




Opinions and Experiences of Patients Receiving Oral Chemotherapy: A Qualitative Study

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ABSTRACT

Objective: This study is a qualitative study aimed to determine the opinions and experiences of patients receiving oral chemotherapy.

Methods: The study was conducted in 2018 with 18 volunteers who admitted to the outpatient oncology clinic of a university hospital and received oral chemotherapy. In data collection, a description form and a semi-structured interview form were used. In data analysis process, transcription after each interview and evaluation steps through thematic content analysis method were employed. COREQ-Consolidated Criteria for Reporting Qualitative research was used in the structuring and reporting phase of the qualitative study.

Results: The themes obtained in the study were access to drugs, use of medicine, side effects and control of treatment, approach of health professionals and support of family and relatives. There is a need to ensure the continuity of the treatment follow-up period in order to improve treatment compliance of patients, to monitor side effects of treatment and to ensure safe use of medicines.

Conclusion: In this process, it is crucial that nurses take an active role in patient education and counseling among health professionals so that weaknesses in the patient's drug use process and opportunities for improvement could be identified.

Keywords: Oral chemotherapy agents, patient, qualitative study, experience

1. INTRODUCTION

Oral chemotherapy drugs provide patients and caregivers with a great number of benefits socially and economically. The advantages include the feeling of control over treatment and ease of application for patients and caregivers, the ability to maintain daily life activities, the reduction in costs associated with transportation and treatment services, and the reduction in burden due to treatment in terms of health services (1-4). While oral chemotherapy drugs sometimes become complicated for patients considering their narrow therapeutic indices, they can also cause patients and caregivers to get confused due to the intermittent nature of treatment regimens. In addition, there are different factors that affect the compliance of a patient with oral chemotherapy drugs. Amongst these factors can be listed as the accessibility to drugs, costs - a barrier for all age groups, complexity in dosing, obliviousness, side effects and misinterpretation of instructions (4-8).

In the application of oral chemotherapy, the responsibility of the patient in self-management has increased as some traditional responsibilities of healthcare professionals were transferred to patients (9). Moreover, continuous increase

in the application of especially oral chemotherapy and self-application instructions on medicines carried on the agenda the compliance of the patient with treatment. This challenge helps patients to be in compliance with treatment (10). Ruddy et al. (11) emphasize that the indication of patients' optimal compliance with oral chemotherapy could be as 'no dose skipping, no extra doses, no wrong doses or no doses taken at the wrong time'. Özkaraman et al. (1) determined that those who were motivated by patients in the rheumatology and oncology group, who were confident and believed that the treatment would be beneficial, had a high level of compliance.

Recent studies have shown that patients and healthcare workers considered oral chemotherapy as safer than intravenous chemotherapy (12,13). Several people believe that oral chemotherapy drugs are less toxic than IV chemotherapy drugs. Chemotherapy drugs, whether oral or IV, typically have a narrow therapeutic index that places patients at greater risk against harmful effects (14,15). All available drugs should be reviewed with patients or their family members in order to intervene in potential

drug interactions or dietary requirement, and clear dosing instructions should be provided including the instructions to be carried out when a dose is skipped or a dose of vomit occurs. Patients should be trained on the requirements for medication storage such as temperature or light resistance. Patients, their families and caregivers should also be informed of oral chemotherapy, dose adjustments, or safe return of drugs to pharmacies or oncology clinics (16). Side effects experienced by patients could reduce the adherence to treatment, or patients could be generally reluctant to report side effects because of fear of treatment interruption and reduction of doses (17). The involvement of a family member or caregiver in the treatment can help cement the educational knowledge at home and motivate patients to comply with the treatment. This situation is of great importance for especially elderly population whose cognitive challenges are likely to affect the compliance with treatment and for children and adolescents for whom the relationship between parental participation and compliance are critical (18).

