



## SUPPORT OBTAINED BY FAMILIES IN RUNNING PALLIATIVE CARE PROGRAMS FOR ADVANCED CANCER PATIENTS AT HOME

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### ABSTRACT

Palliative care is a service provided to improve the quality of life of patients both physically, psychologically, socially and spiritually. The purpose of this study is to identify the support obtained by families in carrying out palliative care programs for advanced cancer patients at home. This study uses qualitative research design with phenomenological approach with data collection techniques through in-depth interviews with six participants. Data retrieval using snow ball sampling. Found 5 themes of support obtained by families in caring for advanced cancer patients, namely financial support from people around, moral support from people around, support from health workers and hospitals, helping household chores and patients wanting to stay healthy. The palliative care program carried out by families to patients is good because it has received support from health workers, other family members and neighbors or close relatives so that the goal of cancer palliative care is achieved, namely improving the quality of life of patients by meeting physical, psychological, social and spiritual needs.

Keywords: cancer patients; family; palliative care; support

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### INTRODUCTION

Palliative care is a service provided to improve the quality of life of patients both physically, psychologically, socially and spiritually. Treatment of patients who experience severe problems. The level of complexity of severity in treating patients is determined by the signs and symptoms experienced by patients, psychosocial, spiritual and ethical problems of patients.(Knobloch et al., 2021). The complex problems of palliative nursing are not balanced with the community's knowledge of palliative care. Empirical studies show that people have less knowledge about palliative care, so it is necessary to provide information to the community about palliative care. (Mallon et al., 2021). One disease that must be treated with a palliative care program is cancer. Cancer is the uncontrolled growth of cells or tissues and spreads from abnormal cells, if the spread is not controlled then it can cause death (American Cancer Society, 2014).

The leading cause of death predicted in 2019 is cancer. WHO reports that 84 million people died from cancer between 2005 and 2015, and about more than 15 million people worldwide will develop cancer by 2020 and about 10 million people will die from cancer each year as much as 60%. In America recorded 21% of cancer cases with 14.4% died. Cancer in Indonesia (136.2/100,000 population) and Indonesia ranks 8th in Southeast Asia. According to The Centers for Disease Control and Prevention (CDC) the third cause of death in Indonesia is cancer, after stroke and TB. The highest type of cancer is breast cancer (28%), then cervical cancer (12.8%), leukemia (10.4%), lymphoma (8.3%), and finally lung cancer (7.8%) (CDC, 2013).

The Indonesian Basic Health Research (2018) also shows that cancer is ranked seventh in diseases that can cause death. Cervical cancer, breast cancer, lung cancer, and liver cancer are the main types of cancer that cause high mortality. The prevalence of cancer in Indonesia is increasing: from 1.4 per 1000 population in 2008-2013 to 1.79 per 1000 population. from 2013 to 2018. In the midst of increasing numbers of cancer patients and the deficit in the budget of the Social Security Administration of Health in recent years, palliative care for cancer patients at home is a step worthy of being used as a model in addition to hospital care. The step in that direction can begin with socializing to the community how important the care of cancer patients at home is and preparing facilities and medical personnel to support the care. According to a WHO survey in 2019, there were 194 countries, funding for palliative care was available, 68% of countries and only 40% of countries reported that palliative care was affordable. Every year 40 million people need palliative care, 78% of whom live in low- and middle-income countries. For children, 98% who need palliative care live in low- and middle-income countries with nearly half living in Africa. (WHO, 2020).

According to Santosa (2020) in his article, an internal medicine specialist at RSCM named Chospiadi Irawan said that cancer patients need support from their husbands / wives or families who act as caregivers. A caregiver must understand cancer and be able to provide information to patients using simple and easy to understand language, understand psychological conditions and must have empathy, be a good listener, and not easily emotional. A caregiver must be able to discuss with health workers and deepen his knowledge by learning about cancer. Chospiadi also said, in conditions of depression or depression, patients and families also want to get good nutrition, such as supplements and medicines. In addition, there are also patients who stop treatment because they are not satisfied with the treatment given.

