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THE CORRELATION BETWEEN PREPAREDNESS AND BURDEN AMONG FAMILY CAREGIVERS OF CANCER PATIENTS UNDERGOING CHEMOTHERAPY

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ABSTRACT

As a result of the treatment that requires extended time, family caregivers, therefore, demand preparedness, and more than often the treatment process becomes a burden. This study aimed to determine the correlation between the preparedness and the burden among family caregivers of cancer patients undergoing chemotherapy in Yogyakarta. This study is a descriptive correlative design using a cross-sectional approach. A total of 51 family caregivers of cancer patients undergoing chemotherapy were obtained using a purposive sampling technique. The questionnaires used are the Indonesian version of The Preparedness for Caregiving Scale and the Indonesian version of the Caregiver Reaction Assessment. The data in this study were analyzed using the Spearman Rank correlation test. The results of this study indicate that there is a significant correlation between the preparedness and the burden among family caregivers of cancer patients undergoing chemotherapy in Yogyakarta (p-value <0.001) and a correlation coefficient of -0.710 which shows a strong correlation. Health care professionals require to ensure that family caregivers have the right resources and support so they are prepared to care for their loved ones. This preparedness is useful to reduce the burden they feel in the process of caring for cancer patients.

Keywords: burden; cancer; family caregiver; palliative care; preparedness

INTRODUCTION

Cancer has become the second largest contributor to mortality at the world level (World Health Organization, 2018). According to the International Agency for Research on Cancer (IARC) in 2020, there were 19.2 million cases of cancer with a death rate of 9.9 million recorded in the world (International Agency for Research on Cancer (IARC), 2020). Based on 2018 Basic Health Research (Riskesdas) data, the prevalence of cancer in Indonesia has increased to 1.79 per 1000 population, which previously was 1.4 per 1000 population in 2013. Special Region of Yogyakarta Province ranks first with the highest cancer prevalence rate, which is 4.86 per 1000 population, then West Sumatra Province with 2.47 per 1000 population, and Gorontalo Province with 2.44 per 1000 population (Kementerian Kesehatan Republik Indonesia, 2018).

One of the treatments that can be opted to prevent the growth and spread of cancer cells to other organs is chemotherapy (Kim, Park, & Lee, 2021). The impact of chemotherapy on cancer patients is in the form of physiological and psychological impacts (Pratiwi, Widianti, & Solehati, 2017). The perceived physiological impacts are nausea and vomiting, alopecia (hair loss), and decreased appetite (Retnaningsih, Auliyak, Mariyati, & Purnaningsih, 2021). While the psychological impact felt by the patients is depression due to their physical condition, sad, worried, tiredness, lethargy, and even fear of death that will happen to him (Rahayu & Suprapti, 2021).

Given the impact felt by cancer patients, they certainly need treatment assistance. The closest people to those who have treatment are their family members. The term for family members who provide assistance and caregiving to other family members who are sick is called family caregiver (Fuanida & Natalia, 2020). They are spouses, parents, and siblings (Sun, Raz, & Kim, 2019). Family caregivers need high skills and knowledge to provide caregiving for cancer patients at home (Maheshwari & Mahal, 2016). Caregiving aid provided by family caregivers for cancer patients includes, among others, aid to meet daily needs, accompanying patients to undergo treatment, understanding the side effects of drugs consumed, encouraging and seeking health services (Alsirafy et al., 2021) (Thomas et al., 2021).

The role of the family caregiver is greatly needed by cancer patients to help the treatment process while undergoing treatment for an extended time (Chrisnawati, Natalia, & Septi, 2017). While providing caregiving to patients, family caregivers will experience issues that can reduce their quality of life, thus, family caregivers will be at risk of experiencing problems related to the burden of providing care (Nuraini & Hartini, 2021). The burden of providing care or the burden of the family caregiver is the difficulty felt by the family caregiver while caring for family members who are ill, both physically, emotionally, socially, and financially (Ringer, Hazzan, Agarwal, Mutsaers, & Papaioannou, 2017). Family caregiver burden occurs due to several factors that prompt it, including age, gender, education, income, occupation, marital status, family relationships, and support from family (Joanna Briggs Institute, 2012). The effects caused by the burden of providing caregiving toward the health of the family caregiver are feeling tired, experiencing disturbed sleeping patterns, irregular eating patterns, and putting aside their health (Ferrell & Kravitz, 2017). The impact of chemotherapy is also felt by the family of cancer patients, for which the family must take full responsibility for caring for it (Sari, Warsini, & Effendy, 2018).

