As cancer treatment shifts from IV to oral chemotherapy, patients have less contact with nurses and face the increased responsibility of maintaining their own health care. The authors conducted focus group interviews with 18 oncology nurses using the grounded theory approach to explore the nurses’ perceptions of current practices and ideas regarding opportunities to improve nursing practice for patients receiving oral chemotherapy. The nursing presence is becoming invisible and, therefore, these patients are isolated more in current practice. “The need for a nursing presence” emerged as a core category. Nurse involvement in patient entry into oral chemotherapy was perceived as important for identifying patients at risk for nonadherence. In their partnership with patients, nurses should be attentive, connect with patients, elicit patients’ unmet needs, and provide committed patient support. Rather than the traditional reactive approach, proactive patient care is required. In addition, nurses are expected to coordinate patient care and facilitate interpersonal relationships among healthcare providers. Coordinated proactive care leads to predictive care to meet the future needs of patients, including the prevention of adverse events. The roles and responsibilities of nurses in oral chemotherapy must be clarified so that the nursing presence is clear to patients and other healthcare providers.
Methods

This study was approved by the internal review board at Keio University. The authors conducted a qualitative study with focus group interviews using the grounded theory approach (Strauss & Corbin, 1990). After recruiting potential participants from a list of certified oncology nurses published by the Japanese Nursing Association, the authors sent a letter to the nurses asking whether they were currently practicing in chemotherapy settings and wished to participate in the study. For the first recruitment, 9 of 18 nurses who received the authors’ letter agreed to participate in the study. The authors conducted two focus group interviews; however, the data did not reach saturation. The authors approached an additional 21 nurses through theoretical sampling, and nine of those nurses agreed to participate in the study. The reasons for nonparticipation by other potential participants included scheduling problems and currently not being involved in chemotherapy.

A total of four focus group interviews (including the first two) were conducted at Keio University from June to July 2012. The authors obtained written, informed consent for study participation from all nurses. One of the nurse researchers facilitated all focus group interviews using a semi-structured interview guide to ask nurses about current practices (e.g., nurse concerns regarding clinical care, working with other healthcare providers) and opportunities to improve nursing practice for patients receiving oral chemotherapy (e.g., potential nurse contribution to oral chemotherapy). The duration of focus group interviews ranged from 60–90 minutes. All interviews were conducted in Japanese, audio recorded, and transcribed verbatim.

The data were analyzed according to grounded theory (Strauss & Corbin, 1990), and the results were translated into English. The initial concepts were derived from open coding. Categories and subcategories were connected using axial coding. The authors logically related all categories and subcategories to identify a core category. The rigor of the study was confirmed using criteria for qualitative research: credibility, dependability, confirmability, and transferability (Guba & Lincoln, 1994). For credibility and dependability, two of the researchers reviewed the data to determine whether they agreed with the codes and themes identified. The authors confirmed data saturation after the fourth group interview. For confirmability, one of the researchers performed an analysis according to the grounded theory procedure (Strauss & Corbin, 1990), and another researcher confirmed the results. Transferability was reviewed and confirmed by the researchers.

Results

Of the 39 oncology nurses approached by the authors, 18 participated in the study. Participants’ mean age was 36 years, and their mean years of nursing experience and experience with chemotherapy were 17.6 years and 13.6 years, respectively.

“The need for a nursing presence” during oral chemotherapy emerged as a core category. As nursing presence in oral chemotherapy has become increasingly invisible, patients have become isolated in current practice. Nurse involvement in patient entry into oral chemotherapy was perceived as important for identifying patients at risk for nonadherence. The nurses interviewed agreed that patient care should be proactive. Nurses should be attentive, connect with patients, elicit patients’ unmet needs, and commit to patient support. The nursing presence also should be visible to other healthcare providers, with nurses contributing to the coordination of patient care and interpersonal relationships among healthcare providers (see Figure 1).

Patient Isolation in Current Practice

The oncology nurses who participated in the present study were very concerned about current practices in oral chemotherapy. One participant reported, “There are patients who do not tell the truth to their physician because they believe their physician may get upset if they tell them they are not taking their medicine.” According to participants, patients feared that physicians would stop treatment if they did not adhere to the medication regimens or if they experienced side effects. Therefore, patients tried to hide their problems until their condition worsened enough to require emergency admission to the hospital. As one participant said, “Some patients continued to take oral fluoropyrimidine anticancer agent . . . even though they did not feel very well. After they became really sick, they were admitted to the hospital.”

The nurses mostly were unaware of patient conditions outside of the chemotherapy clinic. As one participant said, “We can check patients who come to the chemotherapy clinic, but we cannot intervene with patients who are treated by only oral medication.” In addition, participants reported uncertainty regarding the roles and responsibilities of healthcare providers, and even of nurses in different departments. The following statement describes the situation: “We don’t know exactly how many patients receive oral anticancer agents. That’s the reality.” As a result, patients who receive oral chemotherapy are increasingly isolated in the healthcare system.