In addition, caregivers also have a duty to help with the patient's daily activities such as delivering to the doctor or preparing food, administering medicines or assisting with physical therapy, helping with daily life tasks such as using the bathroom or bathing. Perform remote services via email or phone. Another task is to provide emotional and spiritual support. (National Cancer Institute., 2023). The severity of a caregiver's job has an impact on work. Caregivers must be allowed not to come to work and some even stop working to focus on caring for cancer patients so that patients recover quickly (American Cancer Society, 2019),

Once the weight of the caregiver's role in this case is the family, it is necessary to provide support that must be provided by the family in order to care for patients well, so the author wants to dig deeper into the purpose of family experiences getting support while caring for advanced cancer patients at home, where in previous studies many researchers discussed the experience of cancer patients themselves who need support from family and people around.

The purpose of this study was to identify the support obtained by families in carrying out palliative care programs for advanced cancer patients at home.

## METHOD

The method in this study is a qualitative research design with a phenomenological approach model with in-depth interview data collection techniques for six participants and snow ball sampling data collection methods. Data analysis techniques using the Nvivo 11 plus application. The study was conducted in May 2021 on six participants living in the Jakarta area of Indonesia. Participants were families who had family members suffering from advanced cancer who were undergoing outpatient treatment with an age range of 35 – 60 years and a duration of treatment of 3 to 10 years. Economic status of the lower middle class and junior high and high school education.

## RESULTS

**Theme 1 (Financial support from people around).** Treatment and care received by patients in hospitals are indeed borne by the government. However, operational costs when delivering patients to the hospital and even looking after patients while outpatient in the hospital are borne by the patient and his own family. On the theme of financial support from people around, four participants were found, namely Mr. C, Mr. D, Mrs. A and Mrs. B.

The following is an interview with Mr. C. *"To avoid feeling sad in patients, I like to take my mother to her friends who have cancer so that she shares her experience, because I think experience is the best thing, so that patients will understand more about their condition. A lot of support was obtained apart from the family, especially her children who helped with housework, also from the workplace who helped for medical expenses that were not paid by BPJS such as alternative medicine, my workplace leader was very supportive of mother's care and treatment. Both the financial assistance and motivation given and the time given if the mother will seek treatment must have allowed her not to work, so as to focus on caring for his wife at home"*.

The following is an interview with Mr. D. *"Support is obtained a lot from children and neighbors, children like to provide support in the form of finances and also motivation to families to patiently care for patients, as well as from neighbors who like to provide food if patients are relapsing, and they always provide motivation so that patients recover quickly"*.

Here's an interview with Mrs. A. *"Her son helped drive her to a referral hospital, provided motivation and helped the economy a little while seeking treatment"*. Here's an interview with Mrs. B. *"The support that the family gets is that the family helps each other in the form of financial assistance from siblings and neighbors"*.

*The interview above showed that both close family such as adult children, siblings, workplace leaders and neighbors of patients provide financial support to patients for transportation costs to the hospital and other costs that are not not paid by the Social Security Administration. This shows considerable financial support from the patient's environment to continue to receive treatment from the hospital.*

**Theme 2 (Moral support from people around).** The form of support of people around the patient is not only in financial form but also a moral support or motivation for care care and always be patient in facing the disease suffered. On the theme of moral support from people around, five participants were found, namely Mr. C, Mr. D, Mr. E, Mr. F and Mrs. B.

The following is an interview with Mr. C. *"You get a lot of support apart from family, especially his children who help with housework, also from Mr. C's workplace who are very supportive of mother's care and treatment. Both financial assistance and motivation provided"*.

The following is an interview with Mr. D: *"A lot of support is obtained from children and neighbors, children like to provide financial support and also motivation to families to patiently care for patients, as well as from neighbors who like to provide food if patients are relapsing, and they always provide motivation so that patients recover quickly"*.

The following interview with Mr. E. Mr. E said *"Palliative health cadres are very helpful in the process of care and treatment of his wife, according to him, the cadres are the reinforcements who share stories and get advice and motivation, because the family itself is an immigrant. To take him to the hospital assisted by his married son"*.

The following interview with Mr. F. Mr. F said *"Support is obtained from family, neighbors who always provide support so that his wife recovers and he is strong and patient to take care of besides support in the form of funds from his married and working children and from neighbors"*.

