



Original Article

“It's a part of the patient”: The experiences of patients with cancer undergoing home-based chemotherapy from patients' and nurses' perspectives



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ABSTRACT

Objective: Home-based chemotherapy is widely used and offers advantages in terms of patient-centeredness, hospital capacity, and cost-effectiveness. However, in practice, patients experience difficulties with self-management and handling the elastomeric infuser. In this study, we aimed to explore the experiences of patients undergoing home-based chemotherapy based on patients' and nurses' perspectives. Additionally, we aimed to identify patients' unmet needs.

Methods: A qualitative descriptive study was conducted in a tertiary hospital in South Korea. Ten patients undergoing home-based chemotherapy and ten nurses with experience in home-based chemotherapy participated. Data were collected by using semi-structured individual interviews and analyzed by using inductive content analysis.

Results: Four main categories were identified based on the interviews: (1) ambivalence regarding comfort vs. enduring the discomfort, (2) acceptance of the discomfort as a part of them, (3) the need for more precise, numerical measurements, and (4) the realization that they need similar hands-on care at home as in a hospital.

Conclusions: Although patients were satisfied with home-based chemotherapy, they were enduring the difficulties they experienced at home alone. Nurses should make an effort to identify patient needs and devise tailored nursing interventions to improve their safety.

Introduction

The number of new cancer cases worldwide increased from 18.1 million in 2018¹ to 19.3 million in 2020.² It has been estimated that it will reach 30.2 million in 2040² and continue to increase thereafter. Given this trend, the demand for cancer treatment, in particular chemotherapy, has increased sharply.³ The main treatment environment has changed from the hospital to the home for the provision of cost-effective, safe, and high-quality treatment for an increasing number of patients with cancer.⁴⁻⁶ Home-based chemotherapy (HC) started in the 1980s in Western countries, in the early 2000s in Asian countries, including Hong Kong⁷ and Korea, and in the 2010s in Thailand.⁸ As the

number of Asian patients receiving HC is expected to increase in the future, it is necessary to identify their nursing needs.

Previous studies on HC were mainly focused on its financial benefits. The cost of outpatient treatment was reportedly lower than that of inpatient-based chemotherapy;⁸⁻¹¹ for patients with stage III colon cancer in Thailand, the annual cost was \$830,000 lower.⁸ However, there have been inconsistent results in studies in which quality-adjusted life years (QALY) were used as a health outcome,^{8,10} making any conclusions on cost-effectiveness in terms of QALY difficult. A study reported that patients' quality of life improved from the first visit to the fifth visit, thereby warranting the belief that more patients will come to accept HC.¹² In a study comparing HC and inpatient treatment,⁹ the average

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patient satisfaction was statistically significantly higher in the HC group; however, satisfaction in terms of the management of adverse effects of chemotherapy and the ease of management of the injection site was statistically significantly lower in the HC group. This demonstrates the need to improve nursing care for problems related to adverse effects and chemotherapy administrations while HC patients receive chemotherapy at home.

In a study on adverse effects of chemotherapy, nausea, mucositis, and fatigue were reportedly more common in the HC group than in the inpatient group.¹³ Additionally, HC poses difficulties such as discomfort due to wearing the elastomeric infuser for infusing anticancer drugs, obstruction of the infuser line, and a delay in the termination of chemotherapy infusion. Therefore, in this study, we aimed to explore the experiences of patients with cancer undergoing HC and identify their unmet needs through their perspective and that of nurses who work with cancer patients. Our results are expected to assist with the development of suitable nursing interventions and effective healthcare systems for such patients.

Methods

Study design

This was a qualitative descriptive study in which we used individual, semi-structured interviews to explore the experiences of patients with cancer undergoing HC from patients and nurses who work with cancer patients.

