



FAMILY ACTIONS TO OVERCOME THE SIDE EFFECTS OF CHEMOTHERAPY IN PATIENTS AT HOME

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Abstract

To cancer patients, families are the first home care and support providers who help meet all their needs. This study aims to define their actions that help the patients deal with the side effects of chemotherapy at home. This is a descriptive quantitative research involving cancer outpatients who are taking chemotherapies in Arifin Achmad Hospital of Riau Province. A consecutive sampling technique obtained 134 families as samples, from which the data were collected using a questionnaire and analyzed univariately. The results showed several major actions in helping their members get through the side effects of chemotherapy, which include helping overcome nausea and vomiting by providing preferable food (in as many as 84 patients or 63%), helping overcome hair loss by keeping hair short and easy to manage (in as many as 54 patients or 40.5%), helping overcome fatigue by assisting to manage routines (in as many as 83 patients or 62.2%), helping battle appetite loss by preparing favorite foods on demand (in as many as 99 patients or 74.2%), and helping overcome diarrhea by giving 8-10 glasses of water per day (in as many as 91 patients or 68.2%). These actions have given proper results in helping the patients overcome chemotherapy side effects at home. Therefore, our study is expected to be a reference for other families whose members are dealing with similar conditions.

Keywords: *cancer; chemotherapy side effects; family action*

1. Introduction

Cancer is a disease that grows destructively in the human body. It continues to increase in size and number as it changes cells mechanisms of growing and proliferating to become invasive to the surrounding tissues or other areas of the body (Black & Jane, 2014). The types of cancer most frequently found worldwide are respectively breast cancer, colorectal cancer, lung cancer, cervical cancer, thyroid, uterine carcinoma, stomach cancer, and other types of cancer (GLOBOCAN, 2020).

According to the World Health Organization (WHO, 2020), cancer is the second leading cause of death with 9.6 million casualties worldwide. The Indonesian incidence rate is the 23rd and 8th largest respectively in Asia and Southeast Asia. The number of cancer incidences

in Indonesia is around 136.2/100,000 population, accelerated from just 1.4/1000 population in 2013 and 1.79/1000 population in 2018.

Riau Province alone recorded a prevalence of 1.67% or as many as 26,085 people in all population ages in 2018 (Kementerian Kesehatan RI, 2018). Based on the medical records of Arifin Achmad Hospital in Riau Province, with new cases of 9322 in 2020, in 2018 there were a total of 23,163 cancer patients who had been undergoing treatment, surgery, and chemotherapy at the hospital. Based on several previous studies, breast cancer has been the most common among the patients in the hospital, for which the chemotherapy itself has several adverse effects such as nausea, vomiting, hair loss, fatigue, diarrhea, appetite loss, myalgia, neuropathy, weight loss, fever, susceptibility to infection, constipation, stomatitis, mucositis, and swallowing difficulty (Al-Jabbariyah, 2018);

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(Faisel, 2012); (Gaol, 2017); (Khairani, 2019); (Kurniawan and Tri M.A, 2014).

An initial survey was conducted by the researchers on 8th - 9th February 2021 by interviewing 10 families whose members were undergoing chemotherapy in the Seruni room at Arifin Achmad Hospital. The families took different actions to deal with the side effects of the chemotherapy, in which seven families took actions while the other three did not at all. The actions included buying medicine for the nausea and bringing the patients to the clinics when they became unbearable. From the psychological point of view the family encouraged the patient, helped manage with the food intakes, and gave a lot of water. They also mentioned about encouraging them to eat, making porridge, juice, milk, fruit, or other types of liquid food, or let the side effects subsided by themselves.

2. Method

This type of research is quantitative with a simple descriptive design. The population in this study were 202 adult patients who were chemotherapy outpatients in the Integrated Cancer Room or the Seruni Room of Arifin Achmad Hospital in Riau Province in January 2021. Their families were taken as samples by the following criteria: living in the same house with the patients, having the responsibility to give home care to the patients, and having members with histories of at least two cycles of chemotherapy. A consecutive sampling technique was used along with a questionnaire sheet as data collection tools.