There is no single standard intervention to overcome obstacles in patient compliance (19). However, multidisciplinary and multimodal strategies are considered to be effective. Patient education is primarily emphasized in the literature (10,20). Patient education is a significant component for the enhancement of adherence to treatment. It should be tailored for each patient individually and patients should prefer direct interaction in general with health care providers. Healthcare professionals should consistently keep a tab on patients in order to answer their questions, and remind them about counseling and treatment regimens. Primarily oncology nurses, who are constantly interacting with patients, play a crucial role in providing the patients with education on many aspects of the treatment regimen of oral chemotherapy treatment. Training for oral chemotherapy is not a one-off event but should be continued throughout the treatment. The follow-up of patients provides the opportunity for nurses to reinforce previously discussed concepts, educate them on symptom management, and assess the compliance with treatment. Oncology nurses have a unique position to step into new roles that emphasize patient and family education and support. Individualized patient support will be of vital importance in quality patient care and family, and management of side effects during oral chemotherapy. Patient education, communication, symptom management and proactive follow-up are among the primary roles of oncology nurses (9,10,20,21). In conclusion, it is stressed that the safe administration of oral chemotherapy would have a positive impact on the clinical and care outcomes of patients.

The related literature examined reveals that the studies, conducted with patients who received oral chemotherapy, are quantitative studies and that these studies mostly evaluate the knowledge and application related to drug use and compliance (1,13). However, very little is known about the experience of patients with such medication. In the study designed to better understand how these gaps could be filled and how patients manage oral chemotherapy, it is

aimed to identify the weak points and recovery opportunities of patients during oral chemotherapy. Therefore, multidisciplinary approaches are needed to safely use oral chemotherapeutics and to reduce medical errors. This study was carried out with a phenomenological research pattern within the scope of qualitative research model in order to determine the opinions and experiences of cancer patients receiving oral chemotherapy.

2. METHODS

2.1. Study Design

The study was carried out on 18 people in total, 10 women and 8 men, who agreed to participate in the study and submitted their informed consent out of the patients who stayed in the oncology clinic at a university hospital, were diagnosed to have cancer, have been taking oral chemotherapy after being admitted to the oncology clinic of a university hospital with diagnosis of cancer. In qualitative research, there is no set rule for sample size. The size of the sample can vary according to the status of getting sufficient information from the participant and the diversity of the sample chosen. In qualitative research, the sample size is generally determined based on the information needs. One of the principles guiding this issue is data saturation. In other words, the sampling reaches a point where no new information is obtained and reaches the surplus (22). COREQ-Consolidated Criteria for Reporting Qualitative research was used in the structuring and reporting phase of the qualitative study.

2.2. Procedure

The study aimed to investigate in-depth the issue through semi-structured interview guide examining the problems which patients face due to the use of oral chemotherapy, the ways they cope with and the problems related to the access to drugs, how they paid attention to security measurement related to the preparation and storing of medication and whether they receive support. The questions in the interview guide were determined following the experiences of researchers and review of the related literature. The interviews were held in the interview rooms, which were quiet, well-lit and comfortable enough for individuals to express themselves without interruption. Interviews and analyzes were carried out by researchers who participated in qualitative research course and had previous qualitative study experience. The purpose of the study was explained to the patients who came to the outpatient appointment. After receiving verbal and written consent from the patients, a semi-structured interview was conducted using face-to-face interview technique. A voice recorder was employed to record the data obtained during the interview.

2.3. Measures

An identification form and interview guide were used to obtain the data in this study. Identification form includes details

about the age, sex, marital status, educational background, diagnosis, drugs used in oral chemotherapy and whether information has been provided on oral chemotherapy drugs. The semi-structured questionnaire was created from the researchers' experiences and academic literature.

The questions in the interview guide were as follows:

1. Please tell us your name and introduce yourself briefly.
2. Can you share with us your life experiences since you started taking oral chemotherapy?
 - What are the convenience/difficulty, advantage/disadvantage you have experienced with the use of oral chemotherapy? How are their effects on your daily life?
 - Are there problems with access to drug? What kind of problems?
 - Have you experienced any of the side effects? What kind of applications do you do to reduce the side effects?
 - What are the difficulties you have regarding the storing, preparing and using your drugs?
3. What should be the approach of health professionals from the moment you start taking oral chemotherapy? What are the issues you are in need of support?
4. What do you think of the support you receive during the course of your treatment from your family members and immediate circle?

