対する看護ケアの記述内容を抽出した。②意味内容をもつ記録単位に分割した。③記録単位の意味内容を損なわないように内容を要約しコードを作成した。④類似性をもとにコードをまとめてカテゴリを作成した。

データの真実性を高めるために、フォローアップ・データシートの記述からの分析過程について、他者が妥当性を判断できるように記録を残した。また、コードがどのカテゴリに該当するか判定するために、がん看護の経験が10年以上の看護師2名により独立して判定してもらい、一致しない部分は研究者が再度コード名を検討した。全体を通して、看護学研究者で確認を行いながら進めた。

本研究は,研究実施施設の研究倫理審査委員会の承認を得て 実施された.

#### 研究結果

#### ① 対象患者の背景(表 1)

対象となった患者は 66 名で, 男性 58 名 (87.9%), 平均年齢 69.2歳 (範囲 49~88歳) であった. 食道がん根治術のアプローチは, 開胸 (50.0%), 食道亜全摘 (40.3%), 3 領域リンパ節郭清 (92.4%), 胃管による再建 (90.9%), 後縦隔経路再建 (83.3%) が最も多かった. 入院期間は, 中央値 24 日 (範囲 12~149日) であっ

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分析対象の外来の受診時期は, 退院後中央値 2.3 カ月 (範囲 2週目〜12カ月目), 受診回数は中央値 3回 (範囲 1〜7回) であった

#### ② 退院時に実施されていた指導内容

退院指導の内容としてパンフレットに記載されていた内容は、「食事の種類・量、特殊な嚥下法(息こらえ嚥下、顎引き嚥下、横向き嚥下)、痛みへの対処、下痢・便秘への対処、飲酒・喫煙に関する注意、内服に関すること、緊急時の対応」であった.

#### ③ 胸部食道がん術後外来における看護ケアの分析

胸部食道がん術後患者 66 名に対する外来看護ケアに関する 記録単位は 372 抽出され, 12 カテゴリ, 74 コードに分類された (表 2). また, それぞれのコードの件数と構成するカテゴリの コード合計件数も表 2 に記載した. 以下, カテゴリを「」に, コードを『』に提示し、結果の概要を解説する.

#### 1) 「手術後の経過をふまえた系統的なアセスメントによる 異常の早期発見と対処」

これは、形態・機能の変化に伴う手術後の影響を効果的にアセスメントし対応するためのカテゴリであり、7コードからなった. 内容は、周術期合併症や反回神経麻痺など、『手術後の所見(反回神経麻痺・吻合部縫合不全、肺炎)からハイリスク患者のアセスメント』『手術後の形態・機能の変化に伴う症状(嗄声、むせ、つかえ、逆流、ダンピング)のアセスメント』『呼吸器症状(呼吸困難・息切れ・咳・痰)のアセスメント』『経腸栄養カテーテル挿入部(抜去部)のアセスメント』を実施することで全身の体調をアセスメントし、『処置・処方の必要性のアセスメントと実施への調整(経腸栄養カテーテル抜去、創処置、食道拡張術、内服)』を行っていた.

#### 2)「多職種と連携したケアの実施」

これは、専門職同士の連携の下でのケアの実施のことで、5 コードからなった. 内容は、皮膚・排泄ケア認定看護師、摂食・ 嚥下障害看護認定看護師、栄養士、ソーシャルワーカーらと連 携してケアを実施していた.

#### 3) 「症状・徴候の理解とセルフモニタリング促進へのケア」

これは、形態・機能の変化に伴う症状やセルフケア行動に関する自己観察が適切にできるためのカテゴリであり、6 コードからなった. 内容は、患者の身体の変化やセルフモニタリングに関する認識や実施状況の確認など『体調・症状の悪化要因に関する患者の認識のアセスメント』や、セルフモニタリング状況、促進・阻害要因をアセスメントするとともに、体調悪化のアセスメントと指導を行っていた.

