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## ***Family Support in Self-Management at Home: a Descriptive Study among Children with Cancer***

Cory Febrina, Imelda Rahmayunia Kartika, Fitriana Rezkiki & Rina Mariyana



**UNIVERSITAS  
FORT DE KOCK  
BUKITTINGGI**

Nursing Study Program  
Universitas Fort de Kock Bukittinggi, Indonesia

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### Corresponding author:

Cory Febrina  
[c.febrina6@gmail.com](mailto:c.febrina6@gmail.com)

Department of Nursing,  
Fort De Kock University  
Bukittinggi

Cory Febrina, Imelda Rahmayunia Kartika, Fitriana Rezkiki & Rina Maryana

### ABSTRACT

**Background:** Cancer is still a significant health problem today. In 2020, an estimated 19.3 million new cancer cases and nearly 10 million cancer deaths occurred worldwide. Cancer patients and their families need support to manage them effectively, emotionally and lifestyle. This study aims to see a picture of family support for clients with cancer.

**Methods:** This research uses a quantitative research Home in Padang City, in mid-August 2024. The sample for this study was 26 who filled out the questionnaire, describing the characteristics of the respondents.

**Results:** The most significant data with the highest category value can be seen in the first statement which represents the indicator of emotional support. The instrument used "My family encouraged me when I was afraid about the long-term treatment process I was undergoing" namely with a category value of 2.95 (1.139) and a lowest value was in Instrumental support, namely providing vehicles and direct support at 2.01 (1,155).

**Conclusion:** From the research it can be concluded that indicators of family support must always be improved and strengthen social networks between families of cancer sufferers with social observers and seek support from local NGOs according to family reach.

## Introduction

The involvement of caregivers, both at home and at community resource centers, through better self-management adjustments and other duties for living with illness, is closely linked to the recovery of cancer patients worldwide. In 2021, Well et al. The majority of people choose for conventional therapies that use herbs to prevent the formation of cancer cells.

The use of natural ingredients in traditional therapy has been shown to

reduce client complaints and discomfort symptoms. The most crucial factor in a cancer patient's recovery is their parents. In order to handle the medical components of cancer, such as physical symptoms and treatment side effects, psychosocial repercussions, role and lifestyle changes, and other duties for living with cancer, self-management entails using a set of cognitive and behavioral abilities. (Howell et al., 2021). The majority of people choose traditional treatments using herbs to



fight the growth of cancer cells, the selection of therapy. Traditionally therapy using natural ingredients, the therapy is able to reduce complaints and symptoms of discomfort felt by clients, the selection of the right information related to ingredients, doses and methods sourced from health workers will reduce misinformation in the management of cancer patients (Illian et al., 2021).

Families with children with cancer often experience economic difficulties, difficulties in socialization, physical and psychological fatigue, as well as difficulties in building relationships and expanding relationships. Cancer survivors really need and appreciate social support, especially from family and friends, social support greatly affects the psychosocial of cancer patients, namely post-traumatic growth, psychological stress and physical activity. Previous research has described social support as a key variable that is very helpful in improving the health of children and adolescents with cancer (Deegan et al., 2023). Caregivers of cancer patients who come from communities other than family have a very important role. Families with children with cancer tend to be more stressed and sometimes find it difficult to make the right decisions.

Caregivers who have a workload are more likely to need additional support so that they can maintain the health status of cancer clients. Social support

networks are a mixture of relationships and roles, this support cannot be ignored. The focus in the community has often ignored social support for cancer patients, this is influenced by cultural factors, knowledge and stigma that exist in society. Family support can be placed on the highest support for cancer clients, without neglecting social support.. The family traditionally may play a more important role (Guo et al., 2021) This means that the higher the social support, the higher the emotional well-being you have. The research results found that some of the emotional well-being of sufferers is shown by the ability to manage negative emotions into positive emotions, where cancer sufferers have accepted their situation by always thinking positively and trying to live their lives as destined by the Almighty. Emotional well-being is influenced by several factors, including social support. The burden experienced by caregivers of children with cancer greatly affects the health condition of the caregiver himself. (Adashek & Subbiah, 2020).

