



## BARRIERS TO PALLIATIVE KADER IN ASSISTING CANCER PATIENTS AND FAMILIES AT HOME

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### ABSTRACT

Palliative care programs are important to improve the quality of life of patients and families in the face of life-threatening disease problems through prevention and alleviation of symptoms. This research aims to explore the barriers of palliative kader's in providing care and assistance to cancer patients and families. This qualitative research is using a descriptive method. The sampling technique in this study was the purposive sampling technique. Participants in this study were 10 palliative kader in the DKI Jakarta area who provided services in the form of care and assistance to cancer patients and families, data collection techniques using in-depth interviews. Four themes emerged in the form of (1) lack of family support, (2) inadequate health promotion media, (3) lack of support system for palliative kader's, and (4) lack of confidence in the care and assistance of cancer patients and families. This study emphasizes the importance of adaptive coping mechanisms for patients and families so that they can support palliative kader in care and assistance in the form of meeting basic needs. Empowerment increases the ability of palliative kader's through training to strengthen the duties and roles of kader and coordinate with relevant stakeholders who can accommodate the solution of any obstacles experienced by palliative kader.

Keywords: barriers; cancer; kader; palliative; patient

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## INTRODUCTION

Cancer is one of the leading causes of death in the world. Evidence-based strategies are needed to address the increasing incidence of cancer in the world. Efforts to control the increase in cancer cases in Indonesia require strategies to control key risk factors associated with cancer incidence. Currently, data on the distribution of cancer in Indonesia is limited. Key risk factors for cancer can be known from the type of cancer that exists. The availability of information to determine the distribution of cancer is expected to be one of the references in cancer prevention in Indonesia. World Cancer Data Research Fund International in 2023 revealed that there were an estimated 18.1 million cancer cases worldwide in 2020. From all cases, 9.3 million cases occurred in men and 8.8 million in women. Breast and lung cancer are the most common cancers worldwide, accounting for 12.5% and 12.2% of the total number of new cases diagnosed in 2020. Colorectal cancer was the third most common cancer with 1.9 million new cases in 2020, accounting for 10.7% of new cases (Kementerian Kesehatan RI, 2022). Palliative care programs as an approach taken to improve the quality of life of patients and families in dealing with life-threatening disease problems through prevention and reducing symptoms. Palliative care can meet the needs of patients and families ranging from symptom management, psychosocial, and supportive especially when patients

are in advanced stages and have a very low chance of being cured, or when they face the final phase of the disease (Komisi Penanggulangan Kanker Nasional, 2019).

Palliative kader's are health kader who come from the community and family. Palliative kader's in the DKI Jakarta province area come from several elements mostly through family health empowerment. Palliative kader's who have served in their respective regions have completed a series of training organized by the Indonesian Cancer Foundation of DKI Jakarta Province through the Education and Counseling Division. The series of training has been followed by prospective palliative Kader's in the form of basic palliative training, cancer alert technical guidance, advanced palliative training, and monitoring and evaluation of palliative kader services. The process of care and assistance services for cancer patients in the region by palliative kader's is under the supervision of health workers in their respective regions.

Family Welfare Empowerment is a community in carrying out a community movement that was born because of the needs of the community (Rodiah et al., 2016). The Family Welfare Empowerment mobilizing team exists from the central level to the village or kelurahan and there are also working groups. The role of NGOs that can reach out to the wider community makes them dynamic in providing services (Chandra et al., 2022). The activities of empowering kader's in the care of cancer patients through training and mentoring is to realize cancer palliative health kader's to be alert in the prevention, early detection, and treatment of cancer patients, help people who need a broader view of cancer in general so that they can prevent, early detection and treatment of cancer patients, and help people who need cancer-related treatment, so it is also expected to increase community productivity.

Palliative care is care that emphasizes improving the comfort and quality of life of individuals facing serious illness. The result of palliative care is to provide relief from distressing symptoms, reduce pain, and improve quality of life. Palliative care uses an approach that aims to improve the quality of life of patients and their families in dealing with problems related to life-threatening and progressive diseases. Palliative care is carried out through prevention and measures to alleviate the pain, physical and social, and spiritual problems faced by patients during treatment (Mauruh et al., 2022). Based on several studies conducted that kader training in palliative care of cancer patients that is sustainable and continuous must be given to kader's to improve skills and knowledge and kader confidence. Palliative kader training affects in increasing their confidence, knowledge, and attitudes. Confidence in caring for cancer patients and families can positively influence palliative care practices (Widani, 2020).