#### 4)「適切な摂食・嚥下に向けたケア」

これは、個別性に合った適切な栄養摂取を促進するカテゴリであり、10 コードからなった. 内容は、食事の形態・量、捕食・摂食・嚥下状況とむせ・咳き込みなど、摂食・嚥下行動と症状との関連を確認し、適切な捕食の速度・量、咀嚼法などを指導するとともに、誤嚥予防の重要性の説明や特殊嚥下方法・食形態指導など、誤嚥を回避する嚥下法が実施できるように指導していた。

#### 5) 「摂取カロリーの増加に向けたケア」

これは、摂取カロリーを高めるためのカテゴリであり、5

表 1 胸部食道がん根治手術を受け、術後外来の看護ケアを受けた対象者の背景 (n=66)

	n (%)	平均	範囲
男性	58 (87.9)		
女性	8 (12.1)		
年齢 (歳)		69.2	49~88
術前治療			
Chemo-radio therapy (CRT)	5 ( 7.6)		
Docetaxel, cisplatin, 5-fluorouracil (DCF)	3 ( 4.5)		
Cisplatin, 5-fluorouracil (FP)	14 (21.2)		
その他	2 ( 3.0)		
術後治療			
Chemo-radio therapy	5 ( 7.6)		
Chemotherapy	8 (12.1)		
Radiotherapy	1 ( 1.5)		
術式 : アプローチ			
開胸術	33 (50.0)		
開胸開腹術	12 (18.2)		
非開胸	6 ( 9.1)		
胸腔鏡補助下 (VATS)	25 (37.9)		
術式:切除			
食道亜全摘	27 (40.9)		
食道切除	22 (33.3)		
食道抜去	7 (10.6)		
術式:リンパ節郭清			
3 領域	61 (92.4)		
2 領域またはそれ以下	4 ( 6.1)		
術式:再建臓器			
胃管	60 (90.9)		
その他 (十二指腸, 結腸)	6 ( 9.1)		
術式:再建法			
後縦隔経路	55 (83.3)		
その他 (後胸骨経路 など)	11 (16.7)		

注)一部のデータに, 不明や欠損値がある.

コードからなった. 内容は、『栄養補助食品の使用・摂取カロ リーのアセスメント』を実施し、食事の種類、分割食、経腸栄養 との組み合わせなどを工夫することで、摂取カロリーの確保・ 増量法が実施できるように指導していた.

#### 6) 「消化液逆流による苦痛緩和に向けたケア」

これは、形態・機能の変化による消化液逆流に伴う苦痛への ケアであり、6コードからなった. 内容は、『逆流の程度・発生 状況・対処のアセスメント』を行い, 夜間にも苦痛が強い症状 である消化液逆流による苦痛が緩和するように指導していた.

#### 7)「適切な身体活動の実施に向けたケア」

これは、回復過程に患者の個別性に合った行動拡大を促す力 テゴリであり、8 コードよりなった. 内容は、身体活動の範囲・ 頻度や体調の変化など『身体活動の範囲・程度のアセスメン ト』を行い、社会復帰に伴い増加する身体活動量に見合った栄 養摂取ができているか『身体活動と栄養のバランスのアセス メント』を行い、栄養のアセスメントとともに患者に合った身 体活動の方法が理解できるように指導していた.

#### 8) 「職場復帰の円滑化に向けたケア」

これは、手術による休職から職場に復帰するための支援であ り,3コードよりなった.内容は、『職場復帰状況・阻害要因の アセスメント』を行い,職場復帰に伴う生活の仕方の相談にの るなど,職場復帰が円滑に進むように指導していた.

#### 9) 「苦痛の緩和と効果的な日常生活の促進に向けたケア」

これは、日常生活における多様な苦痛に関するケアであり、6 コードよりなった. 内容は, 節酒指導, 不眠への指導, 経腸栄養 指導などの状況が示された.

#### 10) 「回復促進のための生活を行う自信を高めるケア」

これは、患者が退院後の生活において自信をもてるためのカ テゴリであり、7コードよりなった. 内容は、『症状・対処の妥 当性への不安の傾聴』を行い、不安や意欲を低下させる要因を 引き出して共感し、順調に回復していることを伝え、回復を実 感できる関わりを行っていた. また, 『療養行動の妥当性を承 認』することで、患者の頑張りを認め自己肯定感を高めること、 症状のなりゆきの説明を行い、情緒的・認知的に支援していた.