A research showed that the burden experienced by 157 families of cancer patients in Nigeria includes not having any burden 44 (28%), light burden 82 (52.2%), moderate burden category 27 (17%), and heavy load category 4 (2.5%) (Jite, Adetunji, Folasire, Akinyemi, & Bello, 2021). A study also showed that as many as 11 respondents (18.3%) are included in the heavy load category, then 31 respondents (51.7%) are in the medium load category, as many as 9 respondents (15%) are in the light load category, and the last as many as 9 respondents (15%) with no burden category (Werdani, 2018). Research that involving 178 respondents obtained the results at 8.43% with a minimal load category, a light to moderate load level of 70.22%, and a moderate to a heavy load of 21.38% (Mishra et al., 2021).

It is remarked that the burden felt by the family caregiver arises because of the unpreparedness of the family for caregiving and accepting the situation. Preparedness that is vital to be actualized by family caregivers of cancer patients includes providing emotional support, providing physical care, providing support services, and balancing the burden of responsibility while caring for other family members who are sick (Petruzzo et al., 2017). The study in Yogyakarta showed that the level of preparedness of family caregivers to care for their families suffering from cancer is at a moderate level with an average of (2.83 ± 0.40) where as many as 82.5% of family caregivers admit that they have never received information about cancer and there are as many as 40% of family caregivers who seek treatment, namely chemotherapy treatment (Sari & Nirmalasari, 2020). Research from India also found that the level of preparedness of family caregivers for cancer patients was at a low level (Maheshwari & Mahal, 2016).

Family caregivers must be ready to provide total care to meet physical needs and provide positive enthusiasm for cancer patients (Kent et al., 2016). The treatment that requires an extended time and occurs continuously causes the family caregiver to enjoy less free time, thus triggering the emergence of stress. If stress occurs continuously without being interspersed with activities that calmed the mind and relaxed the body, it can trigger boredom and increase the burden on the family caregiver (Werdani, 2018).

A preliminary study conducted on March 7, 2022, at one of the private hospital in Yogyakarta found that for one month approximately 27 to 40 cancer patients underwent chemotherapy with a treatment frequency of 21 days. Researchers conducted interviews with 3 family caregivers who care for cancer patients undergoing chemotherapy using a preparedness questionnaire (I-PCS) and a family caregiver burden questionnaire (CRA-ID) and found that two out of three family caregivers claimed to be less than prepared in caregiving and experienced burden during the treatment. Family caregivers who are not prepared to provide care namely less prepared to seek information, arrange treatment services, and muster several things properly, such as preparing the heart, soul, and body for caring. Meanwhile, family caregivers who feel burdened claim that since taking up caregiving they have lost some personal activities such as diminishing time to visit relatives and friends and difficulty finding time to relax. Research on the correlation between the preparedness and the burden on family caregivers of cancer patients undergoing chemotherapy is still relatively small. Based on the explanation above, the purpose of this study was to determine the correlation between the preparedness and the burden of family caregivers among cancer patients undergoing chemotherapy in Yogyakarta.

METHOD

This study was a descriptive correlative design using a cross-sectional approach. Data collection was carried out on June 30-21 July 2022 in the One Day Care (ODC) room which is the part of the oncology clinic at one of private hospital in Yogyakarta. The number of samples required is 51 family caregivers obtained using a purposive sampling technique. The inclusion criteria in this study were: (1) the patient's family regularly accompanies cancer patients undergoing chemotherapy; (2) the family involved in caring for the patient in the last two months; (3) over 18 years of age; (4) willing to be a respondent. Meanwhile, the exclusion criteria were: (1) more than 1 family caring for a sick family member (chronic illness).

