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THE ROLE OF LAY WORKERS IN PROVIDING PSYCHOSOCIAL SUPPORT FOR CANCER PATIENTS

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ABSTRACT

Psychosocial support plays an important role in improving the quality of life of cancer patients, especially through assistance by lay workers. This study aimed to explore lay workers' experiences in providing psychosocial support to cancer patients. This study used a qualitative approach with an in-depth interview method with 14 participants selected by purposive sampling. Participants were lay workers who had attended basic and advanced palliative training, as well as cancer awareness guidance, and had experience in providing palliative assistance to cancer patients for more than one year. The data collection technique used was deep interviews, which were conducted directly with participants. The data collected were thematically analysed through interview transcription, coding, pattern identification, theme review, and research report preparation. The research identified four main themes: (1) forms of psychosocial mentoring, (2) challenges in mentoring, (3) support and collaboration during mentoring, and (4) strategies and development of psychosocial mentoring. Lay workers used various approaches, including emotional presence, relaxation techniques, moral support, and education to help patients overcome anxiety, fear, and loneliness. The main challenges faced included difficulties in building patient openness, limited lay worker skills, and lack of family support. Support from health workers and collaboration with families play a role in optimizing assistance. Further training is needed to improve lay workers' skills in dealing with complex psychological problems. A more personalized, empathy-based and integrated approach can strengthen support and increase the effectiveness of psychosocial assistance.

Keywords: cancer; lay worker; palliative; psychosocial

INTRODUCTION

Cancer is a disease with a significant impact on various aspects of a patient's life, including physical, psychological and social. The disease not only causes health problems, but also causes deep emotional distress for patients and their families. Data from Globocan released by the World Health Organization (WHO) in 2020 noted that there were 396,914 new cases of cancer in Indonesia, with the number of deaths reaching 234,511 cases. Globally, the number of new cancer cases reached 20 million with 9.7 million deaths in the same year. This high incidence rate shows that cancer is a public health problem that needs serious attention, including in the psychosocial aspects of patients (Utami & Mustikasari, 2017) (Lestari et al., 2020).

The physical impact of cancer is often accompanied by severe psychological distress, contributing to a decline in patients' quality of life. A cancer diagnosis can trigger various mental disorders, such as anxiety, stress, and depression in patients and their families. Various studies have shown a high prevalence of psychosocial disorders in cancer patients, which further exacerbates their health conditions (Lestari et al., 2020; Candra & Sastrawan, 2022). A study in Indonesia reported that 34.4% of cancer patients experienced mental emotional disorders, such as depression and anxiety (Khoiriyah & Handayani, 2020). Another study found that 23% of cancer patients undergoing chemotherapy experienced depression, 40%

experienced generalized anxiety disorder, and 21% experienced stress stress (Larira et al., 2023). Globally, the prevalence of psychological disorders in cancer patients ranges from 29% to 47%, indicating that psychosocial support is needed in the patient care process (Habimana et al., 2023).

Previous research has discussed various methods of dealing with psychosocial disorders in cancer patients, such as psychotherapeutic interventions, group therapy, and social support from family (Putri & Suryanto, 2020). Some of these interventions have proven effective in reducing anxiety and improving the psychological well-being of cancer patients. However, research that specifically addresses the role of lay workers in psychosocial assistance for cancer patients is still limited. Lay workers are an important element in the health care system that plays a role in providing support to cancer patients, especially in psychosocial aspects. Therefore, further research is needed to understand how lay workers face challenges in carrying out this role, as well as strategies that can be implemented to improve the effectiveness of their assistance (Dahniar et al., 2023); (Ndruru et al., 2023).

As part of the palliative care system, lay workers have duties that are not only limited to medical assistance, but also include emotional, social, and spiritual support for cancer patients. lay workers play a role in helping patients deal with the psychological challenges they experience and become a link between patients and health services. In addition, lay workers also play a role in providing education to patients' families so that they can support patients more effectively (Aisyah et al., 2020). The role of lay workers is increasingly important given the high incidence of cancer in Indonesia, which reaches 136 people per 100,000 population and ranks Indonesia 8th in Southeast Asia (Widani, 2020). Therefore, understanding the challenges faced by lay workers in providing psychosocial assistance is crucial to improving the quality of palliative care in Indonesia.