#### 11) 「患者の意思決定の促進に向けたケア」

これは、困難な事柄に関する意思決定を促すカテゴリであ り,5コードよりなった.内容は,意思決定への迷いに共感し, 意思決定に必要な情報を提供するとともに, 医師へ患者の意向 を伝える橋渡しを行っていた.

#### 12) 「家族の心身の疲労を緩和し患者への適切な関わりを促 **すケア**|

これは、家族の負担・不安の緩和のためのカテゴリであり、6

## 表 2 胸部食道がん患者に対する看護外来におけるケア内容

表 2 胸部食道がん患者に対する看護外来におけるケア内容	1 2 11 (- 1 > #4 >
カテゴリ (コード数) n	カテゴリ (コード数) コード
	The state of the s
1. 手術後の経過をふまえた系統的なアセスメントによる	6. 消化液逆流による苦痛緩和に向けたケア (18) 逆流の程度・発生状況・対処のアセスメント ········ 9
異常の早期発見と対処 (72) 手術後の所見 (反回神経麻痺・吻合部縫合不全, 肺炎)	を聞の逆流と睡眠状態のアセスメント・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・
からハイリスク患者のアセスメント	逆流の原因・悪化の要因についての説明 ······ 1
手術後の形態・機能の変化に伴う症状 (嗄声, むせ,	III
つかえ, 逆流, ダンピング) のアセスメント 20	逆流を予防するための体位の指導 · · · · · · · 1
呼吸器症状 (呼吸困難・息切れ・咳・痰) の	逆流に対する服薬指導 ······ 1
アセスメント ····································	7. 適切な身体活動の実施に向けたケア (30)
創状態のアセスメント	7. 適切なす体内動の実施に同りたり (30)
体重減少のアセスメント	身体活動拡大に関する患者の認識のアセスメント… 1
経腸栄養カテーテル挿入部 (抜去部) のアセスメント・・11	身体活動時の体調のアセスメント · · · · · · 1
処置・処方の必要性のアセスメントと実施への調整	身体活動と栄養のバランスのアセスメント ········· 2
(経腸栄養カテーテル抜去, 創処置, 食道拡張術, 内服)… 18	身体活動の拡大を阻害する要因のアセスメント 3
2. 多職種と連携したケアの実施 (14)	身体活動の必要性の説明 7
難治性の皮膚障害に対して皮膚・排泄ケア認定	患者に合った身体活動の拡大方法の説明 7
看護師と連携したケアの実施	適切な身体活動と栄養のバランスを保つ必要性の説明 … 7
不適切な摂食・嚥下方法に対して摂食・嚥下障害	8. 職場復帰の円滑化に向けたケア (9)
看護認定看護師と連携したケアの実施 2	職場復帰状況・阻害要因のアセスメント ······ 5
栄養に関して栄養士と連携したケアの実施 1	職場復帰に伴う生活の仕方の指導
地域への看護ニーズの継続のための訪問看護師と	追加治療の準備のための生活指導・・・・・・・・・・・ 3
連携したケアの実施4	9. 苦痛の緩和と効果的な日常生活の促進に向けたケア (66)
介護保険申請等経済的な側面に対してソーシャル	排便状態のアセスメントと排便コントロール指導 … 10
ワーカーと連携したケアの実施 2	疼痛および緩和方法のアセスメントと対処方法指導 … 20
3. 症状・徴候の理解とセルフモニタリング促進へのケア (18)	飲酒状況のアセスメントと節酒指導
体調・症状の悪化要因に関する患者の認識の	睡眠状況のアセスメントと不眠の対処法の説明 4
アセスメント	経腸栄養の管理法の説明 9
セルフモニタリング状況のアセスメント 3	創の処置方法の説明 12
セルフモニタリング促進・阻害要因のアセスメント … 2	10. 回復促進のための生活を行う自信を高めるケア (44)
体調管理に必要なセルフモニタリング項目および	症状・対処の妥当性への不安の傾聴 ······ 12
方法の説明 1	順調に回復していると承認
症状の機序・悪化要因についての説明 7	療養行動の妥当性を承認
医療者に報告すべき内容の患者への説明 4	症状が異常ではなく通常の経過であると説明 4
4. 適切な摂食・嚥下に向けたケア (61)	改善しない症状への不安・あせりが当然であると共感 … 1
食事の回数・形態・内容・量と症状との関連の	持続する症状への不安に症状の成り行きを説明 2
アセスメント	再発への不安を傾聴し共感
捕食・咀嚼・嚥下の速度と症状との関連の	11. 患者の意思決定の促進に向けたケア (6)
アセスメント	術後の追加治療に関する意向の確認 1
食事形態とむせ, 咳き込みの関連のアセスメント 5	患者が自己の意思を決定できない状況が当然である
嚥下時の姿勢 (顎の位置, 下向き, 横向き) による	ことへの共感 1
むせ, 咳き込みの関連のアセスメント 5	治療の選択肢に関する補足説明2
特殊な嚥下法の難易度の認識・負担感のアセスメント・・ 1	患者の迷いを医師に伝達 1
つかえが生じる状況・食事形態のアセスメント 9	患者の意向を医師に伝える重要性を説明 1
捕食・咀嚼の速度の説明・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・	12. 家族の心身の疲労を緩和し患者への適切な関わりを促す
空腹感がない場合,一定間隔で食事摂取するよう説明 … 1	ケア (17)
誤嚥を回避する特殊な嚥下法の指導(顎引き嚥下,	家族の患者支援状況, 疲労の程度のアセスメント 5
息こらえ嚥下, 横向き嚥下, 声門内転訓練)・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・	家族の不安への傾聴・共感
誤嚥のハイリスク患者に対する適切な食事形態の説明 … 1	家族の相談 (食事, 症状, カテーテル管理) への対応 … 4
5. 摂取カロリーの増加に向けたケア (17)	家族の頑張りへの慰労
栄養補助食品の使用・摂取カロリーのアセスメント … 1	患者と家族間のコミュニケーションのアセスメント… 1
栄養補助食品・栄養価の高い食品の使用・調理法の	患者と家族間のコミュニケーションの促進 1
説明・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・	合 計 372
分割食による食事摂取の説明 · · · · · 1	
経腸栄養量と経口摂取量との調整の説明 ······ 4 経腸栄養中止後の適切な栄養摂取法の説明 ····· 2	
性肠不食中止後ツ迴りは不食摂取広り就明 2	