Training of palliative kader's on the care and assistance of cancer patients and families is expected to provide the understanding and knowledge needed to improve the attitudes and skills of palliative kader's in providing care in meeting basic daily needs. With the knowledge and skills possessed, palliative kader's will take the right attitude in providing services, namely providing the best possible care and assistance without disturbing or reducing the independence of patients and families. The purpose of this study was to explore the barriers and constraints in the care of cancer patients and families.

## **METHOD**

The research design used in this research is a qualitative research design with descriptive methods. Qualitative research with a descriptive approach is a study that defines and presents a situation or phenomenon as it is and seeks problem-solving based on data from the investigation (Fadli, 2021). Qualitative descriptive research is research that is suitable for conducting program evaluations such as participant perceptions (Sugiyono, 2020). The

sampling technique in this study was *purposive sampling*. *Purposive sampling* is well used in descriptive qualitative because it can increase the rigor of the research (Fauzy, 2019). There were 10 participants involved in this study. All participants met the inclusion criteria, which were palliative kader's who had provided care and assistance to cancer patients at home. The data collection technique in this research uses deep interviews and is supported by field notes to ensure the accuracy of the results obtained. Interviews with participants were conducted using the Zoom Meeting application where the interview time ranged from 32 minutes 50 seconds to 55 minutes 46 seconds. Data were analyzed using thematic analysis, which is a method that systematically identifies, organizes, and offers insights into patterns of meaning (themes) within a set of data, which can then be connected to broader theoretical and conceptual issues (Pahleviannur et al., 2022). The data analysis process consists of six stages, which are: data familiarization by first making verbatim interview recordings, coding, searching for themes, reviewing potential themes, defining and naming themes, and then writing them down.

Recruitment of participants in this study used key informants to find potential participants who fit the inclusion criteria. After finding potential participants, the researcher contacted all potential participants and made an appointment for an explanation regarding the research being conducted using a Zoom meeting. The researcher explained the benefits of the study, how potential participants were selected, and the guarantee of data confidentiality. The researcher asked for the willingness of potential participants to be involved in the study and gave them one twenty-four-hour period to make a decision. Once the potential participant agreed, the researcher provided *informed consent* to be signed digitally and made an appointment for the interview. In conducting this research, the researcher conducts self-reflection to realize and acknowledge the possibility of the subjectivity of perception that affects the process of data collection. The advantages of this research are that the researcher conducts regular meetings to reveal the possibility of bias and wrong assumptions from the researcher, confirmation of the research is carried out, the order of data collection, the method of analysis by checking verbatim, and makes a presentation in the form of themes so that it can determine the truth of the research.

**RESULTS**

There were 10 participants in this study. The age of participants in this study was 25-54 years. The education level of the participants varied, seven (7) participants graduated from high school, and three (3) participants graduated with a Diploma. The marital status of all participants is known to be married. The duration of being a palliative kader has been 2 - 7 years since 2018.

Table 1.  
Participant Characteristics

Initials	Age (years)	Education Level	Role Duration (years)
P1	34	High School	4
P2	28	Diploma 3	2
P3	25	Diploma 3	2
P4	54	High School	5
P5	42	High School	3
P6	26	High School	3
P7	49	High School	7
P8	35	Diploma 3	3
P9	41	High School	7
P10	28	High School	3

This study resulted in four themes, which are the lack of family support and family rejection, inadequate health promotion media in prevention, lack of *support system*, and the lack of self-confidence of cancer palliative kader's. This was expressed by several participants as follows:

### **Theme 1: Lack of Family Support in the Care and Assistance of cancer patients during home care**

This theme emerged due to several conflicts that exist in the family in supporting the process of care and assistance of cancer patients, family maladaptive coping, and low self-esteem experienced by patients and families. Some expressions that illustrate this theme are:

- ...initially did not allow us to meet the cancer family (P1)*
- ...when he first came was rejected by the family (P2)*
- ...I'm uncomfortable, uncomfortable and reluctant because my family doesn't want me to (P3)*
- ...the last visit I didn't feel good, and I wanted to end the visit quickly (P3)*
- ...during the family visit, the family cried alone and said there was no need to come again (P2)*
- ...the kader mother must understand us, for now, we don't need other people's help (P4)*
- ...trying to think hard again, is it still trying to come even though the family closes itself (P5)*
- ...it seems that the family does not want us to come to visit to get acquainted and see the patient's condition (P2)*

### **Theme 2: Limited media and teaching aids in cancer prevention health promotion for patient families**

This theme emerged because of the obstacles found by palliative kader's to deliver health promotion to patient families to prevent and early detection of cancer in inpatient families and the community. Some of the participants' expressions that illustrate this theme are:

- ...the prevention promotion tools we brought were only posters from the training (P1).*
- ...most of the patient's family only received the leaflet but skimmed it because it might not be interesting (P2)*
- ...want to prepare a good back sheet for cancer prevention from choosing children's food (P3)*
- ...people prefer to see promotional videos but we don't have any (P4)*
- ...suddenly want to learn to make promotional videos on TikTok so that they are good (P5)*
- ...there is a sense of shame and reluctance because the props brought are old-fashioned (P2)*

### **Theme 3: Support system needed by palliative kader's in providing care and assistance to cancer patients**

This theme arises because there are obstacles in the aspect of the external support system for palliative Kader's. Palliative Kader's have obstacles in the form of considerable distances in reaching cancer patients and families and the absence of transportation equipment owned by palliative Kader's. Some of the participants' expressions that illustrate this theme are:

- ...when I got the task of visiting there was a cancer patient but the destination was quite far from home and there was no vehicle so transportation was difficult (P1)*
- ... when I visited there was no vehicle, I wanted to take public transportation but it took a long time and the patient was already waiting so it was not as promised (P2)*
- ...Finally, my kader friends who are on duty also informed me that it is difficult to work if there is no transportation fee (P3).*

*...I don't have a vehicle sir to go to the houses if I want to visit and see patients but I don't have the money (P4).*

*...when chatting with fellow Kader's, if there is no vehicle, we accompany patients who are close by (P5).*

#### **Theme 4: Lack of confidence experienced by palliative Kader's in fulfilling the basic needs of cancer patients and families**

This theme emerged due to the process of self-confidence experienced by palliative kader's, responses from families who asked several questions that could not be answered perfectly by kader's so that they lacked confidence in carrying out further care. The expression of some participants that illustrate this theme are:

*...after receiving palliative care training, I am still not sure I can assist families in caring for patients (P1).*

*...this is probably because I haven't had any experience treating cancer patients so far (P2)*

*...I don't feel confident so I think I need to be accompanied by someone who can (P2)*

*...if you want to meet the patient or meet the family, there must be a senior or pushes a person who comes (P2)*

*...if there are families who ask a lot of questions, I become even less confident in coming again (P3).*

*...when I'm with patients, I'm often seen and monitored, so I'm even more insecure (P4).*

*...I didn't want to at first because if the action was difficult we would be embarrassed (P5).*

*...the first time I went to the patient's house, I was stiff and embarrassed because I was afraid I couldn't do it (P2).*

*...the patient's husband told me when I was in the hospital that there was a quick way to help bathe (P3).*

Another interesting thing that was found from several participants who revealed that another solution needed to overcome the lack of confidence of kader's during assistance was in the form of palliative training again to strengthen the role of kader's in assisting cancer patients and families in fulfilling basic needs. The expressions of some participants are:

*...it's good that we still need to be trained more and practice more ways of caring for patients (P1)*

*...there must be more training with seniors so that they are not embarrassed and not confident in front of the patient's family (P2).*