In caring for children with cancer, families often experience difficulties and anxiety. Depression in family members can also have a negative impact even to the point of difficulty in forming good and balanced self-management in cancer patients. (Fridriksdóttir et al., 2011). The child's parents often feel responsible for their child's condition,

giving rise to feelings of anxiety, guilt, helplessness, and inability (Shadi et al., 2024). Chronic patient self-management is the ability of an individual to consider his or her health condition which will affect behavior, knowledge, and emotions to support a satisfactory quality of life. Self-management is "a single approach that can minimize the impact of a patient's chronic illness in daily life. For example, a patient struggling with chronic pain that causes reduced ability can be empowered by setting goals, aspects of self-management to identify specific, achievable needs. Good self-management can be achieved through proper decision-making (Lu et al., 2024). Based on this conceptual knowledge of how resilience might function in the context of cancer caregiving, **the goal of this study was to explore whether self-perceived resilience is related to readiness for future decision-making and preparedness for caregiving. This research novelty to investigate the potential correlation between caregivers' distress levels and resilience. Our hypothesis was that greater resilience in caregivers would be linked to less suffering as well as greater caregiving preparation and preparedness for future decision-making. The reasoning behind this analysis was that the findings might help determine whether resilience is a promising area for interventions aimed at improving outcomes for patients and their families with advanced cancer.** (Dionne-Odom et al., 2021)

## Methods

This research uses a quantitative research design with a descriptive approach, where the researcher describes the management of family support for cancer patients who are hospitalized at a government hospital. This research was conducted at the "CAHAYA" cancer shelter in Padang City, in **mid-August 2024**. The sample for this research was **26 respondents with cancer**. Respondents filled out a questionnaire that described family support while undergoing treatment both at home and in the hospital. The **questionnaire** was using the Family Support Questionnaire consist of the reliability tested that was assessed by using Cronbach's alpha coefficient with the yielding coefficients were 0.82 for the Family Support Questionnaire (Bethika, 2010). This questionnaire is a modification of four indicators of family support, namely (1) emotional support, (2) assessment and reward support, (3) instrumental support, (4) informational support,. The questionnaire consists of 10 questions with a Likert scale that describes the achievement of quality indicators in the room, namely "strongly disagree", "disagree", "agree" and "strongly agree". The data was analyzed descriptively to see a picture of family support. This research has an ethics test In Universitas Fort de Kock with a code of ethics 292/KEPK/VIII/2024. This Studi was also conducted by following **ethical** principles by maintaining confidentiality and providing informed

consent before starting treatment on all respondents

the characteristics of respondents in terms of age, type of cancer, stage of cancer, length of time suffering from cancer. Characteristic data can be seen in table 1.

## Results

This research obtains an overview of

**Tabel 1. Characteristic Respondent**

Variable	Mean (SD)	Frequency	Percentage (%)
<b>Age</b>	14.13 (0.689)		
<b>Type of Cancer</b>			
RetinaBlastoa			
Leukemia ALL		2	7.6
Leukemia AML		20	76.9
Leukemia LGK		1	3.8
Osteosarcoma		1	3.8
		2	7.6
<b>Stage of Cancer</b>			
Stage 1		7	26.9
Stage 2		5	19.2
Stage 3		9	34.6
Unknown		4	15.3
<b>Time of suffering from cancer</b>			
More than 5 years		9	34.6
Less than 5 years		17	65.4

From table 1, it is known that the average age of respondents, in this case, is in early adolescent (Mean: 14.13, SD=0.689), the most common type of nurse cancer is Leukemia ALL at 20 (76.9%), next the

data is related to the stage of the majority of cancers. stage 3 was 9 (34.6%), then the majority of people suffering from cancer were 17 (65.4%).

**Table 2. Family Support**

Variables	Category	Min-Max	a*
1 My family encouraged me when I was afraid about the long-term treatment process I was undergoing.	2.95 (1.319)	1-4	1
2 My family reminds me when I feel bored to take care of my health	2.09 (1.036)	1-4	9
3 My family helped me to build confidence that my illness would be cured.	2.56 (1.077)	1-4	3

	Variables	Category	Min-Max	a*
4	My family helps me to pay for treatment, care and transportation.	2.19 (1.035)	1-4	8
5	My family accompanies me when I go to see a doctor.	2.38 (1.198)	1-4	5
6	My family supports me with transportation when I go for treatment.	2.01 (1.155)	1-4	10
7	My family helps me to find information about my disease	2.58 (1.295)	1-4	2
8	My family gave me information about how to prevent disease recurrence	2.33 (1.143)	1-4	6
9	My family is happy when I continue to maintain my health.	2.28 (1.120)	1-4	7
10	My family allows me to participate in decisions about my treatment.	2.52 (1.062)	1-4	4