コードよりなった. 内容は、『家族の患者支援状況、疲労の程度のアセスメント』とともに、不安の傾聴・共感、疑問への対応を行い、頑張りを認め、慰労をしていた.

#### 考察

今回対象となった胸部食道がん術後患者の術式等は,典型的なものが大半を占めた. 対象患者に対し,外来において看護師が実践していた看護ケアの内容を分析したところ,症状・徴候に対するケアや精神的なケアを含み,栄養・摂食・嚥下に関すること,身体活動に関すること,セルフモニタリングに関することなどに分類された.

1 患者のニーズの把握と多職種連携による処置・ケアの実施コード数の最も多かったカテゴリは、「手術後の経過をふまえた系統的なアセスメントによる異常の早期発見と対処」であり、その中でも『手術後の形態・機能の変化に伴う症状(嗄声, むせ, つかえ, 逆流, ダンピング)のアセスメント』が多かった。食道がん手術における症状の発症時期や程度は個人差が大きくり、個別性に合わせたケアを提供する前提でこれらのアセスメントを実施する必要がある。また、ケアの実施として、『処置・処方の必要性のアセスメントと実施への調整(経腸栄養カテーテル抜去、創処置、食道拡張術、内服)』が次に多かった.

これらから、多様な職種とともにケアを実施している実態が示され、看護師がアセスメントした内容について、医師を含め 多職種に伝えていく必要性が示された.

#### ② 患者のセルフモニタリングのケアへの活用

胸部食道がん術後患者に対し、「症状・徴候の理解とセルフモニタリング促進へのケア」として、外来において『セルフモニタリング状況のアセスメント』、および『医療者に報告すべき内容の患者への説明』を行っていた、特に、患者に症状の理解を促すために『症状の機序・悪化要因についての説明』を行っていることが結果から示された、食道がんの手術を受けた患者の症状は前述のように個別性が高いことが報告されておりり、外来における看護では、患者が自宅で自分の状況を理解して経過を把握するためにセルフモニタリングを効果的に活用することが不可欠である。

セルフモニタリングとは、"自らの健康や病気を適切に管理するために、病気の症状や身体感覚を定期的に測定したり、記録したり、観察して認識すること"であり、"セルフマネジメントはより良いセルフモニタリングにより改善する"と言われている<sup>15</sup>.