3. Result and Discussion

Respondent characteristics

Tabel 1. Characteristics on age of the families whose members on chemotherapy at Seruni outpatient ward of Arifin Achmad Hospital of Riau Province

N	Mean	SD	Median	Min-Max
134	37.69	10.698	37.00	20-60

Table 1 shows that for the chemotherapy patients in the Seruni outpatient ward, the average families' age was 37.69 years with a range of 20 to 60 years. These numbers are typical for the breast cancer case being the most common type in the ward, and interestingly the families under the study also fall into this range of age. This is due to the fact that with this type

of cancer the families taking actions for chemotherapy side effects are typically spouses or relatives whose age are not so different from the patients' or parents who are older than them.

From the research conducted by Kamariyah & Nurlinawati (2020), at their adulthood families function as caretakers for their members who have health problems. These functions include being able to recognize the health problems of their members, making decisions in treatment or care efforts, and making health care efforts. They are shown in this study where the families take appropriate actions against the side effects of the patients' chemotherapy, maintain conducive, healthy environments, maintain good communications and attitudes, and utilize health service facilities for the health needs of all family members.

Tabel 2. Frequency distribution of gender, education, ethnicity, and family relationships of patients with chemotherapy

Characteristics	f	%
Gender		
a. Male	76	56.7
b. Female	58	43.3
Education		
a. Elementary school or equivalent	5	3.7
b. Junior high school or equivalent	15	11.2
c. High school or equivalent	79	59
d. College	35	26.1
Profession		
a. Civil Servant	11	8.2
b. Entrepreneur	30	22.4
c. Private	62	46.3
d. Housewife	12	9
e. Honorary	3	2.2
f. Farmer	2	1.5
g. Not Working	14	10.4
Ethnic group		
a. Malay	30	22.4
b. Minang	17	12.7
c. Batak	24	17.9
d. Java	51	38.1
e. Banjar	8	6
f. Bugis	2	1.5
g. Nias	2	1.5
Family relationship		
a. Wife	23	17.2
b. Husband	59	44
c. Child	39	29.1
d. Mother	7	5.2
e. Older brother/sister	2	1.5
f. Younger brother/sister	4	3
Total	134	100

Table 2 depicts the frequency of the distribution of gender, education, ethnicity, and family relationships in the patients with

chemotherapy. As seen in table 2, it was found that the majority or as many as 76 people (56.7%) of the caretakers of the chemotherapy patients were male. Again, this is because breast cancer is the most common in the ward and it illustrates that the family actions in patients with chemotherapy are mostly carried out by the patient's spouse or partner.

Women who have had a mastectomy and undergone chemotherapy programs, family support, especially that of a partner, is very important. Family support includes the attitude, action, and acceptance of the family towards the sick family members, and will be very helpful for them in the process of healing. Being a wife's soulmate, a husband who accepts his partner's condition well will encourage his wife's best in getting through chemotherapy despite her fear of the side effects (Sudrajat et al., 2020).

The majority of the patients' families are also shown to have the latest degree of high school education, or as many as 79 people (59%). This indicates that the families have been able to calculate problems and take the right actions in relation to the patients' conditions. As a person's level of education affects his or her response to external conditions, highly educated people respond more rationally to information and think further about the prospects of an idea. The level of education is also responsible for people's ability to be in control of their lives and those of the family members under his care. Positive life attitudes motivate individuals to maintain better health by conducting regular health checks (Hamidah & Indah W. S., 2017)

It is also indicated in Table 2 that the private professionals dominate among the home caretakers, with a total of 62 people (46.3%). This study illustrates that family actions to help patients get through chemo effects at home are mostly carried out by men and women who have private jobs.

According to research conducted by Puspitarini, regarding the relationship between quality of life and the need for palliative care in cancer patients at Dr. Sardjito Hospital, it is stated that 23% of the cancer patients were housewives whose head of the family worked as entrepreneurs. This indicates that one's job also determines one's health status. Siti Musrifah believes that there is a connecting line between the attitude of housewives and their practice of preventing cervical cancer. Based on the data, only 33.7% of the housewives practice prevention of cervical cancer. This was due to the lack of the husbands' and the health workers'

support. Family encouragement or support is an important factor in increasing women's participation in disease prevention.