Various challenges are faced by lay workers in providing psychosocial assistance to cancer patients, both from internal and external aspects. One of the main obstacles is the lack of specialized training related to psychosocial approaches for patients with chronic diseases, which leads to limited skills in providing emotional support effectively (Dahniar et al., 2023). In addition, high emotional burden is also an obstacle because they often have to deal with patients' worsening conditions, which can trigger stress in lay workers (Rakhmaningrum & Idris, 2019). On the other hand, limited resources in the form of facilities, time, and personnel are also challenges that must be faced in the palliative care system. Support from the patient's family, which is still less than optimal, further complicates the task of lay workers in providing comprehensive assistance, so strategies to increase the capacity of lay workers are needed (Etnis & Ruhukai, 2021).

This study aims to explore the challenges faced by lay workers in assisting the psychosocial needs of cancer patients. Through a qualitative approach, this study will explore the experiences and obstacles faced by lay workers in carrying out their roles. In-depth interviews will be used to identify factors that influence the effectiveness of psychosocial assistance by lay workers. In addition, this study will also explore strategies that can be implemented to improve the effectiveness of mentoring. As such, this study is expected to provide greater insight into the factors that contribute to the effectiveness of lay workers in supporting cancer patients.

The results of this study are expected to provide greater insight into the challenges faced by lay workers in assisting cancer patients, particularly in psychosocial aspects. In addition, this study is also expected to provide recommendations for the development of a better psychosocial assistance system, especially through increasing the capacity of cadres and optimizing support from health workers. With more optimal support for lay workers, their effectiveness in carrying out their roles will increase, so that cancer patients get better psychosocial assistance. Thus, lay workers who are better equipped to carry out their duties will contribute to improving the quality of life of cancer patients.

The aim of this study was to explore the challenges faced by lay workers in assisting the psychosocial needs of cancer patients. The study explored lay workers' experiences in providing emotional, moral and educational support to patients, as well as the barriers they face in carrying out this role. In addition, this study also aims to identify strategies that can be implemented to improve the effectiveness of psychosocial assistance by lay workers, so as to provide recommendations for the development of training programs and optimization of support systems in palliative care. The results of this study are expected to serve as a basis for the formulation of policies that support the capacity building of palliative lay workers in providing more effective and sustainable psychosocial assistance.

METHOD

This study used a qualitative research design with a descriptive approach. The qualitative approach aims to explore participants' understanding, experiences, and perceptions regarding the challenges faced by lay workers in psychosocial assistance to cancer patients. This approach allows researchers to describe the phenomena that occur in detail without any manipulation of variables, and provides a deeper understanding of the reality faced by lay workers (Surayya, 2020). The descriptive design is also relevant for identifying factors that influence the effectiveness of psychosocial assistance and uncovering themes that emerged during the interview process.

This study involved 14 cancer Palliative Care Lay Workers who had attended basic, advanced palliative training, as well as cancer awareness guidance, and had experience in providing palliative assistance to cancer patients for more than one year. Participants were selected based on these criteria to ensure that participants had knowledge and experience relevant to the research topic. The study was conducted in December 2024 to explore the direct experiences of lay workers who are active in providing psychosocial support to cancer patients. The sampling techniques used in this study were purposive sampling and snowball sampling. Purposive sampling was used to select participants who have certain experiences and qualifications relevant to the research objectives, namely lay workers who have played an active role in assisting cancer patients and have more than one year of experience in providing psychosocial support. This sampling aims to obtain more in-depth data from participants who have direct experience with the phenomenon under study (Fauzy, 2019).

Snowball sampling was used to expand the number of participants who could be interviewed. This method involved the first selected participant recommending other lay workers who met the inclusion criteria. This process allowed the researcher to access a wider network of lay workers, resulting in more representative and varied data. This study involved 14 participants who were selected based on their experience and the relevance of their tasks in psychosocial assistance for cancer patients. The data collection technique used was deep interviews, which were conducted directly with participants. This interview aims to obtain more in-depth and personalized information about the experiences and challenges faced by lay workers (Fiantika et al., 2022). Field notes were also used to record important observations during the interviews, which could enrich the data obtained. The interview process was conducted with a responsive approach, where researchers responded to participants' answers to explore further if needed. Data saturation was reached after the sixth participant interview, indicating that the information obtained was sufficient to answer the research questions.

The data collected was then analysed using thematic analysis, which aims to identify, organize, and offer insights into the patterns of meaning that emerged in the data. The data analysis process was carried out in several stages, namely transcription of verbatim interviews to ensure all information was recorded accurately. Next, coding was done to mark emerging themes, which were then further analysed to look for relevant relationships and patterns. A review of the themes found was conducted to ensure compatibility and fit with the existing data. After that, the identified themes were given definitions and names, before finally being compiled in the form of a research report.