さらに、患者指導においては、患者個別の問題に特化した情報提供が、患者の理解度を高め、不安を緩和し、満足度を高めると報告されている<sup>16</sup>.このことからも、患者の自己観察・セルフモニタリングに沿った個別的な課題に対する指導を行えば、その効果が高くなるものと期待される.

# ③ 患者の回復過程をふまえた適切な栄養摂取に向けたケアの実施

食事に関する内容として、「適切な摂食・嚥下に向けたケア」 「摂取カロリーの増加に向けたケア」「消化液逆流による苦痛 緩和に向けたケア」のカテゴリがあった. 研究結果から、看護 師は、捕食・摂食の速度・量についてのアセスメント・指導、 誤嚥を回避する嚥下法、つかえや逆流に対する指導を行ってい た

調査施設では、退院時に食事内容・方法に関して指導を行っており、退院指導パンフレットにも記載されている。そのうえで、本研究結果においても示されたとおり、外来において自宅で退院指導が活かされているかアセスメントを行うとともに、適切な摂食・嚥下方法の再指導、摂取カロリー増加に向けたケアなど、継続した指導が必要である症例もいたことが示された。このことから、患者への指導時期は退院時のみとするのではなく、外来でも継続する必要性が示された。

また、研究結果から、退院後『経腸栄養中止後の適切な栄養 摂取法の説明』として、経腸栄養において補っていた栄養をす べて経口摂取に切り替えることや、退院後の身体活動量の増加 により『身体活動と栄養のバランスのアセスメント』をふま え、身体活動量の増加に伴う摂取カロリー増加への指導を行っ ていた。このように、回復過程では食事の種類や量を変化させ る状況がある。患者は、自己の行動の妥当性について退院時に 指導されていても、改善しない症状への不安や焦りから、自己 の療養行動に対する疑問をもつことがしばしばある。結果に示 されたように、看護師は患者に対して『療養行動の妥当性を承 認』し、『症状が異常ではなく通常の経過であると説明』する ことで、患者の自信を高めるケアを実施していた。このような ケアは患者のみではなく、家族も含めて実施される必要性が示 された。これらのケアは、回復過程で患者が新たに体験する局 面を予測した重要な看護ケアであることが示唆された。

「適切な摂食・嚥下に向けたケア」は、特に、誤嚥を回避する 嚥下法について指導の頻度が多い結果であった。日本に多くみ られる胸部食道がんでは、頸部上縦隔リンパ節郭清を行うこと が多いため、術後障害として反回神経麻痺も多く、それに伴う むせや誤嚥、嗄声などの症状に関する文献が多くみられる<sup>17,18)</sup>. 患者は、嚥下のたびに頸を回旋させたり、顎を引くなど手術前 とは異なった嚥下法が必要となるが、これまでとは異なる食事 の習慣を体得することは容易ではなく、退院後も継続的な指導 が重要であることが示された。

誤嚥のリスクをもつ患者に対する摂食・嚥下法は, おもに 脳卒中や耳鼻咽喉科疾患の患者に対するケアとして普及して きており<sup>19,20</sup>, 食道がん術後患者に関する摂食・嚥下法の研究報告は少ない<sup>21)</sup>. しかし, 反回神経麻痺のある患者に対する摂食・嚥下方法の指導としては, 頸部前屈, 息こらえ嚥下法をは じめ, 横向き嚥下などが推奨されてきている<sup>22)</sup>. 胸部食道がん患者の手術後のフォローアップには, 術直後から看護師が系統的なアセスメントを行い, 必要時には上記の特殊な嚥下法を患者に指導できることが重要であると考える.