Participants and setting

A total of ten patients and ten nurses were recruited at the outpatient chemotherapy center of Yonsei University tertiary hospital, one of the largest hospitals in Korea. The inclusion criteria for patients were adult patients who underwent HC with an elastomeric infuser. The inclusion criterion for nurses was being a certified oncology nurse. Since nurses working in Yonsei University tertiary hospital's outpatient chemotherapy center have provided care for many patients receiving HC, they were interviewed as well to understand patients' various experiences from their perspectives. All patients and nurses were recruited through purposive sampling. Researcher HJ, who had no conflict of interest in recruiting the patients and nurses as potential study participants, conducted the recruitment. We fully explained the study to potential participants and obtained their written informed consent stating that they voluntarily agreed to participate in the study. The patients were interviewed at the outpatient chemotherapy center while waiting for their anticancer drugs to be prepared or while receiving anticancer drugs, such as oxaliplatin or irinotecan, which take approximately 2–3 h to be injected. Nurses were interviewed after they finished work, based on their availability.

In Korea, HC is provided to patients treated with regimens such as FOLFOX (Folinic acid, fluorouracil, oxaliplatin), FOLFIRI (Folinic acid, fluorouracil, irinotecan), and FOLFIRINOX (Folinic acid, fluorouracil, irinotecan, oxaliplatin), which include 5-fluorouracil (5-FU) anticancer drugs that require long-term administration of more than 48 h. In the outpatient clinic, if the doctor determines that the patient is healthy enough to receive chemotherapy, HC drugs are prescribed. Then, patients receive short-term anticancer drugs such as oxaliplatin or irinotecan, at the outpatient chemotherapy center, and the elastomeric infuser containing 5-FU anticancer drug is connected to the chemo port needle before going home. When it is determined that the infusion of 5-FU is completed—when the balloon in the elastomeric infuser is fully inflated—patients visit the hospital to remove the chemo port needle and the infuser because they cannot remove it themselves. If the patients live close to the hospital where they receive chemotherapy, they visit the outpatient chemotherapy center to remove it. However, patients visit hospitals near their homes because the use of the center at night, early in

the morning, or on weekends is limited. Additionally, patients who live far from the hospital where they receive chemotherapy, visit a hospital close to where they live to get it removed. Before starting the first HC, nurses educate patients on how to determine whether anticancer drugs are being injected through the elastomeric infuser and inform them to be careful not to pull out the infuser or chemo port needle. In addition, if patients have problems regarding HC, they can contact the hospital, following which the nurses provide consultation.

Data collection

Data were collected through in-depth individual interviews, according to semi-structured questions, conducted from February 2020 to February 2021. During the data collection process, we sequentially recruited the key informants who would be able to provide us with the best information about HC experiences at the outpatient chemotherapy center of Yonsei University tertiary hospital. Ten patients and ten nurses who volunteered to participate in the study were selected, and all of them completed the interviews. Theoretical saturation was considered to be achieved when it was identified that there was no new content and that contents were duplicated in the 8th and 9th interviews. Data collection was terminated after interviewing a total of 20 participants. Researcher H.J. conducted the interview after receiving training, and each interview lasted from 30 to 60 min. During the data analysis process, if necessary, additional face-to-face or telephone interviews with some patients were conducted, which lasted approximately 10 to 20 min. The interviews were conducted in a private room, for example, a single patient room or an education room in the outpatient chemotherapy center. An interview guide was developed by the researchers based on the study's purpose. The main questions for patients were as follows: (1) How do you feel about receiving chemotherapy at home? (2) What are the benefits or difficulties of receiving chemotherapy at home? (3) What kind of help would you like to get from nurses regarding HC, or do you have any special needs? The interview questions for nurses were modified versions of the questions asked to patients. The questions for nurses were as follows: (1) What are the challenges faced by the patients receiving HC? (2) What kind of help do you think patients receiving HC want from nurses? (3) What are the needs of patients receiving HC? We also asked probing questions depending on participant responses.