\*a= ranking variabel

There is a description of the statement items and the average respondents' answers which can be seen in table 2. In the results table above, data related to the application of family support indicators can be described. The most significant data with the highest mean value can be seen in the first statement "My family encouraged me when I was afraid about the long-term treatment process I was undergoing," namely with a category value of 2.95 (1,139). This can be interpreted as almost always the family providing support and motivation in the process of treating cancer patients. It can also be seen from the statement data with the lowest category value, the lowest statement is "My family supports me with transportation when I go for treatment." namely with a category value of 2.01 (1,155).

## Discussion

The results show that the average age of respondents who in this case were cancer patients were mostly at an average age of early adolescent. Age is one of the factors that influence maturity in decision making and work implementation, including in cancer treatment both before and in the post-chemotherapy phase, including in making decisions regarding long-term care and influences psychological maturity in accepting health conditions and in determining appropriate health service facilities chosen. With the drastic increase in survival rates in childhood cancer, attention is increasingly focused on the psychosocial aspects of the cancer experience. Clearly, the experience of cancer diagnosis and cancer treatment

places demands on adolescents' ability to cope (Meunier et al., 2007). On average, older cancer patients prefer to receive less information about their disease and treatment and take a less active role in making treatment decisions. They also tend not to collect and analyze all relevant information to make optimal decisions. The observed age differences are, in part, explained by age-related cognitive decline. Age differences are, on average, small to moderate, and older patients prefer to be well informed. Despite this, only a small percentage of them want to play an active role in decision making. Given their lower preference for active participation in decision making, older adults may show less positive psychological effects of active participation, but this question requires research. Implications for working with cancer patients older adults are discussed (Yoon et al., 2017) Regarding age-related differences, Derevensky and colleagues reported differences in the level of importance of social support for older adolescents compared to younger children. As children grow older, support from peers is described as increasingly important while the need for family support continues (Meunier et al., 2007).

Furthermore **cancer type** The most common type of Leukemia ALL with 20 (76.9%) types of cancer has a higher prevalence compared to the types of Retinal Blastoma, AML Leukemia and LGK

Leukemia, Osteosarcoma, the type and location of cancer determines patient survival, a study conducted by (Mathers et al., 2001). Next, regarding data on cancer stages, the majority are at stage 3, amounting to (36.4%) the incidence of cancer detected at an advanced stage and undergoing long-term treatment is very common in the community with a variety of symptoms that appear. The severity of cancer at an advanced stage will be greater. Major consequences in terms of care, time and costs. A similar study states that those in Stages IIIA and IIIB are two groups with different prognoses, treatment options and long-term results that differ from each other, there are differences in therapy with type A requiring surgery and IIIB not requiring surgery (Yoon et al., 2017) Next, related to the length of time the client suffered from cancer, it was less than 5 years, 17 (65.4%) underwent long-term cancer treatment, until achieving healing or death required major consequences, strong support and motivation from the client and family. A similar study describes individuals diagnosed with cancer experiencing devastating life changes that threaten their bodies (Caterino et al., 2019)

Cancer treatment with a very high burden results in the client having a desire to die. The role of nurses is required to be maximized on clients who have a burden during treatment with chronic diseases. Families and nurses must have enough information in the self-management of cancer patients. The physical suffering

that cancer patients feel is excruciating pain. However, an important study identifies that the understanding of suffering should not be limited to physical stress, arguing that suffering is a complex situation in which the resulting illness and condition can threaten a person's integrity and this can be exacerbated by treatment. Suffering occurs when all the negative aspects of cancer appear at the peak of helplessness, alienation, helplessness, and sadness (World Health Organisation, 2017). There are three phases of cancer removal, namely: illness, living with terminal cancer, and being at the end of life. In the first period, the majority of patients feel uncomfortable and always remember when they were declared to have cancer. The most pronounced fear in cancer patients is death. In the second phase, living with advanced cancer, patients usually enter a stage of life dominated by cancer treatment, and medical appointments with considerable physical or psychosocial pain, Physical symptoms, including pain and weakening of physical strength, affect the patient's ability to move freely, which can increase dependence on others and the inability to participate in activities in the community. (Illian et al., 2021). Psychologically, you may feel excluded from social life, especially when others focus on the disease and its treatment. In such situations, patients feel unable to control their lives and the sense of isolation makes the suffering even more pronounced.