Furthermore, it was interesting to note that as many as 51 families (38.1%) became the majority in terms of ethnicity, which was Javanese. Although Indonesia has various tribes and cultures with different backgrounds that characterize each region, the Javanese becomes the largest ethnic group with a population of 95.2 million people, or about 40.2% of the population in Indonesia. Many Javanese come from Central Java, East Java, and Yogyakarta Special Region. In the province of Riau, the Javanese ranks second most at around 29.20% (Badan Pusat Statistik Provinsi Riau, 2020). The uniqueness of the Javanese compared to the other tribes is the existence of *kejawen* which teaches them about supernatural powers called *kasekten* and believes in the existence of the spirits of the ancestors and the spirit of nature in human life. These unique beliefs manifest through the whole of their daily lives including in the process of seeking treatment, ranging from not acting or doing nothing, self-medicating, seeking for traditional or alternative medicines, to government health facilities (Nopen, 2019).

Javanese culture believes that the extent of healing efforts an individual makes needs to be congruent with his perception of the threats, diseases or pains suffered. Therefore, for example, when the pain is still perceived to be mild a Javanese generally seeks self-medication or delays treatment in the hope of its recovering by itself. However, if the disease is felt to be life-threatening, they will immediately seek treatment services according to their beliefs, which are supported by the family or the environment. If a person has been sentenced to be sick by himself, his family, and the environment, he will start looking for a health service center to deal with the feelings that interfere with his physical and mental being. In Javanese culture, the attitude of seeking health services to solve problems cannot be separated from the surrounding people who have experienced and treated sick people. It is these experiences that makes him decide what to follow and where to go to seek treatment for his healing process (Sunarno, 2012).

Meanwhile, in terms of family relationship, husbands dominate among the home caretakers of these chemotherapy patients, being as many as 59 people (44%). This is still in line with the fact that breast cancer is the highest case among the subject patients and that the family actions in

helping with the side effects are mostly performed by their husbands. Husbands carry out their roles and functions such as accompanying and being the main supporters of their wives in getting through the chemotherapy cycles (Dewi, 2018).

Husbands' roles in building psychological support have been discussed by by Muhith and Nasir (2011) in Selvia, et al., (2019). They described the importance of husbands' roles during chemotherapy such as creating a situation where the sick members can understand what possible danger they are facing in their activities, reducing fear by giving direction, helping them feel calm and happy with the therapy process, encouraging to accept expertise and to continue doing their roles well so that they can be open and build self-esteem in undergoing chemotherapy.

Table 3. Distribution of the frequency of diagnosis of patient's disease, and history of chemotherapy patients in the Seruni outpatient ward Arifin Achmad Hospital, Riau Province

Characteristics	f	%
Patient Disease Diagnosis		
a. Trophoblastic Neoplastic Gestational Cancer	1	0.7
b. Lymph node cancer		
c. Colon Cancer	12	9
d. Skin cancer	1	0.7
e. Tongue Cancer	1	0.7
f. Eye Cancer	2	1.5
g. Naso Pharyngeal Cancer	1	0.7
h. Ovarian Cancer	16	11.9
i. Breast cancer		
j. Cervical cancer	21	15.7
k. Sinonasal Cancer	62	46.3
l. Squamous Cell Cancer	8	6
m. Thyroid Cancer	1	0.7
n. Lymph node tumor	1	0.7
	5	3.7
	2	1.5
Patient's history of chemotherapy		
a. 2nd		
b. 3rd	6	4.5
c. 4th	13	9.7
d. 5th	19	14.2
e. 6th	27	20.1
f. 7th	26	19.4
g. 8th	21	15.7
h. 9th	15	11.2
i. 10th	3	2.2
j. 12 th	2	1.5
	2	1.5
Total	134	100

It is illustrated in Table 3 that the majority of the patients undergoing chemotherapy were suffering from breast cancer in as many as 62 people (46.3%). Breast cancer in women is a major health problem for people around the

world. This type of cancer is one of the most common among women. According to WHO, in 2020 alone, women diagnosed with breast cancer amounted to 2.3 million with 685,000 cases of death globally. Up until the end of 2020, there were 7.8 million women diagnosed with breast cancer during the last 5 years. At Arifin Achmad Hospital in 2018, breast cancer became the most cases with 6,650 sufferers, and one of the treatments for which is chemotherapy.