2.4. Data Analysis

The data obtained from face-to-face interviews were analyzed using thematic analysis method. Voice recordings were documented immediately after the interview. Qualitative content analysis method was used in data analysis. According to Braun and Clarke (23), the content analysis method includes the following steps: (1) practice with data;

(2) generation of initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes and (6) generating the report. Researchers with qualitative research knowledge and experience applied content analysis and identified themes independently of each other, based on the specified steps. Each transcription process took about 30-45 minutes. The researchers debated until they agreed on the data and identified the themes that were thought to best describe the findings. In the research, codes such as H1, H2, H3... were used for the interviewers.

2.5. Ethical Considerations

Before the study was conducted, researchers obtained the necessary approvals from the institution, where the study would take place and the Ethics Commission at Gazi University (77082166-604.01.02-). Patients were informed that the decision on whether they wanted to participate in the study or not was entirely up to them, that the data to be collected through the study would only be used for purposes of this research and that their privacy would be protected.

3. RESULTS

3.1. Description of the Participants

The patients, taking oral chemotherapy, are in the age range of 36-58 years, dominantly female (n=10), married (n=15), unemployed (n=12) and have middle income. A majority of patients (n=10) have a chronic disease such as diabetes and hypertension, have admission medical records (n=16), are mostly diagnosed with colon cancer (n=8) and are using capecitabine for oral chemotherapy (n=9).The findings of the study were categorized under such topics as access to drugs, drug use, approach of health professionals, support of family members and close relatives, and side effects and control of the treatment (Figure 1).

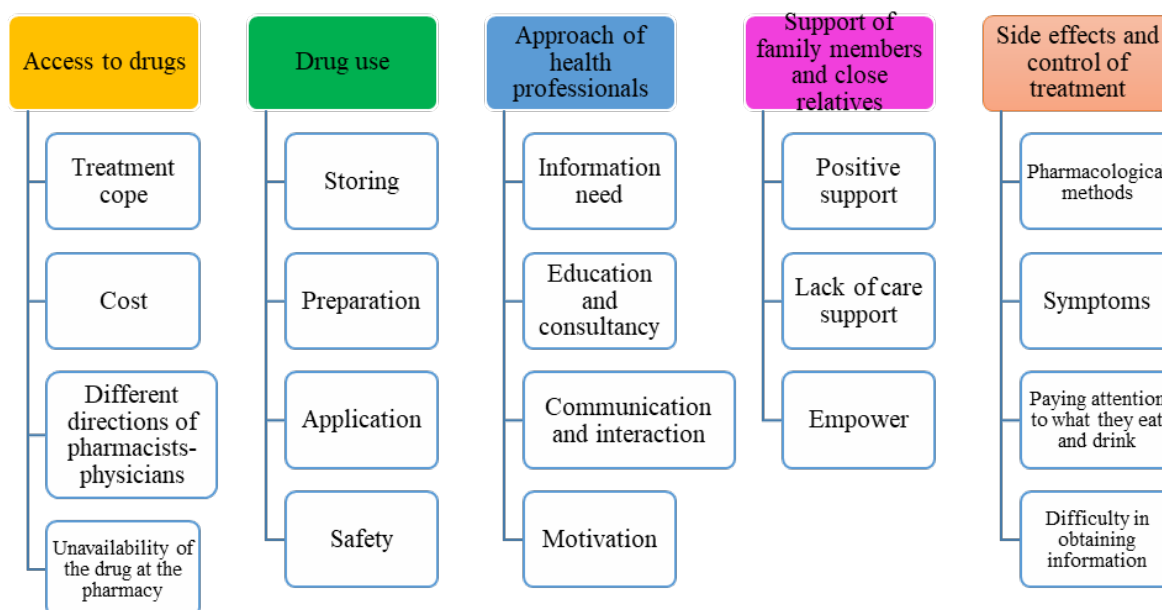


Figure 1. Themes and sub-themes

3.2. Theme 1: Access to Drugs

While most of the patients stated that they did not have any problems with access to drugs, they encountered problems with the costs, scope, different directives of pharmacists-physicians and unavailability of the drug at the pharmacy. A few statements of the patients are shown as in the following:

"There are times when I could not find the drug at the pharmacy..." (H1)

"We could not find the drug in any pharmacy'. Later, we found it in a drug warehouse. They were so nice and helped us. Otherwise, we had to keep searching for the drug..." (H4)

"The statements of our pharmacist about the use of the drug contradicted with the statement of our doctors. Why is there such a dilemma?..." (H5)

3.3. Theme 2: Drug Use (Storing, Preparation, Application)

Majority of the patients stated that they did not have any difficulties using oral chemotherapy drugs. However, according to the statements of the patients, they did not have enough knowledge on the safety measures on such issues as the preparation and preservation of the drug. Elderly patients are supported by their family members due to the loss in their motor skills and cognitive level. They receive help in such activities as remembering the drug, calculating the dose, and opening the drug lid. Some of the statements of the patients are illustrated as follows:

"My daughter often reminds me to take my medication on time and keeps a note of the time I take the dose of the drug. We keep the drugs in their own packages. She makes cleaning twice after I go to toilet..." (H6)

"I take the pill in my hand and swallow it. I am able to fulfil my own needs. I take the drug in my house so there is no need to come and go between the house and hospital. It is easier this way..." (H12)

"I keep it in the cupboards to which my child cannot reach. I do the same for all medication. Apart from that... (thinking), there is nothing I pay attention to, indeed..." (H13)

"We searched on the web and learned that there was a lot to pay attention to... I am worried that I am also putting my family at risk..." (H18)

3.4. Theme 3: Approach of Health Professionals

A few patients in our study reported that their doctors informed them of the intake method and dose of the drug in the first clinical encounter in which oral chemotherapy was prescribed so that they could meet their needs. The statements of the patients with regards to the approach of health professionals showed that no communication and interaction on education and consultation regarding the management of oral chemotherapy treatment. The statements of the patients are listed below:

"We receive information on the drug from our doctor. We go to Emergency Department when we face a problem. We sometimes consult with a pharmacist..." (H2)

"Healthcare professionals are good at giving moral support and motivation. They are friendly. I also have difficulty in hearing. They speak loudly, for instance..." (H7)

"When I started to receive treatment through the vein, they gave me a paper. I read the information about the treatment and gave my approval for it. I also read the booklet they gave me..." (H11)

"While taking medication from the vein, they informed me briefly about the possible side effects such as hair loss, anemia and nausea. However, I did not get any other education about the drug..." (H14)

3.5. Theme 4: Support of Family Members and Close Relatives

The patients interviewed for the study often expressed the positive support they received from their families. Only one patient stated that he was not taken care of by his wife and family. The statements of the related patients are listed below:

"My family has been there for me throughout the entire treatment process... They show their support in many ways. They help me come to the hospital and get my medication from the pharmacy. Even though I sometimes feel bad about it, it gives me strength to know that they are with me..." (H11)

"I need care. I have a husband...(hesitating). Since he is a man, he cannot help me much. In other words, I need care. My family does not support me. That is why the members of my family are very busy and my parents have many babies. They have 10 children and it is a lot to take care of. I ... (thinking) am the one who needs care more. It is so difficult to deal with this disease. It is so difficult..." (H15)

3.6. Theme 5: Side Effects and Control of the Treatment

Majority of the patients reported to have experienced one or more of the side effects that might be associated with oral chemotherapy. While controlling the side effects, they mentioned that they applied to pharmacological methods and paid attention to eating habits. Below are a few examples of the side effects experienced by the patients:

"It slightly lowers my resistance, also causing nausea and fatigue..." (H9)

"It shakes me up so much. My hands and feet become numb. It caused all my nails to fall off. My toenails also fell off. It makes me suffer from insomnia. I became an alarming person..." (H10)

"...it only causes constipation at an extreme level. That was the only side effect I had... I used a herbal medicine for constipation..."

"I had many sores in my mouth. I was not even able to drink water. I could not eat. I ate less. But later they started to heal little by little..."

