

## Family's experience in Caring of Cancer Patient undergoing Oral Chemotherapy : A Study Phenomenology

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### ABSTRAK

Penggunaan kemoterapi oral semakin meningkat saat ini. Keluarga yang secara langsung terlibat dalam merawat pasien harus menyadari efek samping dan cara menangani terapi ini dengan aman. Penelitian kualitatif dengan pendekatan fenomenologi dilakukan untuk mendapatkan gambaran mengenai pengalaman keluarga dalam mengelola perawatan pasien yang menerima kemoterapi oral. Data dikumpulkan secara semi terstruktur melalui wawancara. Penelitian ini terdiri dari 10 partisipan keluarga yang memenuhi kriteria inklusi. Hasil penelitian menunjukkan terdapat tiga tema terkait bagaimana keluarga merawat pasien dengan oral chemotherapy di rumah. Ketiga tema tersebut adalah 1) kurangnya pengetahuan keluarga tentang oral kemoterapi, 2) kebingungan keluarga dalam penanganan keamanan oral chemotherapy dan 3) ketidakmampuan keluarga dalam menangani efek samping dan menjaga kepatuhan. Ketiga hal ini dianggap masih belum bisa dilakukan oleh keluarga dan membutuhkan bimbingan serta informasi dari petugas kesehatan. Oleh karena itu, petugas kesehatan profesional terutama perawat diharapkan dapat memberikan edukasi dan perhatian yang lebih kepada keluarga tentang bagaimana pemberian kemoterapi oral yang baik, penanganan yang aman serta peningkatan kepatuhan dalam menjalani perawatan. Pemberian intervensi multikomponen yang mencakup pendidikan, peralatan pendukung, dan teknologi dipercaya dapat meningkatkan kemampuan dalam perawatan dan kepatuhan dalam menjalani kemoterapi oral, sehingga dapat membantu keluarga untuk memberikan rasa aman dan kasih sayang yang kepada pasien.

**Kata Kunci:** Keluarga, Kemoterapi oral, Perawatan, studi kualitatif

### ABSTRACT

The use of Oral Chemotherapy is increasing nowadays. A family who directly involves in caring the patient should be aware of the side effect and how to handle this agent safely. Phenomenology approach of the qualitative study was conducted to get illustration regarding family experience in managing the care of the patient receiving oral chemotherapy. Data were collected by semi-structured interview. The study gathered from 10 participants from the family who meet inclusion criteria. The current study showed that three thematic items related to how they manage to care for their family's member. Those are 1) Lack of knowledge about oral chemotherapy, 2) Confusing in handling safe oral chemotherapy, and 3) lack of ability in caring patients when side effect appeared and the following adherence. These three things are considered lacked by the patients. Therefore, health care professional, especially nurses,

*are expected to give more education and attention about administering oral chemotherapy agents, safe handling, adherence, and managing side effects both of in clinical and home setting. Multi-component interventions that include education, equipment, and technology can improve compliance with oral chemotherapy and will help families to secure and provide the appropriate affection to them.*

**Keywords:** *Family, oral chemotherapy, care, qualitative study*

## INTRODUCTION

Cancer is one of the leading causes of worldwide death. By 2017 it is predicted to nearly 9 million people worldwide and will continue to increase to 13 million people per year by 2030. The prevalence of cancer in Indonesia is 1.4 per 100 inhabitants or about 347,000 people (Kemenkes, 2017). The most significant causes of cancer deaths at any time are among others caused by lung cancer, breast cancer, liver cancer, and colorectal cancer.

One of the most commonly used measures for cancer management is chemotherapy. Chemotherapy is the provision of drugs to kill cancer cells. Chemotherapy measures differ from local radiation or surgery. Chemotherapy is a systemic therapy, which means the drug spreads throughout the body and can reach cancer cells that have spread far or metastasize to other places (Rasjidi, 2010). In this type of disease, oral chemotherapy is a type of chemotherapy that is given by oral administration. This chemotherapy has many benefits, such as reducing the risk of cancer recurrence, reducing the spread of cancer so that the life expectancy of cancer patients improved (Baradero, Dayrit & Siswadi, 2007).

Provision of oral chemotherapy is made, giving side effects as well as other chemotherapy. Side effects that occur include patients will experience a disruption in the digestive system such as diarrhea, nausea, vomiting, stomatitis, and pain in the abdominal area. These side effects also occur in integumentary system disorders such as palms and feet feeling itchy, sore, swollen and redness, presence of spots on the skin, dry and itchy skin, dermatitis (dermatitis), fatigue and fever (Baradero Dayrit & Siswadi, 2007). It makes patients find it difficult to accept the situation, low self-esteem, and feel unconfi-

dent when meeting others. Physical changes that occur in the patient's body due to the side effects of chemotherapy can cause the patient to feel different to show the attitude of rejection of the physical, if not treated immediately, it can cause severe psychological problems (Romadoni, Husni & Rukiyati, 2012).