4 患者が効果的に身体活動の拡大ができるためのケアの実施 本研究結果から、看護師は胸部食道がん患者に対して、「適切 な身体活動の実施に向けたケア」「職場復帰の円滑化に向けた ケア」を実施していた.

胸部食道がん患者は、開胸術を実施するために、早期の離床など呼吸器障害の改善のためにも身体活動の拡大が推奨されている<sup>11, 23, 24)</sup>. 食道がん術後の患者の身体機能は低く、健康関連 QOL に影響していたこと<sup>25)</sup> や、消化器系がんの術後患者に関する研究では、身体機能の高い患者群は身体機能の低い患者

群よりも,抑うつの発生率が有意に低かったことが報告されている<sup>26</sup>

このように、胸部食道がん患者に対しては、適切に身体活動を促進し、症状や苦痛を緩和することにより、呼吸機能の改善、QOLの向上や倦怠感の緩和などが期待される. 患者の退院時における体力や呼吸機能は十分に回復していないため、外来においても、身体活動の拡大を促す指導や自信を高めるケアは大変重要であると考える.

#### ⑤ 患者・家族の意思の尊重と、家族を含めたケアの実施

看護師は「患者の意思決定の促進に向けたケア」として,治療の選択肢についての患者の理解を高め,情緒的な支援を行うとともに,医師につなぐ重要な役割を果たしていた.患者に加えて,「家族の心身の疲労を緩和し患者への適切な関わりを促すケア」を提供し,患者が効果的な回復過程をたどれるよう家族も含めて支援しており,そのような看護ケアの重要性が示された

#### 本研究の限界

本研究は、胸部食道がんにおいて標準的な根治術を受けた66名の患者に対応した、専門性の高い看護師による外来看護ケアの実態であり、今後のケアを一般化するために意義があると考える。しかし、1施設におけるケアであること、および対応した看護師が2名であったことから、今後さらに一般化するには、多様な施設や看護師を対象としたデータ収集と検討を重ねていく必要があると考える。

#### 結論

胸部食道がん根治術後の患者に対して、外来において看護師が行っているケアについて分析したところ、看護師が個別の状況をアセスメントし、それに応じて効果的な回復を促進するケアを提供している実態が明らかとなった.

症状・徴候は主観的であるため、患者の主体的なセルフモニタリングを効果的に活用し、患者の回復過程に合った栄養摂取と身体活動を促進するケアが重要であることが示された。退院時においてセルフケア指導は実施されているものの、症状・徴候は長期間にわたるため、タイムリーな時期に看護師が関わることで、患者の不安を緩和し、回復に向けた意欲を向上し、適切な保健行動を促すことが重要であることが示唆された。

今後,これらの結果を構造化し,患者と医師・看護師連携による胸部食道がん患者の術後回復を促進するための系統的な プログラムを考案していきたい.

本研究は, 厚生労働科学研究費補助金(第3次対がん総合戦略研究事業)「上部消化器術後障害をもつがん患者の活力とQOL向上をめざすリハビリテーション開発」および公益財団法人高松宮癌研究基金「胸部食道がん術後の『退院後の生活』に安心と自信をもたらす患者指導法の開発」(研究課題番号:12-24409)により実施したものである.

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著者の申告すべき利益相反なし

# **Original Research**

# Content analysis of nurses' interventions for post thoracic esophagectomy cancer patients at the outpatient clinic

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Background: Patients having thoracic esophagectomy, a standardized treatment for esophageal cancer patients in Japan, are known to have various postsurgical signs and symptoms for a period of time. The current status of nursing interventions at outpatients need to be clarified. Purpose: This study aimed at identifying the nurses' interventions for cancer patients at the outpatient setting who previously had thoracic radical esophagectomy. Methods: Patients who had esophagectomy at a cancer center hospital in Japan were prospectively observed and interviewed by outpatient nurses between January 2009 and December 2010. Their documented responses in medical record were prospectively investigated and were qualitatively analyzed via content analysis method. This study was approved by the study hospital's research ethics committee. Results and discussion: The data analysis of nursing interventions for 66 patients yielded 372 extracts, 12 categories, and 74 codes. Nurses were assessing patients' signs and symptoms affected by postsurgical changes, and were utilizing patients' active self-monitoring skills. The results also showed the significance of facilitating postsurgical recovery in relation to nutritional intake and physical activity in patients' daily life. Implications: Based upon the study results, the development of a systematic program is underway, which facilitates esophageal cancer patients' postsurgical recovery. Palliat Care Res 2014; 9(3): 110-7