"I was suffering for 2-3 days when I used this drug. I mean, I did not suffer, but rather drinking water tasted different for instance..." (H14)

"I am extra careful when it comes to my food I eat yogurt every day. I drink as much water as I can. I drink two jugs of water. There are times I drink one jug of water..." (H15)

"It gets harder to consult when side effects occur as I am a patient at the outpatient clinic..." (H17)

"I do not think that the drug is that effective... Let me put it this way. I have been using this drug for nearly two years. However, I did not see any changes... It does not work on me..." (H18)

4. DISCUSSION

On the fundamental basis of application of oral chemotherapy in an efficient and successful way lies patient's compliance with the treatment. Noncompliance with treatment reduces the efficiency of oral chemotherapy treatment (21,24). The opinions and experiences of the patients who are using oral chemotherapy drugs were examined in this study in order to better understand how they would deal with oral chemotherapy. Findings obtained in line with the opinions of the patients were discussed according to the following titles.

4.1. Theme 1: Access to Drugs

It is important for patients to have easy access to health care and home care services. Oral chemotherapy is usually performed at home under the supervision of the patient (24,25). This is the most significant advantage of oral chemotherapy. Patients usually have the opportunity of choosing oral chemotherapy because of the easy method of using the drug in the comfort of their home. They think that it reduces the number of visits to the hospital, reduces anxiety, allows them to maintain their work, and enables them to avoid complications arising from intravenous injections. Liu et al. chose to use oral chemotherapy (89%) due to convenience of treatment (57%), issues related to IV administration and needles (55%) and environmental control (using drugs at home) in the study they conducted with 103 patients with terminal cancer. Factors such as the high cost of the drug and not being able to find it in drug stores affect the patients using oral chemotherapy and their relatives physically, financially and emotionally (26). However, the loss of dose and the delay of treatment slow down the process. Similarly, the patients often stated in our study that they had problems finding the drug in pharmacies.

4.2. Theme 2: Drug Use (Storing, Preparation, Application)

The correct and safe use of the drugs during the course of the treatment is important for the efficacy of the treatment

(1). When the relevant literature on the accurate and safe use of oral chemotherapeutics is reviewed, safety measures such as washing hands before touching the drug, keeping antineoplastic drugs separate from other drugs, interaction of oral chemotherapy with other drugs and return of unused drugs should be taken. The drug that drips onto the table, sink, floor and clothes could enter the body through skin contact during the preparation and administration of the drug. Patients and caregivers are advised to immediately transfer the drug from its packaging to a drug container before taking it so that they will not touch the drug with their bare hands. In case the tablet breaks or crushes and the capsule opens or the drug falls onto the floor, the drug could enter the body via inhalation. If the patient is having difficulty swallowing solid oral dosage forms, the patient or caregiver needs to contact a pharmacist for information (14,25,27). Patients should be briefed on not chewing or crushing tablets or not opening capsules before getting in touch with a pharmacist to get information about how to make the process safer. Oral chemotherapeutics should be kept in safe places where children and animals cannot reach. In addition, improper disposal of drugs and drug disposal, which remain after the preparation and administration of drugs, cause environmental contamination (14,22,25,27,28). In our study, it was found out that a vast majority of the patients taking oral chemotherapy did not have adequate knowledge of the safe use of the drug. This result indicates that it influences adversely patients' coping with side effects related to compliance with treatment and treatment itself.

4.3. Theme 3: Approach of Health Professionals

The activities of healthcare providers and their attitudes towards patients strongly influence adherence to drugs. During the course of treatment, nurses are responsible for informing patients taking oral chemotherapy about drugs, potential side effects, and measures to mitigate the side effects (29,30). Patient's physical and psychosocial state, recognition state of diagnosis and scheduled treatment should be initially evaluated. Nurses should plan training sessions for patients and their families about approaches to the side effects of drugs, recognition and evaluation of the side effects and minimization of the side effects. They should make time for the questions of patients and their families and cooperate with other health professionals when needed. Health professionals need to be aware of possible problems and keep an eye on these issues in order to maintain the effectiveness of oral chemotherapeutics (14,24,25,29,30). It is necessary to determine the variable levels of absorption of oral chemotherapeutics, unexpected and incomplete bioavailability, and uncertainties in patient compliance. On the other hand, as suggested in the statements of the patients in our study, training materials and counseling on patients taking intravenous chemotherapy are of particular importance. The study proved that the patients were often in touch with their physicians during their appointments at the outpatient clinics. They stated that their physicians informed them about the use of drugs. The training and counseling

needs of patients should also be met by nurses who have a long-term association with patients in order to ensure the sustainability of treatment and to improve the quality of care (14,24,25,29-31).