Surgery and chemotherapy had been used as modalities in this hospital to treat cancer, in her data 23 patients underwent surgery (43.4%), 7 chemotherapy (13.2%), and 23 surgery and chemotherapy (43.3%). Suwankhong in Wang (2017) explains that almost all breast cancer patients experience adverse effects of chemotherapy such as nausea, vomiting, fatigue, hair loss, and appetite loss. They can also have further psychological developments such as plummeting self-confidence, self-pity, self-reproach and even self-alienation (NurKhamida et al., 2019).

The majority of our patients had a history of the fifth chemotherapy as their latest treatment, or as many as 27 people (20.1%). We found that our patients had gone through several chemotherapy sessions, and the fifth chemotherapy was the chemotherapy that was in the second cycle. Chemotherapy treatment is given based on the type and stage of the cancer. The working principle of chemotherapy is to weaken, control and stop the growth, and eventually kill cancer cells in the hope that they will not spread to other parts of the body (ACS, 2016).

Family actions to overcome the side effects of chemotherapy

Table 4 illustrates most families, or as many as 84 people (63%), help overcome their members' nausea and vomiting by providing favorite food that the patients like. Most of the family knew that the appropriate feeding for a chemo patient is by giving small portions of food with a frequency of 6-8 times/day, and avoiding giving foods with smell stimulation (Hudayani, 2014).

The act of giving eucalyptus oil is also appropriate to overcome nausea with aromatherapy. Aromatherapy reduces post-chemo-nausea vomiting and the effective materials include peppermint, lavender, and essential oil aromas as they provide comforting

effects, increase body relaxation, and improve psychological conditions that trigger nausea and vomiting in post-chemotherapy patients (Nurrohmi et al., 2021).

Table 4. Distribution of the frequency of family actions that help overcome nausea and vomiting in patients with chemotherapy

Family action	f	%
Provide favorite food.	84	63
Provide snacks throughout the day such as juices, puddings, and processed fruit foods.	77	57.7
Cover or remove foods with strong or unpleasant odors.	75	56.2
Give small portions of food but often.	65	48.7
Give the medicine given by the doctor.	58	43.5
Assist when the patient vomits, by helping sit up straight after vomiting.	54	40.5
Suggest inhaling eucalyptus oil.	47	35.2
Provide ginger herbal supplementation of no more than 4 grams a day.	28	21
Give ginger aromatherapy.	6	4.5
Give honey.	1	0.7
Provide vitamin C to increase body immunity	1	0.7
Provide formulated milk (Ensure®).	1	0.7

Aromatherapy uses essential oils as therapeutic agents. They are high concentrations of substances produced from extracts of flowers, leaves, stems, or stems of plants, fruits, roots, and distillation of resin (Ali et al., 2015). Several methods of using essential oils include massage, inhalation, or simply skin-swab. One common plant producing essential oil that is used globally is *Eucalyptus globulus* or commonly called eucalyptus oil plant (Wijayanti, 2017).

As described by Kely & Carman (2013), providing prescribed drugs is also appropriate to prevent nausea and vomiting. The common use of antiemetic drugs is before chemotherapy and on a regular schedule around the first few hours for 2 days, and not on demand. In line, a research of Zakiah & Mustofa (2015) stated that administration of anti-nausea and anti-vomiting drugs are effective (Zakiah & Mustofa, 2015). However, the act of overcoming nausea and vomiting by providing food according to the patient's wishes is an inappropriate action and that not all preferred foods can overcome nausea and vomiting (Hudayani, 2014).

Based on table 5, it was found that the majority of family actions in helping to overcome hair loss in chemotherapy patients were by keeping the hair short and easy to style as many as 54 people (40.5%). As seen in table 5, the majority of the families, or as many as 54 people (40.5%), help overcome hair loss side-effects by

keeping their members' hair short and easy to style.