Data analysis

Interviews were audio-recorded and transcribed verbatim. Data analysis was carried out by two researchers S.K. and H.J. according to Elo and Kyngäs's¹⁴ inductive content analysis method employed in nursing. The analysis was performed in three steps: open coding, category creation, and abstraction. The detailed process was as follows: (1) The researchers read the transcribed texts repeatedly for familiarization; (2) Meaningful expressions or sentences were highlighted as they were read; (3) Open coding was performed on meaningful statements; (4) A coding list was made in consideration of the appropriateness of the vocabulary and the accuracy of the meaning; (5) The codes were grouped into subcategories according to similarities and differences; (6) Through identification and interpretation of similarities and differences, subcategories were grouped into generic categories, and generic categories were grouped into main categories via abstraction.

Rigor

In this study, rigor was based on four criteria by Lincoln and Guba.¹⁵ For credibility, the analysis and interpretation of the data were confirmed through consultation with researcher S.K., who had extensive experience in qualitative studies. For transferability, researcher M.P. and one participant nurse confirmed whether the findings were applicable to other patients with cancer. For dependability, we prepared a manual for the overall research performance. For confirmability, we continuously

audited the study process in the form of research notes.

Ethical considerations

The study was carried out in accordance with the Declaration of Helsinki and local ethical committees. It was approved by the Yonsei University Health System's Institutional Review Board (Approval No. 4-2019-1197). The researchers assured the participants that their data would only be used for research purposes and kept confidential. Participants could cancel their participation in the study at any time without any reason or disadvantage.

Results

Table 1 presents the patients' demographic characteristics, and Table 2 presents their clinical characteristics. The patients' mean age was 53.3 years, and four visited hospitals near their homes for removal of the elastomeric infuser. All the patients had gastrointestinal cancer, and nine patients had received palliative chemotherapy for stage IV cancer. Additionally, three patients had previously received HC. The patient who received the most HC received it 32 times, and the patient with the least HC experience received it two times. Table 3 summarizes the nurses' characteristics. Nurses' mean age was 40.0 years, and besides one nurse with a master's degree, all others had bachelor's degrees. The clinical experience of nurses in working with patients undergoing HC was 4.8 years on average, and their total average clinical experience was 16.22 years.

The main phenomena experienced by patients with cancer undergoing HC could be classified into four main categories, as follows: (1) ambivalence regarding comfort vs. enduring the discomfort; (2) acceptance of the discomfort as a part of them; (3) the need for more precise, numerical measurements; and (4) the realization that they need similar hands-on care at home as in a hospital. In addition, nine generic categories and 25 subcategories were derived (Table 4).

Ambivalence regarding comfort vs. enduring the discomfort

Sense of freedom and comfort derived from maintaining regular daily life in a familiar space

Most of the patients were most satisfied with the fact that they could live with their families and receive treatments in the comfort and freedom of their homes.

Patient 2: "Rather than being hospitalized, I prefer being treated while watching the kids at home ... because there are no restrictions on my activities. Rather, it would have been inconvenient if I were in the hospital, having to stay inside at all times. Staying at home is much better."

Another patient mentioned that they preferred HC because they did not have to share a ward with other patients and did not have to be confronted with the fact that they are patients, which improved her quality of life.

Table 1
Patients' demographic characteristics (n = 10).

ID	Gender	Age (years)	Marital status	Education	Occupational status	Current residential region	Hospital visited for the elastomeric infuser removal
P1	Man	62	Married	High school	Employed	Rural area	Clinic near home
P2	Woman	49	Married	High school	Unemployed	Seoul	Tertiary hospital, currently receiving chemotherapy
P3	Man	49	Married	≥ University	Employed	Seoul	Tertiary hospital, currently receiving chemotherapy
P4	Woman	67	Married	≥ University	Unemployed	Seoul	Home care service
P5	Woman	50	Unmarried	High school	Unemployed	Seoul	Tertiary hospital, currently receiving chemotherapy
P6	Man	60	Married	≥ University	Employed	Rural area	General hospital near home
P7	Man	50	Unmarried	≥ University	Unemployed	Rural area	Tertiary hospital, currently receiving chemotherapy
P8	Woman	50	Married	High school	Employed	Rural area	General hospital near home
P9	Man	40	Married	≥ University	Employed	Rural area	General hospital near home
P10	Man	56	Married	High school	Employed	Seoul	Tertiary hospital, currently receiving chemotherapy

Patient 5: "I feel less conscious that I am a patient. I could perhaps put it as a different quality of life ... ? Hospitalization involves a collective group lifestyle, which is uncomfortable ... There are problems with using the bathroom and sleeping, staying up all night."