The following interview with Mrs. B. *"The help was in the form of motivation and convinced me to remain patient and strong in caring for both from family, neighbors and from health workers. Similarly, the advice given by the family to the patient is always given by his family"*. The interview above shows that moral support in the form of motivation and encouragement from the closest people such as relatives or neighbors is very meaningful for patients and families. Moral support from people around strengthens patients to remain patient and obey the recommendations of health workers in treatment and limit their activities and food consumption.

**Theme 3 (Support of health workers and hospitals).** The hospital and its existing health workers are committed to improving the quality of life of patients with indicators of achieving the goal of meeting physical, psychological, social and spiritual needs through palliative care. On the theme of support for medical personnel and hospitals, six participants were found, namely Mr. C, Mr. D, Mr. E, Mr. F, Mrs. A and Mrs. B.

The following is an interview with Mr. C. *"In addition, health workers who handle mothers very well, they always provide moral and spiritual support to stay closer to Allah SWT. The family said that the family has been treated for 5 years."*

The following is an interview with Mr. D. *"I admit that the DKI Regional Government is good: All medicines are free, the facilities are complete, the service is also good, and the medical personnel are friendly, both doctors and nurses. The family also said they often go back and forth to the hospital because in addition to having breast cancer, patients also suffer from asthma and DM. The patient has been treated at the hospital for 10 years."*

Here is an interview with Mr. E. *"All hospital fees are free including medicines, complete facilities, the health workers are very friendly and always provide the best assistance for his wife. I would like to express my gratitude to the government, especially the DKI Regional Government without government assistance, the family would not be able to do treatment in the hospital. In addition to health workers, the family also said that they would like to thank"*

*the cadres for always providing support and motivation to me, so that they remain patient in caring for patients who have been undergoing treatment for 6 years".*

The following is an interview with Mr. F. *"All hospital costs are free including medicines, complete facilities, the health workers are very friendly and always provide the best assistance for his wife. The family also said a lot of thanks to the government because during the treatment in 2 hospitals everything was free including surgery and medicine, according to him without help from the government, the family would not be able to go to the hospital, I admit the DKI Regional Government is good. The family also said that the patient underwent treatment for 7 years".*

Here's an interview with Mrs. A. *"If from the hospital all medicines are free, good service, health workers are also friendly. There are also medicines that families buy if the drug control period has not expired, families usually buy their own drugs with a prescription given by a doctor and the price is affordable. According to the family has been undergoing treatment there for 3 years".*

Here's an interview with Mrs. B. *"The nurses and doctors are friendly and they already know, the waiters are also nice, the medicines are free. The nurse and doctor already consider them like their own family because according to the family they have been in the hospital for about 10 years. They also often provide motivation to continue to carry out treatment and remain sincere and patient with the patient's condition".*

The above interview shows that government support through hospitals for terminal-illness patients is free of charge for medical treatment and medicines. Meanwhile, the medical personnel themselves are providing care to patients while continuously providing moral and spiritual support so that patients remain steadfast in undergoing treatment until the end.

**Theme 4 (Helping with household chores).** The last support that can be given to the family is energy support such as helping with household chores when the patient's illness recurs and must rest. On the theme of helping household chores, three participants were found, namely Mr. D, Mr. F and Mrs. A.

The following is an interview with Mr. D. *"All housework is done by Mr. D such as sweeping, mopping and washing dishes or clothes except cooking done by the patient if his condition has improved, but if he is relapsing, cooking is done by Mr. D".*

Here is an interview with Mr. F. *"I also have to help his wife with all the housework such as cooking, washing and mopping. The responsibility of care and housework is done by Mr. F".*

The following is an interview with Mrs. A. *"The support that the family gets is that the family helps each other in the form of assistance in reducing their workload at home as a housewife, who helps is her teenage child and her mother who lives with the patient and also me as her sister who helps with the patient's homework".*

The interview above shows that the patient's companion from close family such as husband or child, provides energy support in the form of helping complete household chores or cooking for patients so that the workload as a housewife can be reduced and can rest recuperating.

**Theme 5 (Patients want to stay healthy).** What is also a supporting factor is the patient's desire to stay healthy when receiving treatment for his terminal illness. In the theme of patients wanting to stay healthy, one participant was found, namely Mr. E.