People with **stage cancer** end-of-life experience increased suffering due to aggressive treatment, multiple symptoms that are difficult to manage, depression, and anxiety, which are exacerbated by the fact that their life is over (Kolsteren et al., 2022) In many cases, this leads to an increased desire to hasten death (Kanner & Stup, Rogger, 2017). Respondents stated that they experienced a lot of suffering, including physical and psychological suffering. When physical healing is not possible, professionals will try to cure psychological illnesses (Giachello et al., 2019). The patient's suffering can be reduced with appropriate support from health workers and close relatives (Acuna et al., 2017) but can worsen or be prolonged if the condition is not recognized and treated (Deleemans et al., 2020; Sacks, 2013). Therefore, having a deep understanding of suffering and its complex consequences is important for health workers such as nurses and doctors, as well as close relatives of patients to enable them to recognize and deal with suffering and assist healing ((Deegan et al., 2023) Other literature explains the reason for higher scores on depression and anxiety during the second to fifth years, perhaps because patients often complete treatment, or experience relapse or progression during this time, all known pressure points. undergoing or completing initial treatment, while patients who are not disease-free five years post-diagnosis are likely to have experienced recurrence or progression. In

this study, both the prevalence and mean scores of anxiety and depression were higher compared with the Icelandic normal population and among Icelandic cancer patients starting chemotherapy using the same measures (Ferlay et al., 2013)

Deep Family Support **provide information** consists of two statements, namely "My family helps me to find information about my illness" with a category result of 2.58 (1.295) and the next statement describes the family providing information on how to reduce client complaints through the statement "My family provides me with information about ways to prevent disease recurrence" with category 2.33(1.143) meaning that information must be obtained and promoted specifically for cancer patients, followed by marital status, fertility history, lifestyle, employment status, anxiety and depression levels can be evaluated when carrying out the intervention to look at emotional, informational and instrumental support for patients who have undergone surgery. Early and regular screening can help nurses identify patients who are likely to benefit from targeted preventive interventions aimed at emotional, informational, and instrumental support issues (Cai et al., 2021a) Family support for cancer patients undergoing therapy will have a positive influence on physical and psychological well-being.

According to Friedman (2013) family

support is a process that occurs throughout life. The family plays a very big role in the treatment process for cancer clients. From this research, Parental support, especially role, as the main source of support. The family, in general, the elderly are portrayed as a source of information related to the disease. Identifiable as the main source of support for children and adolescents and can be described as particularly important for adolescent cancer survivors, support from family is also described as difficult for these survivors due to the increased time spent with family and reduced privacy. (Rosa et al., 2022) Based on the experience of teenage cancer survivors, they expressed a reluctance to discuss their feelings about the cancer experience with family members. The majority of support from friends is more important for adolescent cancer survivors, including support from friends with cancer and healthy peers. They stated that they were more comfortable when expressing their experiences with peers. Adolescent cancer survivors show a high preference for getting disease-related information from fellow adolescents with cancer. Engaging peers is also described as important to help teens who survive cancer, it is also important for families to know that developing a sense of identity and autonomy, which is considered somewhat threatened by the disease. Adolescents show a high need for support from friends during the early phases of treatment. (Fridriksdóttir et al., 2011).



Cancer survivors also revealed that there has been a change in friendships, as less time to socialize with friends due to the demands of the disease. Information regarding support from healthcare providers is inadequate. Some measures do not include a healthcare provider as an option. However, in an effort that includes health service implementers, i.e. doctors, nurses or with the option to identify anyone deemed supportive (Deegan et al., 2023)

Next, the role of the family in providing **Emotional support** is by providing support when feeling afraid of treatment and providing assistance during the treatment period. The results obtained from respondents' statements illustrate that emotional support plays an important role with the highest value, through the results of the questionnaire through the statement "My family encourages me when I am afraid about the long-term treatment process that I live" with a value of 2.95 (1.195) and the second statement "My family reminds me when I feel bored to look after my health 2.09 (1.036) This result means that emotional support is felt to be really needed by the client. Similar research by Eom, Shin, Kim, Yang, Jo, Kweon, et al (2013) that states the family plays a big role in supporting the client's motivation to undergo therapy. The family also has an influence in various medical procedures such as treatment and care. Someone who gets family support and social support feels cared for, loved, feels valuable, can

share burdens, is confident and grows hope so that they are able to ward off or reduce stress (Suwignjo et al., 2019).