The number of patients receiving oral chemotherapy agents, and the intensity of these agents is predicted to increase shortly. Oral chemotherapy offers many potential advantages, such as patient comfort, elimination of the need for IV access, and the ability to achieve continuous drug levels. One disadvantage is the possibility that oral chemotherapy treatments result in patients rarely meeting healthcare providers, and therefore, how to monitor patients' treatment needs to be changed. Monitoring for Pasien who use oral chemotherapy may be minimal compared to patients who received chemotherapy via IV (Birner, 2003).

Social support is a resource that provides physical and psychological comfort is obtained through the knowledge that cancer patients are loved, cared for, valued by others, and he is also a member of a group based mutual interest. The social support gained has benefits for the individual. The presence of social support can make people realize that there are people who care, respect, and love (King, 2010, Marni & Yuniawati, 2015).

Support from family and people around the patient can be influenced by the knowledge and information obtained by the patient's family. Therefore, patient and family education is the foundation for successful or unsuccessful treatment of oral chemotherapy. Effective learning about oral chemotherapy promotes patient suc-

success and safety, optimal dosage, adherence to care plans, accurate side-effects and toxicity monitoring, and can apply self-care by patients and families (Hartigan, 2003). Based on the above phenomenon, researchers interested to know how the family experience in treating patients with oral chemotherapy. The purpose of this study was to explore the knowledge of families in caring for cancer patients undergoing oral chemotherapy.

## METHOD

This research used qualitative research method with phenomenology approach involving 10 participants based on purposive sampling who meet inclusion criteria. The inclusion criteria for this participants are 1) Family's of the cancer patients who are undergoing chemotherapy Xeloda 2) the age of family's are 21-60 years old 3) first line family of the Patients and Caring patients at least five times in a week.

Data were collected using in-depth semi-structured interviews, who conducted by opened questions. Three semi-structured questions had been being asked to the patients. The items are 1) how far are families knew about oral chemotherapy? 2) How will family handle the chemotherapy drugs at home and 3) how do the family take care of the patients related to the existence of side effect. Data collection tool used in this study is the researchers themselves along with other devices such as interview guides and a tape recorder.

This research uses qualitative research method using phenomenology approach. Chan, Brykczynski, Malone, and Banner (2010) said that qualitative methods used to explore the perception or meaning of an event or experience of one's life. The term phenomenology to show what appears in our consciousness by letting it manifest as it is, without entering the category of our thoughts in it (Riady, 2013).

In addition to interview guidelines, the study also uses other supporting data collection tools such as field notes. Field notes filled with descriptive content such as covering backgrounds, people, actions, and talks. The field notes consist of two parts, i.e., 1) descriptive; is a record of

what is being observed, which occurs according to what is seen, heard, and followed through the researcher's senses. 2) Comment, commentaries, reflections, thoughts, or views of researchers on what is being observed (Tohirin, 2012).

Data analysis performed under the steps of Collaizi's phenomenology study (1978). According to Burn & Groove (2011) those six steps are: 1) copying the recording of the interview process into words; 2) Reread the transcripts repeatedly to get the participants' ideas, by raising keywords related to the research focus, then 3) grouping the keywords into categories, 4) grouping the categories into one sub-theme; 5) sub-subthemes that have the same and related meanings are defined in a structured and conceptual form called the theme; 6) the next step, integrating the overall result into a deeply descriptive narrative form of the phenomenon under study.

## RESULT

The results of the study found that the three thematic items in managing the care of family, which is 1) lack of family's knowledge about oral chemotherapy, 2) confusing in handling safe oral chemotherapy and 3) lack of ability in caring patients when side effect appeared and followed the adherence.

1. Lack of family's knowledge about oral chemotherapy.

The family express that they did not know in detail about oral chemotherapy as in the following statements.