Enduring the suffering due to chemotherapy by controlling the body and mind

Most of the patients and nurses mentioned that patients experienced adverse effects such as nausea, vomiting, loss of appetite, changes in oral sensation, low energy, and numbness. Patients complained of becoming exhausted both physically and mentally and that there were moments during which they wished to give up on the treatment altogether.

Patient 3: "With the increase in the number of times I undergo treatment, certain difficulties continue to emerge ... more psychologically challenging and feeling more drained in the body, those kinds of things ... Because my hands and feet always feel a tingle. Sometimes I really want to give up on the treatment."

To alleviate their mental exhaustion, patients sought self-management methods such as essay-writing, meditation, and physical exercises. They also relied on the support of the people around them to overcome such difficulties.

Patient 5: "Whenever I feel down, I write down something, do something like meditating. I try to exercise and go for a walk. I continuously look out for something to lift my spirits."

Acceptance of the discomfort as part of them

The discomfort and shame associated with daily life With the infuser

All patients and nurses mentioned that it was uncomfortable to carry out activities of daily living with the infuser attached to the waist and that it made the patient anxious when the position of the infuser bag changed or when there was tension on the infusion line.

Patient 4: "It is definitely uncomfortable when carrying out activities ... But now, with an increasing number of treatments, I am getting familiar with it, and it is OK ... The remaining difficulties are things like the line getting in the way when I try to lie down and adjustment of the line, that kind of thing."

Certain patients worried about other people seeing them undergoing chemotherapy as the infuser is conspicuous because of its round, elongated shape.

Patient 7: "This makes my belly look round, especially in summer. To be frank, nobody wants to show it ... I don't want to say that I am a patient when it is not necessary."

Adjusting to the unfamiliar treatment method through experience

When undergoing HC for the first time, patients feel uneasy and anxious about taking high-risk anticancer drugs at home. However, patients psychologically adjusted to it with repeated treatments.

Table 2
Patients' clinical characteristics (n = 10).

ID	Type of cancer	Stage of cancer	Type of chemotherapy	Chemotherapy regimen	Previous experience with home-based chemotherapy	Number of rounds of home-based chemotherapy
P1	Pancreatic cancer	4	Palliative	FOLFIRINOX	Never	9
P2	Anal cancer	4	Palliative	Bevacizumab FOLFIRI	Never	9
P3	Rectal cancer	4	Palliative	Aflibercept FOLFIRI	Yes	Previous HC - 9 Current HC - 8
P4	Pancreatic cancer	2	Adjuvant	FOLFIRINOX	Never	6
P5	Pancreatic cancer	4	Palliative	FOLFIRINOX	Never	4
P6	Rectal cancer	4	Palliative	Bevacizumab FOLFIRI	Yes	Previous HC - 14 Current HC - 3
P7	Advanced gastric cancer	4	Palliative	FOLFIRI	Never	2
P8	Pancreatic cancer	4	Palliative	FOLFIRINOX	Never	32
P9	Rectal cancer	4	Palliative	Bevacizumab FOLFIRI	Yes	Previous HC - 8 Current HC - 23
P10	Sigmoid colon cancer	4	Palliative	Cetuximab FOLFOX	Never	6

FOLFIRINOX, Folinic acid (Leucovorin, FOL), fluorouracil (5-FU, F), irinotecan (Campto, IRI), oxaliplatin (Eloxatin, OX); FOLFIRI, Folinic acid (Leucovorin, FOL), fluorouracil (5-FU, F), irinotecan (Campto, IRI); FOLFOX, Folinic acid (Leucovorin, FOL), fluorouracil (5-FU, F), oxaliplatin (Eloxatin, OX); HC, Home-based chemotherapy.