Involvement in Entry

Most participants emphasized the significance of being involved in patient entry into oral chemotherapy. The participants believed that the patient’s choice to receive oral chemotherapy
should involve healthcare providers who know about the patient’s situation. One of the participants raised the following concern: “Physicians may not consider a patient’s family or living situation when they start oral chemotherapy.” Patient eligibility to receive oral chemotherapy should not be decided based solely on the patient’s medical condition. The patient’s background, socioeconomic status, beliefs and values, and history of discontinuation also are important. Otherwise, as noted by one nurse, “A great amount of social support will be needed later.” Another nurse stated, “I think that assessment at the very beginning before initiation [of oral therapy] is very important.” If nurses are involved in patients’ entry to oral chemotherapy, they will know the patients’ situation and facilitate follow-up for at-risk patients.

Participants warned that detailed information about oral chemotherapy should not be given when the patient is overwhelmed at the moment of diagnosis or recurrence. One of the participants described this situation.

Except [in the case of] adjuvant chemotherapy, oral anticancer agents are often administered to patients with unresectable tumors; so, even though they agree to receive oral therapy, they are often overwhelmed and do not understand what oral therapy really means. They cannot think about oral therapy [at that time]. For example, a patient may be diagnosed with lung cancer today, and oral anticancer therapy might be initiated on the same day. . . . The patient cannot manage her emotions, but treatment starts. . . . All patients are overwhelmed and do not remember the information about oral agents very well.

Nurses need to assess patient psychological conditions at the time of initial prescription.

Proactive Patient Care

Patient care should be proactive rather than reactive. Nurses must pay attention to patients receiving oral chemotherapy. Such attention should be thoughtful and devoted to making patients feel comfortable about consulting with nurses.

The participants reported that they wanted healthcare providers to spend time with each patient, even though physicians, pharmacists, and nurses were busy because of understaffed outpatient clinics. One participant described how they tried to be attentive: “I try to ask patients who take capecitabine about their symptoms.” Another participant said she paid attention to patient behaviors: “I suspect [the truth] based on their everyday behaviors. You know, about the development of symptoms. I asked one patient to bring medicines to the clinic. While we were talking, he told me the truth: ‘I don’t tell my doctor, but I have many [medicines left].’”

The participants felt that they needed to connect with their patients. One of the participants emphasized the importance of establishing a trustful relationship with patients in saying, “I strongly feel that we need time and space to establish a trustful relationship with patients so that they can talk to us honestly.”

The participants stated that they tried not to blame patients when they did not adhere to medication regimens, but, rather, the participants tried to find positive aspects of patient behaviors. One nurse stated, “I always feel it is important for the patient to take the initiative with regard to oral therapy. . . . We should understand how hard patients try, and give them positive feedback to encourage and support self-management.” Some of the participants mentioned communication skills.

I tell my colleagues, “Let’s not press the patient.” Physicians want to know about adherence because they have to check laboratory data, so I ask the patient like this: “If it is hard for you to take medicine, or you are not taking them, tell me. I am not blaming you. Is it hard for you?” Eventually, the patient tells the truth.

After establishing a relationship with patients, nurses can elicit patients’ unmet needs. The participants reported that not only were medical concerns important, but socioeconomic and psychological needs were important as well. Many patients do not want to talk about financial problems, but nurses try to advise patients about social resources that they may need. One participant said, “Patients do not talk about money, but I suggest, ‘There are resources which you may be interested in.’ I help patients to make an appointment for consultation. There are patients who need our help.” Another participant said that while she was talking with one patient about her living situation, the patient started to talk about her problems and began to cry. When nurses are attentive and open, patients’ unmet needs can emerge.

A majority of the participants stressed the need for nurses to remain motivated to provide committed support. One participant stated, “I think that [the] motivation of nurses is very important,” and other participants agreed with that statement. Another said, “Think about what happens if the patient does not take the medicine when this patient really needs the medicine. It is not [enough] just to do what is instructed by the physician.” Nurses need to approach their work as professionals and think about their efforts from the patient’s viewpoint.

These efforts to provide attentive and committed care can lead to predictive care. As one participant said, “We can predict [when] a certain patient will come to visit the emergency clinic this weekend, so I try to prepare a summary. We have an electronic medical chart system so other staff members will understand the process of care [for this patient].”

One of the participants commented on the nature of nursing practice: “How the nurse should be involved in oral therapy is, I believe, to support patients. For instance, it’s the coordination of supportive environments for patients on oral chemotherapy.”

Coordination

One of the participants noted the need for nursing coordination for patients receiving oral chemotherapy: “The patients undergo critical treatment with a lot of problems such as side effects and financial and social problems. The nurses need to follow-up with such patients and coordinate their care.” Oncology nurses also should coordinate interpersonal relationships among healthcare providers. As one participant said,

If the interpersonal relationship between a physician on the team and a pharmacist in the chemotherapy center or collaboration among outpatient clinics of relevant departments is not good, the team will not be functioning. We nurses can coordinate such interpersonal relationships.
The participant also noted that nurses were qualified to perform such coordination: “I believe that the nurse is good at cross-organizational collaboration and asking [other professionals] for cooperation.”