*...I told the palliative group that there should be more reinforcement (P4)*

## **DISCUSSION**

### **Theme 1: Lack of family support in the care and accompaniment of cancer patients during home care**

According to the family one or more individuals who live together, have emotional ties, social interactions, and their respective duties. The role of the family is to carry out the duties of the family function in caring for members who experience health problems. Family support is a relationship process in the form of attitudes, actions, and acceptance of families towards their members who are supportive and provide help to family members. Family support also shows the attitude, actions, and acceptance of the family towards family members. Family members perceive that supportive people are always ready to provide help and assistance if needed (Salamung et al., 2021). In the family health care system, there are five family health tasks that families should do, including recognizing health problems in family members, making

decisions in treatment or health care efforts, making health care efforts, by recognizing causes, threats of disease or infection, or accident risks such as poor lifestyles, environmental hazards, stress factors, maintaining a conducive, healthy environment, and maintaining good communication and attitudes that support treatment programs and utilizing and selecting health care facilities for the health needs of all family members (Wahyuni, 2013).

The family has an important role in providing a sense of physical and mental security for family members. This role always involves fulfilling the security needs of family members both arising from within and outside the family, fostering family security both physically, and psychologically, and from various forms of threats and challenges that come from outside (Widari & Serlinda, 2018). This is very necessary in supporting the problems that exist in sick families. Providing support to patients is very necessary in helping sufferers deal with their problems, the family is one of the encouragers for sufferers to be more enthusiastic in dealing with problems that arise when they are diagnosed until they face treatment. Even sufferers feel that their lives are more meaningful if they get support from their families (Silvia, 2020). Family support is needed to reduce the patient's anxiety level. The higher the support given by the family to cancer patients, the lower the level of anxiety experienced by patients who will undergo treatment. The role of motivational support from family members, and the results of the study said there was a significant relationship for patients to get family support. Family support as motivation and a good first step for cancer patients who will undergo treatment and assistance in increasing the enthusiasm of patients in undergoing a series of treatments, psychological feelings, and their nutrition.

### **Theme 2: Limited media and teaching aids in cancer prevention health promotion for patient families**

One method for disseminating information about cancer and early detection is through health promotion (Vera & Melina, 2019). Health promotion with audio visual media and interactive discussion methods is one of the efforts that can be used to better ensure an increase in knowledge, attitudes, and changes in someone's behavior (Kurnianingsih, 2019). Health promotion targets are selected in the target group according to those around in the form of families and communities. In general, in the process of health promotion for cancer awareness, apart from families, there are target groups for health promotion in the community in the DKI Jakarta area in the form of recitation groups, Posyandu or Posbindu, Youth Organization, Family Welfare Empowerment, Church congregations, Jumantik and Dasawisma.

The use of health promotion media is any form that is utilized in the process of distributing health information (Rachmawati, 2019). The use of health promotion media has various advantages which can involve all five senses, are easier to understand, are more interesting because there are sounds and images, have a relatively larger and wider reach, and as a discussion media can be repeated. Health promotion with audio-visual media and interactive discussions is an *active learning* method that functions as a trigger that can encourage group dynamics to share experiences (Trisutrisno et al., 2022). Answering various information needs in community groups and families about understanding cancer prevention can encourage the active role of palliative kader's and families caring for cancer patients. The role of palliative kader's as motivators so that families and communities can express their experiences and support care and assistance to cancer patients and families.

Health promotion methods through interactive discussions between palliative kader's and families of cancer patients can stimulate the generation of ideas or ideas that can encourage

patients and families to express verbally and respect different opinions. Interactive discussions of palliative Kader's with cancer patients and families create a sense of trust in each other which can stimulate the involvement of all family members to participate and create a pleasant atmosphere, to encourage the process of extracting experiences, knowledge, skills, and the effectiveness of the messages conveyed. This shows that a combination of several health promotion methods is more effective for health promotion to increase family support for the care and assistance of cancer patients. Health promotion with audiovisual media and interactive discussion methods can increase knowledge of cancer and positive attitudes toward care support and assistance for cancer patients and families (Rodiah et al., 2016). Knowledge and positive attitudes towards the urgency of cancer prevention for families can encourage behavior for early detection in families of patients with cancer and encourage changes in early detection behavior for other family members.