This study used three questionnaires as a measuring tool. First, a demographic questionnaire which includes data collection date, name (initials), age, gender, education level, occupation, income, marital status, relationship with patients, and length of care. Second, the preparedness for caregiving questionnaire uses The Indonesian version of The Preparedness for Caregiving Scale (I-PCS) which has been translated into Indonesian and has been tested for validity and reliability (Sari & Nirmalasari, 2021). The total score of PCS was tested using Pearson Correlation with a result value of more than 0.320 and the reliability value of Cronbach's Alpha was 0.933. This questionnaire consists of 8 question items with 5 answer choices using a Likert scale from 0 (not prepared at all) to 4 (very prepared) and there is 1 open question regarding the special preparedness desired in the treatment process. The higher the score, the higher the preparedness of the family caregiver. Third, the family caregiver burden questionnaire uses the Indonesian version of The Caregiver Reaction Assessment (CRA-ID) which has been translated into Indonesian and has been tested for validity and reliability (Kristanti et al., 2018). Five original instrument factors were confirmed, with a 54.89% explained variance. The majority of the CRA-items ID's seems to share the same structure as the original version. Cronbach's alpha values ranged from 0.64 to 0.81 (Kristanti et al., 2018). This questionnaire has 22 question items and all questions use a Likert scale from a range of 1 to 5, namely "strongly disagree",

"disagree", "undecided", "agree", and "strongly agree". The higher the score, the higher the burden on the family caregiver.

To collect the data, the researchers first coordinated with a facilitator to identify potential respondents who meet the inclusion and exclusion criteria that have been decided. The researchers followed the ODC schedule every day. The researchers met the prospective respondents one by one and make an introduction, explain the purpose and objectives of the research, and offer them to be research respondents. After the prospective agreed, the researchers provided an informed consent form to be signed by the respondent as a form of consent to participate in the research and the researcher provides a questionnaire sheet in the form of a demographic questionnaire, a care preparedness questionnaire, and a burden questionnaire to fill out. The questionnaire was filled out while the respondent was waiting for the patient's chemotherapy process with an average time of 1-20 minutes. The respondents who have difficulty were helped to answer by the researcher. After the data was collected, the researcher re-checked and clarified it again with the respondents before being analyzed. There is one research assistant who helps in data collection.

Data analysis used the SPSS application whereas the normality test in this study used Kolmogorov Smirnov to see the distribution of numerical data. The results obtained are that the data is not normally distributed hence the statistical test used is the Spearman Rank test and the data presentation used the median, minimum, and maximum. The research has obtained ethical approval from the Research Ethics Commission of PKU Muhammadiyah Hospital Yogyakarta which was issued on June 22, 2022 (Number 00169/KT.7.4/VI/2022). The family caregivers involved have signed informed consent as a form of approval to participate in the research and they can withdraw at any time without being subject to any fines or sanctions. Researchers assured them to maintain confidentiality, both information, and other matters.

RESULTS

As shown at the demographic characteristics of the respondents in Table 1, the median age of respondents is 46 years, the majority are male, graduated from senior high school, currently employed, have an income less than minimum income level, married, and have relationships with patients as spouse. The median of the length of care was 12 months.

Table 1.

Demographic Characteristics of Respondents (n=51)

Respondents Characteristics	f (%)	Median (Min-Max)
Age (years)		46.00 (25-70)
Gender		
Male	26 (51)	
Female	25 (49)	
Education Level		
Junior High School	10 (19.6)	
Senior High School	26 (51)	
College	15 (29.4)	
Employment Status		
Employed	23 (74.5)	
Unemployed	13 (25.5)	
Income[a]		
>=Minimum Income Level	23 (74.5)	
<Minimum Income Level	28 (54.9)	
Marital Status		
Married	45 (88.2)	
Single	5 (9.8)	
Widow/widower	1 (2)	

Respondents Characteristics	f (%)	Median (Min-Max)
Relationship to patient		
Spouse	27 (52.9)	
Children	18 (35.3)	
Relatives	3 (5.9)	
Other	3 (5.9)	
Length of care (month)		12.00 (2-60)

[a]Regional Minimum Income Level of Yogyakarta: IDR 2,153,970; f: frequency; Min: Minimum; Max: Maximum.

Table 2 lists the preparedness scores among family caregivers. The median score was 24 from a possible score of 0-32 with the lowest score being 16 and the highest score being 32. That is, the higher the score obtained, the better the level of readiness to care for.