The following is an interview with Mr. E. *"The patient himself according to the family has a desire to recover and his physique is also according to the doctor strong, this is if other patients with this mother's condition usually can't do anything but your wife still can".*

The interview above shows that palliative care patients still have the desire to stay physically healed. This will make it easier for medical personnel and hospitals to provide care because patients have high compliance.

## DISCUSSION

The following will describe the results of research on the support obtained by families in carrying out palliative care programs for advanced cancer as follows: **Theme 1 (Financial support from people around).** Treatment and care received by patients in hospitals are indeed borne by the government. However, operational costs when delivering patients to the hospital and even looking after patients while outpatient in the hospital are borne by the patient and his own family. According to Elizabeth (2018) in her article said to build a stronger support system what must be done is to inform family and colleagues about health problems experienced, ask for help from others and have good relationships with patients with the same problems and also caregivers.

According to Chua GP, et.al (2020) in his research, stated that patients who experience advanced cancer need a lot of support in undergoing palliative care both from family and other people. Not only patients who must get comprehensive support but also families who accompany patients during treatment. The same is in accordance with research conducted by Nystatin (2019) says families receive support during caring for terminal patients at home. Participants receive various forms of support while treating patients. The support received came from various parties, ranging from other family members, relatives, neighbors, friends, the surrounding community, the church or business, to the foundation. There are three forms of support received by participants, namely material, moral, and services. This phenomenon is also supported by research by Deshields (2012) states that cancer can affect income in the family. Caregivers in the study Their reduced time to work leads to reduced economic income in the family, because they have to help with housework, so the family needs financial support from people around.

According to Leonard L, et.al (2017) patient companions need support to achieve the expected goals including helping to meet patient needs, educating caregivers how to do good mentoring, empowering companions to work with other palliative teams and assisting companions in doing their work in caring for patients including financial assistance. According to Friedman (2013) sources of family support include social support from family inlivestock such as husband or wife, siblings. Support from outside the nuclear family will get support from other relatives such as uncles or aunts. This support can be in the form of financial support or emotional support. It can be concluded that financial support from other family members or relatives can help families in running palliative care programs for advanced cancer at home.

**Theme 2 (Moral support from people around).** The support that other families get is moral support. They provide motivation to families to continue to care for family members who experience health problems. this is the same as the statement of Nystatin (2019) the family gets from people around. The support comes from relatives, neighbors, family members who do not care for them, foundations and from the church. received from other family members, relatives, neighbors, friends, the surrounding community, the church. According to Alligood (2018), when carrying out palliative care, patients need a sense of security and comfort, free from pain, avoid anxiety, still get a sense of peace, and can socialize with others, want to be valued and have dignity.

The same thing is also needed by a caregiver in this case is a family who provides assistance to pasien. The same is developed by the American Cancer Society (2019) families need support from other family members and friends in caring for patients, support in exercise, healthy diet, spiritual support, such as religious activities, prayer or meditation, time for recreation, and also assistance from trained mental health experts. This is needed because a caregiver also needs a support system in caring for patients. It can be concluded that in addition to patients needing support, caring families also need to get moral support from people around, to strengthen and provide motivation to continue caring for patients until the patient recovers or dies peacefully.

**Theme 3 (Support of health workers and hospitals).** The hospital and its existing health workers are committed to improving the quality of life of patients with indicators of achieving the goal of meeting physical, psychological, social and spiritual needs through palliative care. According to Kilic ST, Oz F. (2019) companions must have a good quality of life, so that in providing assistance to patients will be maximized. So that it really takes support from health workers for companions about information related to health problems experienced by patients, so that when assisting patients, companions can perform tasks optimally. According to Cancer Research UK. (2021) Support for patients and families can be obtained from various parties, including health workers, physiotherapists, occupational therapists, speech and language therapists, nutritionists, community nurses, palliative care specialist nurses, home care nurses, social workers, local support and Cancer Research UK nurses.