Table 3
Nurses' characteristics (n = 10).

ID	Gender	Age (years)	Marital status	Education	Years of current clinical experience	Years of total clinical experience
N1	Woman	40	Married	Bachelor	5 years 5 months	17 years
N2	Woman	40	Married	Bachelor	8 years 3 months	17 years
N3	Woman	40	Unmarried	Master	3 years 5 months	12 years 8 months
N4	Woman	40	Married	Bachelor	7 years	15 years
N5	Woman	38	Married	Bachelor	1 year 5 months	11 years
N6	Woman	36	Married	Bachelor	1 year	13 years 9 months
N7	Woman	45	Married	Bachelor	5 years 6 months	20 years 9 months
N8	Woman	38	Married	Bachelor	4 years	15 years
N9	Woman	36	Married	Bachelor	6 years	15 years
N10	Woman	47	Married	Bachelor	6 years	25 years

Patient 3: "I felt very uncomfortable when I first wore the infuser because it was the first time. But these days, perhaps because I have some experience now, such discomfort has declined greatly compared to the first time. I accept it as it is. It has become a part of me."

The nurses also recognized the anxiety of patients starting HC and considered that communication between the patient and the medical staff played a key role in reducing anxiety.

Nurse 9: "Indeed, as there is much anxiety in bringing the device home, I think that the most important point is that nurses try to have conversations that can give the patients a sense of reassurance."

Feeling like they can fly when the infuser is removed

Patients wanted to have the infuser removed as soon as possible after the completion of the treatment.

Patient 1: "When the infuser is removed, I feel like a burden has been lifted off my chest. I wear this wherever I go, therefore, when it is removed, I feel very relieved."

If the chemotherapy infusion was terminated at night or on holidays, patients complained about the inconvenience of having to spend an additional day wearing the infuser. Patients living in rural areas had greater restrictions in terms of hospital visits for infuser removal. Certain patients used the emergency room even if they had to pay more, and nurses were empathetic and expressed their concerns about the grievances of these patients.

Nurse 5: "They say they want to remove it as soon as possible, and the mere sight of the infuser makes them sick. Yes, I also want to remove it as

soon as possible for them. However, as our hospital has standard operating procedures, patients who want to have it removed immediately use the E&A service."

The need for more precise, numerical measurements

Judging the state of chemotherapy infusion through experience

Over time, patients learned how much the size of the infuser balloon should be reduced during infusion. As the change in the size of the balloon is not clearly visible on an hourly basis, they developed their own methods of judging whether the progress of chemotherapy infusion was normal.

Patient 7: "Frankly, I have no idea if the drugs are getting in properly ... I used to look at the infuser every 3–4 h, thinking I would notice the difference. I got used to it over time, looking at the balloon only once a day, noticing its shrinkage."

Expecting cost-effective devices capable of ensuring safe infusion

Certain patients and nurses expressed their expectations of being able to measure the flow rate and the residual volume in the elastomeric infuser and predict the completion time of chemotherapy infusion. They mentioned that it would not only be helpful in planning the hospital visit for infuser removal but also provide motivation and psychological reassurance to endure the remaining infusion time.

Patient 3: "We want to make predictions, visually, not arbitrary estimation by eye ... If there is a device that is a little more predictable, I think it will help me feel more comfortable. 'Oh, this amount of ml went in. I need to

Table 4
The experiences of patients with cancer undergoing home-based chemotherapy.