Key words: thoracic esophageal cancer, postoperative outpatient, nursing, content analysis

## 原醫

# 胸部食道がん術後患者の退院後の生活における困難の実態

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【目的】胸部食道がん根治術後患者が退院後から1年以内の生活において知覚している困難の実態を明らかにし、外来に おいて必要とされる看護援助について考察する.【方法】がん専門病院の食道外科外来において胸部食道がん手術を受けた 術後患者の診療録を調査し, 術後の症状・徴候・処置, 外来で患者が看護師に相談した困難を抽出し, 内容分析を行った. 本 研究は研究施設の倫理委員会の承認のもと実施した.【結果】胸部食道がんの手術を受けた 66 名の患者が対象となった. 患 者の困難の記録単位は 221, カテゴリは 25, コードは 65 に分類された. これらから, 食事摂取に伴う多様な症状, 身体活動, 不安や日常生活に関する困難が示された.【結論】退院後は多様な困難があり、効果的な自己管理を促進するために継続的 なケアが重要であることが示された

Palliat Care Res 2014; 9(2): 128-35

Key words: 胸部食道がん, 生活における困難, 症状・徴候, 内容分析

#### はじめに

食道がん患者に対する手術法は進歩しているが、手術による 上部消化管の形態・機能の変化は著しく,患者の退院後6カ月 ほどは逆流1,2)、狭窄2,3)などに伴うさまざまな症状・徴候が顕 著にみられている. そのために、体重減少が継続し2, 栄養状態 の低下や身体活動量への影響があり,回復の遅延や QOL の低 下4,5)を招いている.いずれも,症状・徴候の種類・頻度に関 しては、患者の個別の状況や経過に沿って問題を特定し、対応 することが不可欠であると報告されている6.

また、術後の創傷や多様な機能障害が治癒の途上にある術後 1〜2年のうちに、病状が再び進行期に移行することも多い<sup>7,8</sup>. 術後の経過および病態の進行に伴う多様な機能障害が、患者に 複合的に影響を与える<sup>6</sup>ため, 初期治療時から常に, 緩和ケア の提供という観点からトータルペインをふまえた視点で医療 者が患者を的確にアセスメントし、積極的に介入を行う必要が ある.

解剖学的・病理学的には, 欧米は腹部食道を中心とした腺が んが多いのに対し、日本では胸部食道を中心とする扁平上皮が んが9割以上である.日本の大多数の胸部食道がんの術式は、 頸部リンパ節郭清を行うため, 反回神経麻痺が長期間生じやす い9,10). 症状に関する文献は欧米の報告が中心であり,日本独自 の特徴に応じた治療と看護のエビデンスを明らかにする必要 がある.

食道がんの術後急性期を過ぎて退院すると, 患者は回復過程 において、効果的なセルフケアを実施することが求められる. しかし,前述のように食道がん患者の術後は心身の回復に時間 を要し、回復を阻害する要因が多く存在する、先行研究を見る と, 食道がん切除術を受けた患者の多様な困難や生活構築過 程に相当な努力を要することが質的研究により明らかにされ ているが11,12)、対象患者の多くが術後1年半から数年の報告で あった. また, 患者の退院後の精神健康状態に影響する要因を 調査した研究13)では、複数の症状が精神状態に影響を及ぼして いることが示されたが、対象患者は、術後1年以上数年が経過 した者であり、術直後のデータが不明であった.

そこで, 患者のフォローアップ・プログラムの開発に必要な 基礎的資料として、退院後からの胸部食道がん術後患者の生活 における困難の実態を明らかにするため、本研究を実施した.

#### 【用語の操作的定義】

困難:胸部食道がん根治術後患者が退院後の生活において 知覚している身体・心理・社会的な苦痛、対応に困っているこ と,とした.

#### 研究目的

胸部食道がん根治術を受けた患者が退院後の生活において 知覚している困難の実態を明らかにし、外来において必要とさ

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