Similarly, in Jakarta, support from the government for handling cancer cases in Jakarta is very good, According to Sulaiman and Hadid (2019) in their article entitled The Importance of Palliative Care for the Quality of Life of Chronic Patients. Dr. dr. AruSudoyo, SpPD, Khom, Finasim, FACP. Stating chronic disease patients can reduce their quality of life, due to the disease experienced, a sense of helplessness and difficulty carrying out daily activities. The Indonesian Cancer Foundation with the support of the Indonesian Ministry of Health collaborates to provide palliative care training to caregivers and volunteers in hospitals to assist patients in carrying out palliative care programs. Palliative care includes physical, emotional, psychological, social and spiritual care to improve the quality of life of patients.

This is in accordance with the requirements of cancer palliative cadres in Jakarta who said that during the Covid-19 pandemic, they continue to provide assistance to patients' families to treat patients online and in person. The same thing was also stated by all participants that the support of health workers is very good to patients and families, according to him they are friendly, cooperative, like to motivate patients and families to continue undergoing treatment and are patient and sincere with existing conditions, even they consider that patients are part

of a family, so that patients and families feel comfortable when making visits to the hospital.

The same thing was expressed by the management of YKI Jakarta. Sub-district community health center has palliative health cadres spread throughout the sub-district puskesmas in Jakarta. Cancer palliative cadres are trained by YKI Jakarta by being given training on how to perform palliative care for patients. This will help health workers in providing assistance to families on how to care for advanced cancer patients at home. In addition, in Jakarta there is also a referral hospital for cancer patients with complete facilities, qualified health workers and also medicines that are always available.

The above statement is different from those experienced in poor and poor countries that palliative care receives less attention from the government. According to WHO (2020) palliative care programs are not included in government programs, limited training on palliative care, lack of medicines for patients, lack of awareness among policy makers, health professionals and the public about what palliative care is, and the benefits it can offer to patients and health systems; cultural and social barriers, such as beliefs about dying and dying, misconceptions about palliative care, such as only for patients with cancer, or for the last weeks of life and misconceptions that increasing access to opioid analgesia will lead to increased substance abuse.

According to Arya (2020), the SARS-CoV-2 pandemic has experienced a surge in patients and also the risk of death, especially those who have comorbidities and physical weakness, plus a lack of health workers and medicines. Likewise, research conducted by Dwijayanti, et.al (2019) explained that in Bali participants complained that chemotherapy drug purchase services at hospitals had to wait 2 to 4 days, jam was lacking room capacity and the tools in the runagan were also damaged. The same thing was stated by one participant when doing treatment outside Jakarta, according to him "treatment at the hospital made him stressed because the facilities were lacking, doctors and health workers were lacking and many procedures had to be done related to the condition of Covid-19 and the services of his health workers were not friendly".

There is a gap between Jakarta and other regions according to the research above, and also in general in the world which is a developing and poor country, that palliative services in Jakarta are very much considered by the government because the source of funds and resources of health workers is sufficient and the hospital facilities are complete, this is also supported by the high Jakarta APBD. Unlike other regions outside Jakarta where their regional budget is still insufficient for palliative service programs, funding sources and facilities and health workers are still lacking, as well as in other countries that still do not pay attention to cancer palliative services. It is necessary for the role of the central government in this case is the ministry of health to encourage regions and provide financial assistance to improve cancer palliative service programs.

**Theme 4 (Helping with household chores).** The last support that can be provided to patients with terminal illness is energy support such as helping with household chores when the patient's illness recurs and must rest. The results of the interview above show that the patient's companion from close family such as husband or child, provides energy support in the form of helping complete household chores or cooking for patients so that the workload as a housewife can be reduced and can rest recuperating.

This phenomenon is also supported by Deshields research (2012) in his research explained that caregivers must help with homework, this is done to meet the needs of patients, especially the physical needs of clients. This is also supported by research conducted by Dwijayanti, et, all (2019) where changes in roles in the family were also felt by participants. Role change affects changes in the responsibilities of family members either within the family environment or the community. The condition of pain experienced by the patient causes the patient to be unable to carry out activities such as when in good health so that his activities will be replaced by other family members.

The findings in this study are in line with the systematic review conducted by the family, namely the role of carrying out the task of care for patients 24 hours a day a week. Examples of activities carried out by families in the study are arranging patient transportation, thinking about meeting patient nutritional needs, massaging, paying attention to overall patient hygiene, and providing and managing patient treatment (Care, et al., 2015). This also happened in a study conducted by Lopez, et al., (2012) explained that husbands replace their wives who have cancer to do household chores.