Table 2.
Preparedness among Family Caregivers of Cancer Patients Undergoing Chemotherapy (n=51)

Variable	Possible Score	Median (Min-Max)
Preparedness for caregiving	0-32	24.00 (16-32)

Min: Minimum; Max: Maximum

Figure 1 showed the specific needs required by family caregivers in providing care. It is indicate that the most specific needs required by family caregivers are related to the continuation of further treatment (37.3%).

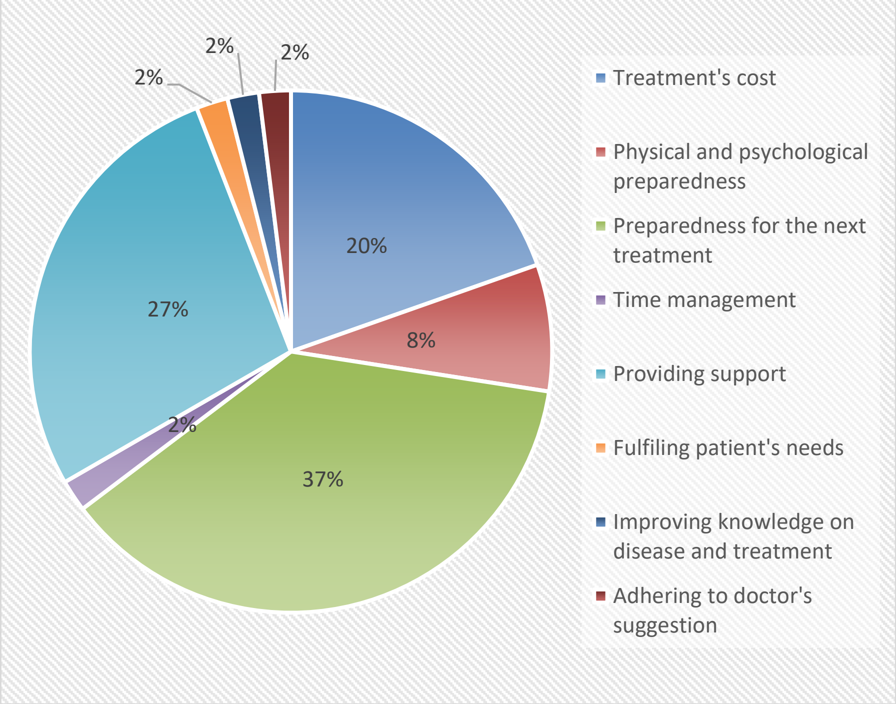

Figure 1. Specific needs required for caregiving (n=51)

The median score of family caregiver burden is 3 from the possible score of 1-5 and has a minimum score of 1.81 and a maximum score of 3.4. The highest burden lies in the financial impact domain with a median score of 3.5 from a score range of 1-5 and a minimum score of 1.5 and a maximum score of 4. This can be seen in the Table 3.

Table 3.
Burden among family caregivers of cancer patients undergoing chemotherapy (n=51)

Variable	Mean Range	Median (Min-Max)
Family Caregivers' Burden (22 items)	1-5	3.00 (1.81-3.40)
Self-esteem	1-5	3.00 (1.16-4.00)
Lack of family support	1-5	2.60 (1.40-3.80)
Financial problem	1-5	3.50 (1.50-4.00)
Disrupted schedule	1-5	3.00 (1.60-3.80)
Health problems	1-5	3.00 (1.50-4.00)

Min: Minimum; Max: Maximum

The results of the analysis using the Spearman Rank test demonstrate that there is a significant correlation between the preparedness and the burden among family caregivers of cancer patients undergoing chemotherapy in Yogyakarta (p<0.001; r = -0.710). This can be seen in the Table 4.

Table 4.
The correlation between preparedness and burden among family caregivers of of cancer patients undergoing chemotherapy in Yogyakarta (n=51)

Preparedness	Family Caregiver Burden	
	p-value	Correlation coefficient *(r)*[a]
	<0.001*	-0.710

*[a]Spearman Rho; *p<0,01 indicate significance*

DISCUSSION

The results showed that the median score of the majority of family caregivers is 46 years old. A person who has entered adulthood is considered to have been able to control his emotions and become an independent person so that he can provide optimal support for his family members who are sick, have clear life goals, think rationally, and do not prioritize their interests, accept advice from others, and wise in making decisions (Utami & Puspita, 2020). The majority of family caregivers in this study were male. This is not in line with previous research which stated that a female family caregiver has a big responsibility in taking care of household chores and has skills and patience in caregiving (Kilic & Oz, 2019). In this study, the majority of those who accompanied chemotherapy were men who were the husbands or children of the patients. In Indonesia, the role of men in the family includes being the leader or head of the family, earning a living, providing a sense of comfort and protection for the family, as well as teaching the function of family matters, namely trying to make family members accepted in society (Singkali, Nihayati, & Margono, 2019) (Suhandjati, 2018).