Subcategory	Generic category	Main category
Treatment in a free and comfortable environment Treatment in a place with family offers a sense of security Treatment while maintaining regular daily routine The hospital setting can make the patient more ill Treatment without having to wait for an available bed in a ward	Sense of freedom and comfort derived from maintaining regular daily life in a familiar space	Ambivalence regarding comfort vs. enduring the discomfort
Difficulties related to symptoms caused by chemotherapy Self-managing and enduring the side effects Overcoming cancer with a positive mindset and help from the support system	Enduring the suffering due to chemotherapy by controlling the body and mind	
Discomfort in daily living due to wearing the infuser bag Hiding the infuser with clothes because they feel conscious about it being noticed by other people Accepting the discomfort due to wearing the infuser and getting accustomed to life with the infuser Anxiety related to the infuser changes to the sense of trust over time with experience Adjusting themselves to the unfamiliar treatment method—home-based chemotherapy	The discomfort and shame associated with daily life with the infuser Adjusting to the unfamiliar treatment method through experience	Acceptance of the discomfort as a part of them
Wishing to remove the infuser as soon as possible Expecting to be able to remove the infuser at any time in the outpatient or inpatient care Expecting a streamlined process for the removal of the infuser at other hospitals	Feeling like they can fly when the infuser is removed	
Learning how to visually judge the status of chemotherapy infusion Difficulties in checking the chemotherapy infusion status by observing changes in the volume of the infuser balloon Expecting an easy-to-use and cost-effective device that can measure the dose and speed of chemotherapy infusion Hoping to be able to predict when the chemotherapy infusion will end for the patient's convenience and psychological stability	Judging the state of chemotherapy infusion through experience Expecting cost-effective devices capable of ensuring safe infusion	The need for more precise, numerical measurements
Requiring training materials that provide a method to learn how to evaluate the status of chemotherapy infusion in a way that reflects actual changes in the infuser balloon Requiring the preparation of an educational tool to provide a sufficient understanding of chemotherapy infusion The need for nursing care tailored to the symptoms and needs of patients undergoing home-based chemotherapy Expecting the provision of immediate countermeasures in case of chemotherapy infusion-related problems, and nursing care for safe chemotherapy infusion Expecting adequate home care services for patients undergoing home-based chemotherapy	The demand for education that reflects the reality The difficulty of receiving immediate care when patient needs arise	The realization that they need similar hands-on care at home as in a hospital

hold on just a little more,' this kind of thinking. Psychologically, it would provide some help to patients."

Nurse 10: "Patients want to know when it will end, to be frank. They want to predict the end time and want to know when exactly it will end, but the current infuser devices have very large margins of error."

Certain nurses mentioned that when re-preparation of the anticancer drug is needed in the course of the chemotherapy infusion, the dose of the required anticancer drug for re-preparation can be accurately determined.

Nurse 10: "Sometimes, in the case of patients who visit the hospital in the middle of their chemotherapy session because of infuser malfunction, the infuser needs to be removed and replaced with a new one because of the expiry date of the anticancer drug. However, we cannot measure exactly how much of the drug went in and how much is left."

The realization that they need similar hands-on care at home as in a hospital

The demand for education that reflects the reality

The interviews revealed that nurses used various materials, such as pamphlets provided by the infuser manufacturer, hospital guide leaflets, and a real infuser, for patients' education on evaluating the state of the elastomeric infuser.

Nurse 5: "We show a real infuser while we explain ... because the patients cannot form an accurate idea when they only see the pamphlet. When they actually see the real infuser, they can learn to check for themselves that the drug is being properly infused."

The nurses recognized the need for improvement of the educational materials to reflect real-world practice because of the differences

between the description in the pamphlet and the actual operation of the infuser.

Nurse 2: *“When we explain, we tell them not to look at the numbers (written on the infuser case). I tell them to look at the shape of the balloon. But, even if we tell them, some patients focus on the numbers ... So, it would be great if there is something like an improved pamphlet on how to check the infuser.”*

The difficulty of receiving immediate care when patient needs arise

Nurses were empathetic and regretful that they could not provide hands-on care in the case of adverse effects while the patients undergo HC or in case of problems related to chemotherapy infusion.