This is in accordance with the statement of Friedman (2013) who said that family support is very important in restoring the condition and improving the quality of life of cancer patients. Support is a person's attitude and actions in family acceptance of family members who experience problems, including emotional, informational, assessment support, and instrumental support. In this condition there will be many problems that arise in patients, here the family must play a role in helping the process of solving problems experienced by patients. The role of the family includes providing motivation and special attention so that the patient's problems can be resolved immediately.

**Theme 5 (Patients want to stay healthy).** The thing that becomes a supporting factor for the family is the patient's desire to stay healthy when receiving treatment for the terminal illness he suffered. The results of the interview above show that palliative care patients still have the desire to stay physically healed. This will make it easier for families, medical personnel and hospitals to provide care because patients have high compliance. According to Utami, R., & Sutantri, S. (2022) showed that from 7 literatures, several themes were found that influence families in providing support to cancer patients, including socio-demographic, health system, public health, political and socio-cultural factors that can affect the level and trajectory of resilience, distress, and unmet needs in cancer patients during COVID-19. The need for support from various sources, especially families, to strengthen the positive coping of cancer patients during a pandemic, both from the nuclear family, extended family, and other social support. The same thing was also stated by Sciences (2019) Two themes were obtained in the study, patients have the desire to remain hospitalized and there is family awareness in the patient's decision making to undergo palliative care. It can be seen that patients want to recover from illness by undergoing treatment provided from the hospital and also support from family.

According to Coelho, et,all (2016) found four themes from the research he conducted, namely palliative care as a response to the needs of patients with advanced disease, efforts to naturalize advanced disease, confrontation with their own vulnerabilities, and openness to the spiritual dimension. This means having the desire to improve the quality of life by carrying out the palliative care provided. This hail is in accordance with the theory of hope proposed by Victor H. Vroom in 1964 in a book written by Ratna (2017). There are three

main assumptions in the theory of expectations, namely 1) Every individual believes that if we behave in a certain way, then we will get certain things. 2) Every outcome has value, or appeal to a particular person. 3) Every outcome is related to a perception of how difficult it is to achieve that outcome. Based on the above statement, it is concluded that every patient has the hope of recovery, the patient can meet his needs independently. This requires support from families who care for patients in carrying out family duties. The task of the family according to Friedman (2013) is to recognize health problems, be able to make decisions, be able to care for sick family members, modify the environment and be able to use health facilities. Good relationships and cooperation between families and health workers must still be maintained. Health workers must also make home visits to see the patient's condition and assist the family in providing assistance to patients, so that palliative care is of higher quality and patients recover faster.

## CONCLUSION

Palliative care programs carried out by families to patients are good because they have received support from health workers, other family members and neighbors or close relatives for the purpose of palliative care. The goal of palliative care is to improve the quality of life of patients including physical, psychological, social and spiritual needs.

## REFERENCES

- Alligood, M. R. (2018). *Nursing Theorist and Their Works*. United States of America: Elsevier.
- American Cancer Society. (2019). *If You're About to Become a Cancer Caregiver*  
<https://www.cancer.org/cancer/caregivers/if-youre-about-to-become-a-cancer-caregiver.html>.
- American Cancer Society. (2014). *Cancer Facts & Figures 2014*. American Cancer Society
- Arya, A. 2020. *Pandemic Palliative care: beyond ventilators and saving lives*. CMAJ .
- Care, H., Reviews, C., Reigada, C., Pais-ribeiro, J. L., S, A. N., & Gonçalves, E. (2015). *The Caregiver Role in Palliative Care: A Systematic Review of the Literature*. *Health Care : Current Reviews*, 03(02). <https://doi.org/10.4172/2375-4273.1000143>
- CDC. 2013. *The Centers for Disease Control and Prevention*. CDC.
- Chua GP, Pang GSY, Yee ACP, Neo PSH, Zhou S, Lim C, Wong YY, Qu DL, Pan FT, Yang GM. (2020). Supporting the patients with advanced cancer and their family caregivers: what are their palliative care needs? *BMC Cancer*. 2020 Aug 15;20(1):768. doi: 10.1186/s12885-020-07239-9. PMID: 32799834; PMCID: PMC7429720.
- Coelho, A, dkk. (2016). *Comf Chua GP, Pang GSY, Yee ACP, Neo PSH, Zhou S, Lim C, Wong YY, Qu DL, Pan FT, Yang GM. Supporting the patients with advanced cancer and their family caregivers: what are their palliative care needs? BMC Cancer*. 2020 Aug 15;20(1):768. doi: 10.1186/s12885-020-07239-9. PMID: 32799834; PMCID: PMC7429720. *ort Experience in Palliativecare: a Phenomenological Study*. *BMC Palliative Care*.
- Deshields, T.L., et al. (2012). *Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers*. *Support Care Cancer*. 20:349-356.