*"... I seldom heard about chemotherapy using this medicine. I know that in the infusion..."* (Participant 3)

*".. I want to know what about chemotherapy by this way (oral), it's important moreover to treat cancer ..."* (Participant 4)

Besides, some participants already know about oral chemotherapy but still do not fully understand the therapy as in the following statement:

*"... there has been spelled out by the officer but still do not understand, still want to*

*know again .." (Participant 1)*

*"Yes already have read-read on Google, but read it alone by yourself sometimes confusing you....it is better to get explanation directly. So, you can ask when there is something that makes you doubt. " (Participant 5)*

*"... In the beginning, it has been explained a little bit, but sometimes it is not enough, you need more information... (Participant 9).*

2. Confusing in handling safe oral chemotherapy

In general, the family did not know how to treat procedure safely when giving oral chemotherapy to the patients. As the appearance of oral chemotherapy was found like pills, they think that oral chemotherapy did not have a similar reaction like intravenous chemotherapy had. Therefore the family wants to be informed about safe handling and chemotherapy procedures. It can be seen from the following statement:

*"... yes, it's still not clear how the drugs work and what can it cause to other people.." (Participant 2).*

*"... There is an explanation, but it is not too clear enough. I am still not fully understanding yet, how to handle this drug...." (Participant 3).*

*".. I am still confused and do not know how to handle it, no one else can help me too ." (Participant 7).*

Other participants also expressed a desire to obtain information about appropriate treatment in patients with oral chemotherapy as in the following statement:

*"... No one of my family members has a medical background. Therefore, I little bit worried about this drugs since health care team said that it is chemotherapy drugs. I am afraid if there will be anything wrong*

*with my mother ..." (Participant 1).*

*"... sometimes I am confused with this drug. If there is anything wrong happened in my husband, what should I do, could I take him to midwife since the medical doctor in oncology lives very far from my home. " (Participant 6).*

*"...it's maybe safe, but I am not sure about this. It is, so hesitate and confused ...and need more information" (Participant 8).*

3. Lack of ability in caring patients when side effect appeared and adherence. Therefore family wants to be informed about the adhesion and side effects of oral chemotherapy. It can be seen in the following statement:

*"... what is the real side effect of this drug? Is it similar to other types of chemotherapy? " (Participant 5)*

Another participant even did not know the side effect of Oral Chemotherapy. They also did not realize that chemotherapy must be administered regularly. It can be expressed in this following sentences.

*".....I want to know about the consequences if the medicine was not taken. What If, I forgot to give these pills once....since I am so busy with my little shop... (Participant 3)....."*

Some of the participants said that they do not know how to maintain compliance when giving oral chemotherapy to their family member. They also do not know what the negative consequences are when they are not following the schedule, as mentioned in this statement:

*.....". We want to control the time when the drug must be taken. Unfortunately, we do not know the way how to make a perfect schedule..." (Participant 8)*

*"...Sometimes, I miss the drugs...but I think that it is not a big problem..." (Participant 10).*

caring patient. Family's support can increase the patient's spirit of life and their commitment to follow therapy. This statements also support by Rahmawati (2009) which state that family's support can increase positive attitude and patient's welfare.

Nurses are in an ideal position to provide more information about oral chemotherapy and educate them on how to manage care when patients are undergoing oral chemotherapy. When a patient receives oral chemotherapy, all of the elements in a patient's life, especially family, is entirely having the responsibility to care and protect their family's member health. Therefore, the knowledge and family's roles are indispensable in the implementation and observance of the therapy being undertaken (Burhenn & Smudde, 2015)

Notoadmojo (2007) describes knowledge is the result of human sensing or the result of knowing a person to the object through the senses possessed. Most of the participants in this study said they had heard the term of oral chemotherapy before, but the knowledge about chemotherapy that they have is less precise. Based on these results, most of the family do not know well about oral chemotherapy since they are not prone to these terms. Therefore they quite confuse, feel anxiety, and do not have full confidence for taking care of their family member. Beside that family also think that oral chemotherapy is similar to other oral drugs who do not have a special effect and unique treatments.

This results of the research have similar finding with the research done by Setiawati (2011). The study found, most of 78.57% of cancer patients have sufficient knowledge about chemotherapy. The data also shows that patients do not fully understand what is chemotherapy treatment actually although they know that there are many side effects will be appeared in patients. Unfortunately, they are not sure what kind of effect side will be existed in detail and homanage these side effects and how to handle this drug safely.

Although oral chemotherapy is associated with ease of administration, it has the same exposure risks to health care practitioners, patients,

and their caregivers as intravenous formulations. Unfortunately, the general misconception has appeared between the family and the patients. They thought that oral chemotherapy has low-risk exposure and therefore, oral chemotherapeutic agents present little risk and are safer to handle (Goodin et al., 2011). They are a higher exposure risk.