Nurse 6: *“If the patient is admitted to the hospital, medical staff can monitor and observe the patient in case of problems such as nausea or vomiting, or difficulties in infusion, and we can immediately act and provide hands-on care.”*

Nurses indicated that they instructed patients to ask for additional prescriptions of antiemetics when they visit the hospital for outpatient appointments to address the limitations in providing hands-on care for side effects during HC.

Nurse 10: *“In the past, when the patients were hospitalized for 3 or 4 days and underwent the chemotherapy infusion during that time, when they had symptoms such as nausea or vomiting or other difficulties, they could get additional fluid therapy or antiemetics. But if they are at home, this type of additional intervention is not possible ... In such cases, we see the patient in the outpatient clinic for a sufficient explanation and to give them a prescription for PRN medication for when difficulties arise.”*

Discussion

This study revealed the experiences of patients undergoing HC. The patients enjoyed the comfort of their own homes while undergoing chemotherapy but noted that it remained a struggle to endure the physical and mental exhaustion it causes. In addition, they found it difficult to judge the infusion rate and completion time of the anticancer drug injection, and they expressed a need for nursing care as soon as difficulties occurred.

The patients were satisfied that they could receive chemotherapy while in the comfort of their homes rather than being in the hospital. This is similar to the results of the study in which patients receiving chemotherapy at home reported higher satisfaction than those receiving chemotherapy at the hospital.⁹ Additionally, this is consistent with the results of a previous study,¹⁶ in which patients with cancer undergoing subcutaneous HC reported that it “fits in with work-life,” “puts my mind at ease having treatment at home,” and “upsets me going to Clatterbridge Cancer Centre, so better at home.” This is also similar to “stress from hospitalization in a multiperson ward,” one of the subcategories in a grounded-theory study on the inpatient treatment experience of patients with lung cancer.¹⁷ Despite positive aspects of HC, patients struggled to overcome the mental and physical exhaustion caused by the chemotherapy at home. Patients previously reported that adverse events such as nausea, vomiting, and peripheral neuropathy are very painful and incessant^{18,19}; in terms of self-management in relation to cancer treatment, patients used facilitators such as “treatment adherence” (using medication for side effects) and “emotional management” (eg, maintaining a positive outlook).²⁰ In a report on chemotherapy-related adverse effects, 41%–67% of respondents answered that they would immediately request treatment for acute effects such as bleeding and fever, whereas only 12%–16% of the patients answered that they would report to the medical staff immediately for chronic adverse events such as tingling or numbness.²¹ Therefore, comprehensive assessment by a nurse

is required in outpatient care, similar to the patient assessment conducted at admission.

Patients mentioned that, as they became accustomed to HC, they accepted the physical and social discomfort as a part of themselves. As the number of rounds of HC increases, patients learn more about the benefits of HC, have the capacity to deal with chemotherapy-related adverse effects or discomfort during social activities related to HC, and it can be considered that they are adapting to HC. Similarly, patients with cancer who underwent colostomy in a previous study reported finding it difficult to come to terms with it because of factors such as fear of discrimination and changes in body image.²² However, certain patients had a positive attitude of willingly adjusting their lives to accept the colostomy, revealed as a subtheme of “stoma self-acceptance.”²³ Although the participants of this study did not have a permanent colostomy, they had to carry an infuser containing anticancer drugs; thus, both types of patients were conscious of what other people thought about it but adapted to the treatment method over time. Therefore, it is necessary not only to provide education on the management of symptoms related to cancer and chemotherapy but also to provide education on anticipated physical, mental, social, and spiritual difficulties so that patients can establish adequate coping strategies at home.