Furthermore **assessment and reward support** plays an important role, tracking data related to assessment support and appreciation through the statement "My family helps me to build confidence that my illness will be cured" with a score of 2.56 (1,077) the cure rate for cancer patients is largely determined by the patient's respect for himself and his appreciation and assessment. also the role of the patient in the family and society. In line with previous research, patients who live with families who isolate them and do not reject their existence, provide family support to cancer patients undergoing chemotherapy in the form of providing behavioral or material assistance information so that cancer patients undergoing chemotherapy feel cared for, valued and loved. From the results of research in The researchers believe that the level of family support will affect the quality of life of cancer sufferers. The better the family support, the better the quality of cancer patients and conversely, the worse the family support, the quality of life will also decrease (Grant, Sun, Fujinami, Sidhu, Otis, Juarez, et al., 2013; Reamer, 2017) in (Suwignjo et al., 2019).

The results of the next study illustrate **instrumental support** namely directly provided by the family through the statement "My family helps me to pay for

treatment, care and transportation. With a category score of 2.19 (1.035) "the second statement is "My family accompanies me when I go to see a doctor" with a score of 2.38 (1.198) the third statement is "My family supports me with transportation when I go for treatment with a score of 2.01 (1.155), support can immediately speed up the patient's recovery, but long-term care, the high cost of treatment can hinder the client's healing and recovery efforts in line with previous studies that identified the profile of . Instrumental, emotional, and informational support in cancer patients in China who have undergone chemotherapy and identify predictors using LCA. Similar research explains that social interaction in this study can be divided into three classes, which are significantly correlated with educational background, monthly family income, and insurance for health, and employment. In addition, patients with low levels of instrumental, emotional, and informational support have high levels of anxiety.(Kolsteren et al., 2022)

The main need for palliative and supportive care is to help the 43.5 million caregivers who care for individuals with serious illnesses. through easier methods. Lack of support can cause caregivers to have difficulty providing maximum care. Instrumental support is highly recommended in improving cancer patients' self-management (assistance with material performance and tasks) to reduce stress among caregivers.

Additionally, patients with low levels of instrumental, emotional, and informational support were more likely to report high levels of anxiety and depression. (Cai et al., 2021b)The results of the study illustrate that seeking social support as a coping mechanism is an important consideration in quality of life.

In similar studies, it can be concluded that the groups with unmet needs are younger family members and also couples as well as those who work outside the home. Although there is no difference between the place of treatment and the time of diagnosis, family members of patients with metastatic cancer will have more needs. This need is not met compared to the needs of the cancer patients themselves. It has been reported that needs may vary at every stage and experience in the treatment of cancer patients. he overall quality of life (QOL) of this sample of family members was good. The average QOL score was the same as the healthy condition in the rest of the population using similar measures. Although the quality of life in this sample is good, other findings explain the importance of identifying family members at risk of experiencing symptoms of psychological disorders by measuring the essential needs associated with patient care, information and communication. The study does not cover the deep problems related to daily activities, financial and social problems, emotional and existential/spiritual needs, contained in the latest family needs assessment

measure for cancer patients receiving treatment, combined with a high response rate, the study can generalize the findings to the family members of cancer patients (Fridriksdóttir et al., 2011).

## Conclusion

This study explains that the pattern of using self-management strategies will differ based on the stage of cancer. This strategy cluster will have a positive impact on the quality of life and overall health condition of cancer patients. Identifying self-management groups of cancer patients with different cancer stages may have clinical implications for supporting health management in cancer patients. Family support for cancer patients takes a long time, continuously and many aspects must be fulfilled, emotional, instrumental, as well as support for assessment and appreciation. The balance of family support over a long period of course needs to be maintained, including cost and operational support in patient care. Family support can be developed by building social networks with health observers, as well as social institutions and cancer observers so that the continuity of family support is also supported by support in community.

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