Many advantages to the use of oral chemotherapy have been described. Despite these advantages, we have to note that multiple factors associated with oral chemotherapy can compromise patient safety and contribute to medication errors, contamination, and inadvertent exposure to other individuals (Schumulster L, 1999 & Bletcher et al., 2008)

Some research proves that the administration of oral chemotherapy is more likely to be susceptible to errors, nonadherence, and increased side effects as a result of a lack of coordinated care. In oral administration, incorrect dosing and limited monitoring, which can lead to underdosing or overdosing, severe toxicity, morbidity, and mortality could happen since they are getting chemotherapy at home (Goodin et al., 2011). Therefore it is crucial issues for handle the oral chemotherapy inappropriate way

Although most patients and family thought that oral chemotherapy is safer than intravenous chemotherapy. But in fact, they are not safe. There will be a risk in accidental exposure to oral chemotherapeutic agents that can occur at various stages during handling oral chemotherapy such as in storage, handling, administration, and disposal.

Based on this research, most of the family did not know how to handle this drug safely and how to protect themselves and other family members. The researcher found that most family member has a perception that oral chemotherapy is safer than intravenous chemotherapy. This perception can lead the less of awareness about safe handling. To ensure the safety for both family and patients safety, the family should understand all information given to patients, including the transport, storage, dispensing, and disposal requirements to ensure safe handling. The family also must collaborate with patients and health

care professional to maintain appropriate dosing for patients in their care and report any treatment-related adverse effects. The family also must follow some safety recommendation to protect them when they look after the patients such as using gloves and washed separately all that patients used from other items, and they must be double-flushed of toilets after use, during and 4 to 7 days after discontinuing chemotherapy. Beside that family member who is pregnant and breastfeeding, should not handle any chemotherapy medications or waste products (National Institute for Occupational Safety and Health (2004).

Moreover, giving more information and teaching them a skill for providing oral chemotherapy to their family member is a must. They can recognize the significant effect on chemotherapy and can help assess the occurrence of side effects in patients. (Hartigan, 2013).

In this research, the third theme that found is lacking the ability of the family to handle side effects. Side effects can be worst for some patients. The family must recognize these side effects and try to support the patient and giving appropriate care. Sometimes, when patients and family cannot overcome side effect, it will lead to noncompliance and discontinued oral chemotherapy. Besides that, if the effect sides don't treat well the patient's quality of life will be worst.

Compliance in the administration of oral chemotherapy is a must, and family plays vital for medication compliance as we know that patients with oral chemotherapy will be less likely to see their health care professional compared to patients undergoing another type of chemotherapy. But in other side, patients have to follow the schedule of oral chemotherapy regularly to get optimal results. Their compliance in this oral chemotherapy is the critical point for their successful treatment. Therefore, some studies suggest that education and reminders about the timing of chemotherapy at the start of therapy is crucial. Developing rapport, helping patients, and providing opportunities for patients and families to ask questions is the primary goal of the teaching process. Likewise, building trust

and encouraging patients to be honest about the dose delay in their oral chemotherapy. Dose adjustments based on adverse events associated with reported doses of patients can negatively impact clinical outcomes if patients do not say honestly. (Hartigan, 2013).

Family and people around the patient are an essential factor for supporting this compliance. The nurse must consider them as a front line people to educate and guide patients in the treatment process. Research suggests that educating patients to improve their adherence in treatments will increase their awareness to follow drugs schedule and achieve the procedures. They also most likely obey the rules of safe handling drug delivery correctly. Several studies have shown that patients who are well informed about their treatment may have better adherence (Schneider, Adams, & Gosselin, 2014). Many patient education tools are available for oral chemotherapy. The Oncology Nursing Society (ONS) has developed a toolkit that provides advice and resources related to the guideline of handling chemotherapy to facilitate compliance (ONS, 2009). Other useful information in this toolkit includes instructions that describe whether the therapy can be given with food, common side effects from oral chemotherapy, obstacles to adherence, how to measure treatment compliance, and other information.

Provision of education alone is not sufficient to improve adherence to oral medication administration. The multicomponent intervention has been shown to improve oral chemotherapy adherence. Some of the interventions in multicomponent plans include education, equipment, and technology.

## CONCLUSION

Oral Chemotherapy is one type of chemotherapy that widely used today since they have more advantages. This research found that there are at least three things that considered lack by family when they are taking care of their family who is undergoing oral

chemotherapy. Those are 1) Lack of knowledge about oral chemotherapy, 2) Confusing in handling safe oral chemotherapy, and 3) lack of ability in caring patients when side effect appeared and the following adherence. Family as a support system of patient's play a vital role to

manage patient's care along with therapy. Therefore, they must have enough knowledge to ensure the given is appropriate. Facilitating and providing support for them by adding some specific knowledge and skill will strengthen their ability in caring for their family's member.

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