- Dwijayanti, et.all. 2019. Pengalaman caregiver keluarga dalam merawat pasien kanker payudara. Bali : Universitas Udayanan.
- Elizabeth B. (2018) Importance of a Strong Support System. <https://www.roswellpark.org/cancertalk/201810/importance-strong-support-system>
- Friedman, M. 2013. Keperawatan Keluarga Riset, Teori dan Praktek. Jakarta : EGC.
- Kilic ST, Oz F. (2019) Family Caregivers' Involvement in Caring with Cancer and their Quality of Life.
- Asian Pac J Cancer Prev. 2019 Jun 1;20(6):1735-1741. doi: 10.31557/APJCP.2019.20.6.1735. PMID: 31244294; PMCID: PMC7021632.
- Knobloch, C. S., Nauck, F., Ostgathe, C., Grüne, B., & Bausewein, C. (2021). Adaptation of the Australian Palliative Care Phase concept to the German palliative care context : a mixed - methods approach using cognitive interviews and cross - sectional data. BMC Palliative Care, 1–11. <https://doi.org/10.1186/s12904-021-00825-z..>
- Leonard L. Berry, Shraddha Mahesh Dalwadi, and Joseph O. Jacobson. (2017). Supporting the Supporters: What Family Caregivers Need to Care for a Loved One With Cancer. Journal of Oncology Practice 2017 13:1, 35-41.
- Lopez, V., et al. (2012). Male caregivers of patients with breast and gynecologic cancer. Cancer Nursing. 35(6):402-410.
- Mallon, A., Hasson, F., Casson, K., Slater, P., & McIlfratrick, S. (2021). Young adults understanding and readiness to engage with palliative care: extending the reach of palliative care through a public health approach: a qualitative study. BMC Palliative Care, 20(1), 1–13. <https://doi.org/10.1186/s12904-021-00808-0>.
- Nastitin. (2019). Pengalaman Keluarga dalam Merawat Anggota Keluarga yang Sakit Terminal di Rumah. Medan : USU.
- National Cancer Institute. (2023). Support for Caregivers of Cancer Patients. <https://www.cancer.gov/about-cancer/coping/caregiver-support>
- Ratna, G. (2027). Apa yang Dimaksud Teori Harapan (Expectancy Theory). <https://www.dictio.id/t/apa-yang-dimaksud-dengan-teori-harapan-expectancy-theory/9037>
- Riskesdas (2018). Badan Penelitian dan Pengembangan Kesehatan Kemenkes RI..Jakarta : Kemenkes RI.
- Santosa, L.W. (2020). Pendamping seperti Apa yang Dibutuhkan Pasien Kanker.Jakarta : Antara.
- Science, K (2019) . Terminal Cancer Patient’s Experience in Decision Making of Palliative Care at Home.BMC Palliative.
- Sulaiman. M.R, dan Hadid R. (2019). Pentingnya Perawatan Paliatif Bagi Kualitas Hidup Pasien Kronis. Jakarta : Suara.com.

Utami, R., & Sutantri, S. (2022). Family Support in Caring for Cancer Patients During the Covid-19 Pandemic. *Jurnal Aisyah : Jurnal Ilmu Kesehatan*, 7(S2), 247-252. doi:<https://doi.org/10.30604/jika.v7iS2.1436>

World Health Organization. (2020). Palliative Care. World Health Organization.