4.4. Theme 4: Support of Family Members and Close Relatives

In addition to the support of health professionals, it is important for patients to get psychosocial and environmental support in order to cope with the issues that occurred over the course of their treatment. In our study, the patients reported that their families cared more about them after they were diagnosed with cancer, that they were pleased about it and that they supported them with the preparation of the drug, reminders for the medication time and management of the side effects. Families have the greatest responsibility in this regard (32). Nevertheless, some of the patients in the study stated that they were worried that they became a burden on their families and jeopardized the safety of their families who were living with them in the same house. Tuncay's study also supports the results of our study. According to this study, patients sometimes think that they burden their families and feel weak against their families who feel sorry and try hard for them (33).

4.5. Theme 5: Side Effects and Control of the Treatment

Like all types of chemotherapy, oral chemotherapy also has side effects. Each individual has a different response for treatment. Hence, the severity and type of side effects can vary from person to person. While the patients in our study stated that they faced some problems such as fatigue, constipation, numbness in hands and feet, loss of appetite and dry mouth, some of them said that they did not have any problems. It should be assessed whether the patients who had no problems were informed about the side effects of the treatment. That is why, in a qualitative study conducted for patients taking oral chemotherapy by Denois et al. (34), it was determined that patients could not identify and report significant signs of toxicity. It was noted that patients should be trained in identifying side effects and reporting.

Özkaraman et al (1) stated that in a quantitative study with patients taking oral anticancer drugs, 41.4% of oncology patients experienced side effects. Nausea-vomiting and malaise are among the first symptoms. In the same study, it was determined that more than half of rheumatology patients experience fear due to side effects that may occur due to oral chemotherapies. It was also found that individuals who do not have the fear of developing side effects due to drugs have better drug compliance (1). Similarly, Joplin et al (35) determined that individuals with rheumatoid arthritis have anxiety about the necessity of treatment against side effects. It can be said that the planning of nursing interventions for questioning the beliefs of patients about the side effects of oral chemotherapeutic agents, understanding their fears and coping will increase the compliance of the treatment.

4.6. Implications for Research and Practice

The use of oral chemotherapy drugs for cancer treatment has an increasing trend. The desired impact in oral chemotherapy treatment can be achieved with patient adherence. Oncology nurses need to take an active role in patient education and counseling and to support patients and their families in increasing their compliance to treatment. It is believed that the drug compliance of individuals using oral chemotherapeutic drugs could be improved through education and support programs, and that the beliefs of patients about treatment regimens could affect drug compliance and treatment process. However, an interdisciplinary approach is considered to be inevitable for the monitoring of the side effects of treatment and the safe use of drugs.

Oncology patients can make use of preliminary and/or periodic training, follow-up by phone, monitoring of self-managing drugs and participation of family members or caregivers in order to improve the compliance of patients to oral treatment regimens. As the therapeutic paradigm for cancer continues to evolve, oncology nurses will play an important role in engaging with patients and providing them with individualized education.

Having one-on-one interviews with the patients in qualitative studies and trying to figure out the management of oral chemotherapy treatment are the strong points of this study. Working with a heterogeneous group is the weak point of the study. Even though the side effects of drugs are generally similar, some drugs have more side effects. Despite the fact that there is a significant increase in the availability and use of oral chemotherapeutic agents, guidelines for safe use are still being developed.

5. CONCLUSION

Patients reported that they were greatly satisfied with oral chemotherapy. However, it was observed that patients need information about access to drugs, use of drugs, education and counseling on symptom management, and social support, that lack of knowledge leads to anxiety, and that patients get information about treatment mostly from doctors. Further research is required to determine the best practice in patient education, monitoring and safety management and to determine the gaps that may appear between the roles and practices of nurses.

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