The level of education background of the family caregivers was senior high school. Someone who has a higher level of education will have extensive knowledge making it easier to find information, find it easier to overcome a problem, and be familiar with stress management techniques (Kilic & Oz, 2019) (Nurhidayati & Rahayu, 2018). In this study, most of the family caregivers were still employed. In addition to the activities of caring for patients, family caregivers who are employed undoubtedly have other activities hence they can earn income that enables them to reduce the financial burden during the treatment process (Ariska, Handayani, & Hartati, 2020). The majority of respondents with employed status increase the burden of caregiving where family caregivers have to divide their time between caregiving and other roles (Putri, Diniari, Setyawati, & Lesmana, 2021).

The most income earned by family caregivers was below the minimum income level. The financial condition of a person with an uncertain income can influence taking medication or other treatments and also increase financial problems during treatment (Kristanti et al., 2018).

The existence of health insurance (Badan Penyelenggara Jaminan Sosial/BPJS) makes family caregivers feel assisted regarding their financial problems, but not all medical expenses are paid by BPJS such as transportation needs during treatment and accommodation costs while undergoing therapy (Fuanida & Natalia, 2020). In this study, the majority of family caregivers were married. Someone married will have double responsibilities, besides taking care of household matters and also providing care for family members who are sick (Ariska et al., 2020). Family caregivers in this study were mostly married partners. Spouses function as encouragement or support for patients (Setyoadi, Nasution, & Kardinasari, 2019). The support provided by the partner in the form of physical and psychological support includes emotional support, information support, and support in solving issues is a form of love and affection for each other (Susanti, 2018).

The results of this study indicate that the median score of the length of care carried out by the family is 12 months. Based on the study in Yogyakarta, the length of care per day has significant correlation with the burden of family caregivers (Sari et al., 2018). Less time is available for their hobbies, social life, and basic necessities as they devote more time each day to caring for their patient (Yoon, Kim, Jung, Kim, & Kim, 2014). The more time a family caregiver spends with the patient, the more reliant the attending family member will be on the caregiver to meet their requirements (Govina et al., 2015). The results of this study showed that the median score of family caregivers' preparedness in caregiving is 24 from a score range of 0-32 and has a minimum score of 16 and a maximum score of 32 with special needs that are most required by family caregivers in carrying out caregiving related to the continuation of further treatment (37.3%). Another study stated that the level of preparedness of family caregivers in caregiving was on average (M = 21.33) included in the category of quite ready (Otto et al., 2021). Also a study showed that caregivers are prepared to be in charge of patient care (Owoo, Ninnoni, Ampofo, & Seidu, 2022). The results of the research conducted in Yogyakarta from 40 respondents showed that the average score of family caregiver preparedness for cancer patients was 2.83 ± 0.40 with the highest special needs required being preparedness related to financial problems (63%) (Sari & Nirmalasari, 2020). The preparedness of family caregivers with low or moderate levels of preparedness is 67% and high preparedness is 54 of 172 respondents and the caregiving that needs to be improved is related to coping (44%), health service information (36%), and treatment (33%) (Gutierrez-Baena & Romero-Grimaldi, 2022). The feeling of being prepared to provide care has a relationship with positive aspects, including reduced burden and anxiety felt by the caregiver, which can increase a strong sense of appreciation and hope hence health also improved (Alvariza, Häger-Tibell, Holm, Steineck, & Kreicbergs, 2020).