Table 5. Distribution of the frequency of family actions that help treat hair loss in patients with chemotherapy

Family action	f	%
Keep hair short and easy to style.	54	40.5
Put sunscreen on the scalp.	49	36.7
Give a wide-toothed comb to ease scalp itchiness or sensitivity.	42	31.5
Instruct the patient to be careful when combing and washing hair.	38	28.5
Apply aloe vera onto the scalp.	35	26.2
Provide hijab.	30	22.5
Avoid applying dye for the first few months.	19	14.2
Provide hats.	15	11.2
Provide a wig according to the patient's preference.	5	3.7
Avoid braids or ponytails, using rollers, blow-drying, or using curling irons.	3	2.2
Provide hazelnut oil onto the scalp.	3	2.2
Provide a scarf.	1	0.7
Apply coconut oil onto the scalp.	1	0.7

Previous discussion about hairdo includes Hidayati's research (2012) in Wijayanti, (2017). She explains getting used to short hair helps the invisibility of hair falls and thus makes it "less dramatic" for the patients. However, if any hair loss provokes patients' insecurity, the use of a wig may be an option. Therefore, cutting hair shorter and/or putting on hair covers such as hats or hijabs have been deemed appropriate to keep up with patient's confidence (Ardhiansyah, 2021).

According to the National Health Service (2016), cancer treatments can cause side effects of hair loss but wigs and hats can overcome this problem. Significantly, hair loss did not occur in some people who had been used to cutting the hair shorter before therapy. Another recommended way to keep hair from falling out too much is by combing gently. Meanwhile, research by Villasantel, Herskovitz, Mauro & Jimenez (2014) explains hair loss in chemotherapy patients must be treated appropriately due to its social impact on the patients (Villasantel et al., 2014).

As seen in Table 6, the majority or 83 families (62.2%) help overcome fatigue in chemotherapy patients by helping manage their daily routines. The act of helping to regulate routines every day can be done by encouraging the patients to do regular exercise, especially walking as it is a good way to relieve fatigue. However, one should remind their members not to exercise too late at night and try to get them to

sleep 7-8 hours a day and avoid drinks containing caffeine (ACS, 2020).

Tabel 6. Distribution of the frequency of family actions that help overcome fatigue in patients with chemotherapy

Family action	f	%
Help set up a daily routine.	83	62.2
Help remind frequently to sit or sleep on feeling tired.	80	60
Help get away from caffeinated drinks.	64	48
Encourage sleeping 7-8 hours per day.	55	41.2
Encourage walking.	54	40.5
Give short breaks of about 30 minutes or less.	52	39
Massage gently following the curves of the body from head to toe.	28	21
Perform back massage.	25	18.7
Help with breathing relaxation activities.	19	14.2

Encouraging patients to exercise walking is also deemed appropriate to deal with chemo side-effects. Regular walking exercises can help reduce frequent fatigue. Regular walking exercises can improve concentration, creativity, and mental health. Exercise increases the amount of oxygen in the blood and speeds up blood flow to the brain. Mild exercise like walking can provide benefits of endurance, while light exercises provoke good hormones in the brain such as adrenaline, serotonin, dopamine, and endorphins (Damayanti et al., 2020).

Meanwhile, family encouragement and control of the patients' good sleep at 7-8 hours per day is effective to battle chemo side-effects at home, following that fatigue affects the quality of sleep of the patient. She mentioned that good sleep is an important need that must be met adequately at 7-9 hours per day (Purwantari & Haryani, 2013). In cancer patients, sleep disturbances disrupt the healing process of their cancer. Cancer patients who are undergoing treatment need quality sleep to optimally maintain their body condition and endurance (Gautama & Ni, 2021). Furthermore, the action to get the sick person away from caffeinated drinks and nicotine have been deemed important to minimize sleep disturbances and to help overcome fatigue (Krisdianto, 2019).

Based on Table 7, preparing favorite food to be eaten on demand dominates among family actions to deal with the patients' loss of appetite, with the number reaching as many as 99 people (74.2%). Providing on demand, healthy, favorite food is deemed appropriate by the research of Browne, Molloy, O'Sullivan, Richmond, & Houston (2012).