### **Theme 3: Support system needed by palliative kader's in providing care and assistance to cancer patients**

The demographic structure in Indonesia described is one of the determining factors in the implementation of palliative care, where Indonesia has a diversity of customs, languages, and cultures, which is a supporting factor. This is certainly different from conditions in the world where most countries only have a few different characteristics. Indonesia with a variety of ethnic groups is unique in the world, but this is one of the obstacles in the application of palliative care. This is also supported by the absence of palliative care guidelines that are a reference for every health service in Indonesia. The barriers experienced by palliative kader's in carrying out their role in meeting the basic needs of patients and families, which results in cancer patients experiencing helplessness or hopelessness. This can reduce their quality of life if experienced by cancer patients. Each cancer patient will need different self-adjustments depending on perceptions, attitudes, and personal experiences related to changes experienced through the role of palliative cadres and families (Komisi Penanggulangan Kanker Nasional, 2019). In addition, one of the things needed by cancer patients is a support system that can be provided by the cadre's own family and stakeholders who support the role of palliative cadres.

Palliative care requires the cooperation of various parties and including the family is the role and function of the family and the palliative kader support system (Mauruh et al., 2022). The level of effectiveness of care and assistance for cancer patients and families carried out by palliative kader's is mostly during home care. This will be more effective if it is based on the running of the role, family function, and support system for palliative kader's who accompany each patient and family. The role of palliative kader's should involve various stakeholders such as the government, health agencies such as the health department, hospital social services, and survivor organizations to provide an increased support system for palliative kader's.

### **Theme 4: Lack of confidence experienced by palliative kader's in fulfilling the basic needs of cancer patients and families**

Barriers in the care and assistance of cancer patients and families can be in the form of lack of confidence from palliative kader's so that patients and families cannot work together during the care process and ultimately cannot carry out activities and cannot assist in meeting the basic needs of cancer patients (Widani, 2020). Palliative kader's have roles and responsibilities in care and assistance as well as educators in health promotion (Komisi Penanggulangan Kanker Nasional, 2019). Palliative kader's are health kader's who have been certified and obtained a certificate as palliative kader, who conduct a role in increasing the knowledge, skills, views, perceptions, and self-confidence of palliative Kader's in providing care and assistance to cancer patients and families. Palliative kader are companions of the

community, families, and cancer patients who support and assist in care and assistance. In the implementation of long-term care and assistance of cancer patients and families, palliative kader's have an important role in assisting cancer patients and families in meeting the basic needs of cancer patients. Therefore, the role of palliative kader's is very important to have special skills in the care and assistance of cancer patients and families to meet their needs and improve the quality of life of cancer patients and family motivation in patient care. The role of palliative kader's is to assist cancer patients and families in fulfilling their bio, psycho, social, and spiritual needs (Ndruru et al., 2023). Palliative kader can provide a role in the care of cancer patients and families by reducing the dependency of the patient's needs due to the disease, preventing complications and accidents, and maintaining or improving the quality of life of cancer patients until the end of life. In the process of care and assistance for cancer patients and families until the end of life, the main role of palliative kader's is to ensure that all processes faced at the end of life are by the choices of patients and families, for example, spiritual assistance by their beliefs so that cancer patients receive what is expected of them and their families.

## **CONCLUSION**

Patients and families experience various psychological responses and coping mechanisms in the process of accepting cancer. Some of the psychological responses found can pose obstacles for palliative kader's in the care and assistance of cancer patients and families. Some psychological responses from the family are sad and embarrassed by the patient's condition so they are less supportive in the care process. Intrapersonal conflicts between family members can also be an obstacle in patient care. Internal factors originating from palliative kader's can be an obstacle in the process of assisting patients and families in the form of lack of media in health promotion, lack of confidence, and lack of support system. Internal factors experienced by palliative Kader's are individual perceptions that the actions of the conditions experienced will affect the expected results of both palliative Kader's, patients, and families.

The coping mechanism often used by cancer patients and families in dealing with various conditions is problem-focused coping. This coping mechanism aims to reduce stress stemming from the demands of patient treatment by developing existing resources to cope. Accurate and comprehensive information can help patients and families understand their condition and reduce feelings of fear and helplessness. Empowering palliative kader's again by conducting training and technical guidance specifically on cancer prevention and developing existing resources is needed by palliative Kader's in supporting their duties to provide care and assistance to cancer patients and families. The recommendations of this research are expected to help palliative kader's in performing and carrying out their duties and roles in providing better care and assistance for cancer patients and families.

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