The results of this study indicate that the median score of burden among family caregivers of cancer patients undergoing chemotherapy in Yogyakarta was 3 with a score range of 1-5 and a minimum score of 1.81 and a maximum score of 3.4 and the highest-burden lies in the domain of financial impact. The results of this study in line with other research that the level of the burden felt by family caregivers is in the moderate burden category (51.7%) (Werdani, 2018). This was because family caregivers suffered difficulty in time distribution, experience fatigue, and seldom to visit relatives or friends. The results of the research conducted in Yogyakarta showed that the average score of family caregiver burden is 2.38±0.38 with the highest-burden located in the impact domain on the schedule with an average of 3.26±0.80 and the lowest burden on the domain of self-esteem is 1.65±0.33 (Sari et al., 2018). The results of other studies also show that the average family caregiver burden score is 28.32±12.72 with a range of 0-57 which is included in the light-moderate burden category of as many as 96 respondents (56.1%) (Anggriani, Rahmawati, & Wahab, 2021).

The results of this study showed that the majority of respondents' income was below the minimum income level and the highest-burden was in the domain of financial impact. This was because the time the caregiver has at work is limited because it must be distributed with time for caregiving, resulting in a decrease in working hours. Moreover, the caregivers' income must be divided again between daily needs and the cost of treating cancer patients as well as the necessary medicines and transportation costs (Lilin & Indriono, 2021). One of the factors that affect the family caregiver's burden is family support, where the greater the family support, the less burden felt by the caregiver. The support received by the caregiver makes them stronger and able to carry out their role (Ariska et al., 2020). Even from an emotional point of view they become more patient and accept sincerely the provisions of God and consider it an obligation to care for their family members who are sick (Fajriyati & Asyanti, 2017).

There was a correlation between the preparedness and the burden among family caregivers of cancer patients undergoing chemotherapy in Yogyakarta. There was a strong correlation between the preparedness and the burden among family caregivers of cancer patients. It means that the higher the preparedness for caregiving, the lower the burden among family caregivers of cancer patients. The results of this study are in line with research on family caregivers of cancer patients in India, although using different statistical tests and the results obtained an average score of 13.56 (2.8%) ranging from 9-22 and a burden of 66.48 (13.3%) ranging from 39 to 92 has a significant level of 0.01 (r = 0.531), which means that there is a relationship when the family has high preparedness for caregiving the perceived burden level is low (Maheshwari & Mahal, 2016). Each increase of one score in preparedness to care can reduce about 17% of caregivers' burden (Bilgin & Ozdemir, 2022).

Knowledge and skills can influence family caregivers in carrying out caregiving tasks, where good knowledge can minimize the burden felt during the treatment process and the quality of caregiving offered can enhance the patient's quality of life (Azali, Sulistyawati, & Adi, 2021). Furthermore, a healthy caregiver's physical condition can assist in providing maximum care for family members who are sick (Ariesti, Ratnawati, & Lestari, 2018). The income earned by respondents is proportional to the increase in expenditures for medical expenses, although the cost of chemotherapy treatment has been covered by health insurance, some costs are not covered by health insurance such as special diagnostic procedures, certain drugs, and transportation costs, thus triggering an increase of the financial burden felt by the family caregiver (Kristanti et al., 2018). When the caregiver feels overwhelmed, the perceived burden will also be high, but seeing the patient's condition improving and the patient having high enthusiasm gives them high preparedness for caregiving (Otto et al., 2021). There were several difficulties and limitations in this study, namely: (1) the number of family caregivers each day is undetermined, this is caused by some cancer patients who are not accompanied by their families during chemotherapy and follow-up visits and the patient's uncertain chemotherapy schedule; (2) some respondents asked the researcher or research assistant to help read the questionnaire. The questions asked are sensitive in nature, so the researcher or research assistant who reads it must be careful not to offend the respondent's feelings and take a long time to collect data; (3) there are other activities carried out by family caregivers such as rushing to work, focusing on waiting in line hence some family caregivers refuse to be respondents and when filling out the questionnaire they are in haste which leads unable them to grasp it in detail.

CONCLUSION

The results of this study indicate that there was a significant correlation between the preparedness and the burden on family caregivers among cancer patients undergoing chemotherapy in Yogyakarta. The special needs required by family caregivers in performing caregiving are mostly related to the continuation of further treatment and the highest-burden lies in the domain of impact on finances. Further researchers can develop and further improve research related to the preparedness for caregiving and the burden of family caregivers on patients with other terminal illnesses.

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