Tabel 7. Distribution of the frequency of family actions that help overcome appetite loss in patients with chemotherapy

Family action	f	%
Prepare favorite foods to be on demand.	99	74.2
Prepare high-calorie and high-protein snacks.	77	57.7
Accompany when dining.	62	46.5
Give small meals 6 - 8 times a day.	60	45
Prepare young coconut water to drink once a day.	50	37.5
Give cold drinks or juices to the patient.	44	33
Upon inflammation, instruct mouthwash post-eating and pre bedtime.	21	15.7
Provide honey.	6	4.5
Give herbal porridge.	1	0.7
Provide vitamins as appetite enhancers.	1	0.7
Give warm drinks.	1	0.7
Provide formulated milk (Ensure®).	1	0.7
Give the contents of the coconut.	1	0.7

They discussed methods in dealing with the loss of appetite, including making the desired food, providing small portions or converting into snacks every 2-3 hours, giving high calorie and protein snacks such as cheese, biscuits, and sandwiches, drink lots of water such as milk, juice, and soup, and invite the family to eat together to make eating more enjoyable.

Preparing young coconut water to drink once a day is deemed appropriate as it contains Cytokinins, an anti-aging and anti-cancer material. Young coconut water is also a sterile natural source of electrolytes containing high levels of potassium and chlorine, while its freshness and coolness can help relieve nausea and increase appetite (Ambarwati & Erlinda K.W., 2015).

Based on table 8, it was found that the family's actions in helping to overcome diarrhea in chemotherapy patients by giving drinking as much as 8-10 glasses per day were 91 people (68.2%). The majority of the families, or 91 people (68.2%), stated that giving drinking as much as 8-10 glasses per day can help overcome diarrhea in chemotherapy patients. As discussed before by Newton, Hickey & Marrs (2009) in Wijayanti, (2017), the treatment of diarrhea after chemotherapy includes accommodating electrolyte balance and rehydration in the body's fluid, eating small portions of food 5-6 times/day, and eating foods rich in sodium and potassium such as bananas, oranges, or potatoes, eat low-fiber foods, provide lactose-free foods or drinks such as milk and dairy products, and clean the perianal area carefully after a bowel movement.

Tabel 8. Distribution of the frequency of family actions that help treat diarrhea in patients with chemotherapy

Family action	f	%
Give drinks as much as 8-10 glasses per day.	91	68.2
Give drinks that contain water, sugar, and salt.	71	53.2
Avoid foods that contain high lactose such as candy, milk, or dairy products.	66	49.5
Give bananas.	50	37.5
Give drugs to treat diarrhea such as Iporamide and others.	38	28.5
Follow the BRAT diet (Banana, Rice, Apple, and Toast).	24	18
No action needed.	3	2.2

Barr, Wendy & Andrew (2014) explained that the treatment of diarrhea can be performed by drinking an oral re-hydration solution, a simple mixture of salt and glucose combined with water, to improve the transport mechanism in the intestine (Barr & Andrew, 2014).

There are several limitations to this study, the first the process of this research was initially expected by respondents to fill out own questionnaire. However, there were some respondents who asked the researcher to reread the content of questionnaire, write down the answers chosen by respondent. Thus making the time to fill out the questionnaire slightly increased. Secondly, in the research process, the respondent is a family waiting for the patient who are undergoing chemotherapy, and the respondents also take care of everything the needs of patients in hospital ranging from administration to other needs, so that when respondent is filling out the questionnaire, there is some respondents who permit briefly to take care of the patient's need, so because of this the charging time is slightly increased.

4. Conclusion and Suggestion

It can be concluded that the respondents are Javanese male and husbands, have the average age of is 37.69 years old with a range of 20 - 60, secondary education levels (High School), and private professions. Most of the patients diagnosed with breast cancer have histories of fifth chemotherapy. The family actions to help patients cope with the side effects of chemotherapy vary but are deemed effective, as supported by findings of previous research.

This research is expected to be used as an educational topic in the field of nursing related to family action to overcome the side effects of chemotherapy in patients. We suggest our respondents keep up the good-work of helping

overcome chemo side-effects at home and always refer to reliable sources such as the experts and scientific results of research. We encourage other cancer patients' families to do likewise. This study can be used as basic data or a reference to conduct research related to chemotherapy side effects and family actions to overcome chemotherapy side effects in patients.

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