Discussion

This study reveals a compelling need for nursing presence in oral chemotherapy. Uncertainty regarding nursing roles and responsibilities in this situation was evident in the focus group interviews. As the nursing presence is becoming invisible in the current fragmented system, patients are increasingly isolated. To make the nursing presence visible, oncology nurses need to provide proactive patient care with self-initiated and anticipatory action.

Nurses should be present at the patient’s entry into oral chemotherapy. Of particular concern in current practice is the fact that nurses do not know about all the patients receiving oral chemotherapy. Nursing assessment adds valuable information when selecting eligible patients for oral medication in consideration of their socioeconomic backgrounds. Patients and their families seek more comprehensive education during the initial prescribing encounter (Simchowitz et al., 2010), and such education has been the most important factor in successful outcomes of patients receiving oral chemotherapy (Moore, 2007). Monitoring patient progress can prevent serious complications and hospitalization (Oakley et al., 2010). Earlier identification of patients at high-risk for nonadherence to an oral medication regimen can help with monitoring and predictive intervention.

As cancer care is transitioning from the traditional reactive care to a proactive approach, oncology nurses should no longer just wait for patients to come to them, but instead should create new ways to have regular contact with patients. Patients often are sensitive to the attitude of their oncologist (Regnier Denois et al., 2011), resulting in over-reporting rates of adherence (Spoelstra & Given, 2011) and under-reporting side effects (Cassidy et al., 2002; Wood, 2011). Building relationships with patients is more important than ever, and such relationships are fundamental to ensuring management and adherence to treatment regimens (Wood, 2011).

Nurses are patient advocates (Vaartio-Rajalin & Leino-Kilpi, 2011; Winkeljohn, 2007), and the relationship between the nurse and the patient is a partnership. Shared understanding about the meaning of illness and treatment and the effect of the experience on a patient’s identity and ongoing life depends on the nurse’s ability to care for patients (Rosedale, 2009). Non directive dialogue along with attentiveness and empathy, in an effort to understand the patient experience, will bring undisclosed aspects of the patient experience to the surface (Jonsdottir, Litchfield, & Pharris, 2004; Rosedale, 2009). Oral chemotherapy allows nurses to spend more time caring for patients than IV chemotherapy, which requires practical administration procedures (Frye, 2009), and increased communication is related to immediate improvements in clinical outcomes (Lee et al., 2011).

Patients with cancer are vulnerable to falling between the service cracks in the complex healthcare system. The participants in this study believed that oncology nurses contribute to the coordination of not only patient care but also interpersonal relationships among healthcare providers. Interdisciplinary patient-centered care is a key to successful oral chemotherapy (Simon et al., 2011).

Limitations

This study has several limitations. The authors conducted theoretical sampling and recruited oncology nurses who were involved in chemotherapy in relatively large hospitals or cancer centers. Their perceptions and experiences of oral chemotherapy may differ from those of other nurses. Because of the nature of the focus group interviews, the participants may have been influenced by the opinions of others.

Implications for Practice

This study provides useful insights to nursing practice in oral chemotherapy. Because the entry into oral chemotherapy is significant, oncology nurses play an active part in patient selection through nursing assessment. Knowing a patient’s background is key to identifying patients at high-risk for nonadherence to oral chemotherapy. The development of an assessment tool designed for patients receiving oral chemotherapy may contribute to improved adherence and treatment outcomes. Self-management is required in oral chemotherapy and, therefore, patient education is essential. Nurses will be responsible for meeting the educational needs of patients in collaboration with physicians and pharmacists.

To provide proactive care, oncology nurses must take the initiative in challenging the current reactive practice: they must think ahead to anticipate the patients’ needs, act in advance, and intervene early. Oncology nurses build a partnership with patients to collaboratively work toward shared goals. Nurses should be attentive, connect with patients, elicit patients’ unmet needs, and commit to patient support. Nursing support includes enhancing patients’ empowerment and self-management, as well as providing psychological and emotional support. Oncology nurses play a vital role in coordinating interpersonal relationships.
with other healthcare providers. The roles and responsibilities of nurses must be clarified in oral chemotherapy so that the nursing presence is clear to patients and other healthcare providers.

Conclusions

Patients receiving oral chemotherapy are increasingly isolated. Oncology nurses should be fully present from the time of patient entry into oral chemotherapy. Proactive care that includes coordinated collaboration with other healthcare providers leads to predictive care to meet patient future needs, including the prevention of adverse events.

Additional studies are needed to develop a new system in which nurses proactively support patients receiving safe and effective oral chemotherapy with coordination among healthcare providers. Based on the results of this qualitative study, the authors plan to conduct a national survey to assess current nursing practice for patients receiving oral chemotherapy in cancer hospitals in Japan.

References


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