In this study, participants expressed difficulties related to the time and dose of chemotherapy infusion. In a study evaluating the performance of the infuser, out of 50 cases for which the infuser was disconnected in the hospital, 50% had completed the chemotherapy infusion on time, but 40% experienced the infusion to be slower than planned, and 35% had 20 ml or more of the anticancer reagent left in the infuser.²⁴ The reliability and accuracy of the infuser play a critical role in ensuring patient comfort and safety in the case of HC with an infuser.²⁵ Therefore, we believe that the development of a monitoring device, which is capable of accurately measuring the infusion status of the elastomeric infuser, is required for safe and accurate treatment.

The nurses expressed regret for not being able to provide hands-on care as soon as the needs of the patient arose. This is consistent with previous patient-reported concerns of “fear of the pump malfunctioning at home” and “lack of hospital staff and supervision.”³ In outpatient care, there are limitations to providing nursing care at a similar level as inpatient care. Since patients starting HC may have some anxiety or fear at first due to the unfamiliar treatment method, a digital system that allows immediate, real-time counseling will be helpful, especially if patients experience HC-related problems at home. Patient satisfaction with HC would improve with the provision of tailored nursing care. This could include the development of cost-effective devices for safe chemotherapy infusion, as revealed in our third main category, as well as the development of mobile applications that nurses can use to monitor patients in the electronic health record. In addition, the contents of such an application may include medication monitoring; records of symptoms, tests, and treatments; symptoms and side-effect management training; and consultation with medical staff, which would provide a sense of reassurance to patients and improve medication adherence and symptom management.^{26–28}

Limitations and strengths

There are some limitations. First, as participants were middle-aged and their educational level was high school or higher, the study may have limited generalizability. In the future, these results should be validated for patients with more diverse characteristics. Second, the participants may have been of high socioeconomic status because patients were hospitalized for chemotherapy if they were unable to manage HC. Therefore, it is necessary to identify the experiences and needs of people of low socioeconomic status and develop an HC system that is suitable for them. Finally, since this study only identified the experiences of patients undergoing HC, we suggest that future studies compare the experiences

and unmet needs of patients undergoing inpatient chemotherapy and those undergoing HC.

Despite these limitations, this study has several strengths. Since previous studies have primarily focused on the cost-effective aspect of HC, this study provides rich and detailed information regarding Asian cancer patients' experiences and nursing needs while receiving HC, especially considering the increase in HC in Asia. Moreover, this study is significant since nurses were also interviewed to understand various nursing needs of patients who were receiving HC.

Conclusions

We discovered that patients tried to deal with the difficulties encountered during HC on their own and desired nursing care at home similar to that available in inpatient care. Nurses should be aware that patients undergoing HC have fewer opportunities to receive direct nursing care than inpatients, and close and continuous assessment of their needs is required. In addition, nurses have to make an effort to identify patients' HC-related health problems and devise nursing interventions to improve patient safety during HC.

Declaration of competing interest

None declared.

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Authors' contributions

Conceived and designed the analysis: Sanghee Kim, DaeEun Kim, Changmin Lee, Mehee Park, & Sunemee Rhue. Collected the data: Hyoeun Jang, Mehee Park, Sunemee Rhue. Contributed data or analysis tools: Hyoeun Jang, Changmin Lee, Seulgee Kim, Byungmun Kang, & Haeri Lee. Performed the analysis: Hyoeun Jang, Sanghee Kim, & Mehee Park. Wrote the first draft: Hyoeun Jang, Sanghee Kim, DaeEun Kim. Review and editing draft: Hyoeun Jang, Sanghee Kim, DaeEun Kim, Mehee Park, Sunemee Rhue, Changmin Lee, Seulgee Kim, Byungmun Kang, & Haeri Lee.

Ethics statement

The study was carried out in accordance with the Declaration of Helsinki and local ethical committees. It was approved by the Yonsei University Health System's Institutional Review Board (Approval No. 4-2019-1197). The researchers assured the participants that their data would only be used for research purposes and kept confidential. Participants could cancel their participation in the study at any time without any reason or disadvantage.

Presentation at a meeting

Poster presentation in part at MASCC/ISOO 2021 Annual meeting.

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