Participant recruitment was conducted by identifying key informants who could direct the researcher to participants who fit the inclusion criteria. Once the participants were identified, the researcher contacted them to provide information about the purpose of the study, its benefits, and the guarantee of data confidentiality. This process also included an explanation of the participants' rights during the research, including consent to participate in the interview. Once the participant agreed, they were asked to digitally sign the informed consent before the interview was scheduled, which ensured the participant understood the purpose of the study and agreed to participate voluntarily.

The researcher conducted self-reflection throughout the research process to ensure that subjectivity did not influence data collection and analysis. This continuous reflection was done by checking for biases that might arise from the researcher in interpreting the data. The data collection process was conducted systematically to increase the accuracy and validity of the data obtained. The organization of themes in the final research report allowed the researcher to present the data in a more structured and easily understood form, providing a clear picture of the challenges faced by lay workers in psychosocial assistance to cancer patients.

Table 1.
Interview Guidelines

No	Main Question
1.	What forms of psychosocial assistance do you usually provide to cancer patients?
2.	What are the biggest challenges you face in psychosocially assisting cancer patients?
3.	How do patients and their families react to the psychosocial support you provide?
4.	How do patients and their families react to the psychosocial support you provide?
5.	What are the main factors that hinder the effectiveness of psychosocial assistance for cancer patients?
6.	How do you receive support from health workers or other parties in carrying out this task?
7.	What strategies do you use to overcome barriers to psychosocial support for cancer patients?
8	What do you think needs to be improved or enhanced to make palliative lay workers more effective in psychosocial assistance for cancer patients?

RESULT

Most of the participants in this study were female, reflecting gender dominance in the role of palliative care in cancer patients. The majority were aged between 35 to 39 years, which provides a balance between life experience and the ability to manage the challenges of assisting patients. Their educational backgrounds were predominantly high school graduates, with some having a Diploma, so practical training was an important aspect in supporting their skills. Mentoring experience ranged from one to six years, indicating a good understanding of the psychosocial challenges faced by cancer patients. By working with one to five patients, they were able to provide more personalized and in-depth support, despite the challenges they faced.

Table 2.
Participant Characteristics

No	Aspect	Participant Characteristics	Total
1	Gender	Male	0
		Female	14
2	Age	30 - 34	5
		35 - 39	7
		40 - 44	2
3	Educational Background and Professional Qualifications	Senior High School	12
		Diploma	2
		Bachelor	0
		Master	0
4	Duration of Palliative Care Assistance	1 – 3 years	5
		4 – 6 years	5
		More than 6 years	4
5	Number of Patients Assisted	1–5 patients	9
		6 –10 patients	4
		11 – 20 patients	1
		More than 20 patients	0

This research resulted in four main themes, namely: (1) forms of psychosocial assistance by lay workers, (2) challenges in psychosocial assistance, (3) support and collaboration during assistance, and (4) strategies and development of psychosocial assistance. These themes were expressed by several participants who contributed to the research.

Theme 1. Forms of psychosocial assistance by lay workers

I focus more on my presence for patients, just by listening they feel calmer (P10)
I listen to patients and give them space to talk about their feelings with empathy (P1)
I use relaxation techniques such as deep breathing to reduce patient anxiety (P9)
I provide moral support, reminding patients to stay positive by the example of others (P5)
I assist patients in daily activities and provide information about their condition (P3)
I support patients psychologically, talking about their fear of treatment (P4)
I educate patients about treatment and how to manage their pain (P8)
I provide space for patients to talk about their feelings without feeling judged (P12)

Theme 2. Challenges in psychosocial assistance

The biggest challenge is patients who feel anxious and afraid of their future, it is difficult to give them peace of mind (P1).
Patients are often not open about their feelings, which is a big challenge in providing psychosocial support (P9)
Patients who feel anxious and lonely find it difficult to receive support, making assistance more complicated (P6)
Patients who refuse to talk about their fears or feelings, making it difficult for me to provide the support needed (P4)
Family lack of support is an obstacle in providing assistance, some families feel that they have done enough (P7)
Patients who are too depressed and feel hopeless are very difficult to talk to or provide motivation (P5)
Patients who feel there is no hope are a big challenge, I have to find a way to raise their spirits (P3).
The main factor hindering assistance is the patients' ignorance of their condition, making them reluctant to accept support (P8)

Theme 3. Support and collaboration during assistance

The support of health workers is very important in providing clear medical information, so that assistance is optimized (P1).
I receive support in conveying treatment information and side effects to patients (P3).
Collaboration with health workers ensures patients receive the right care and feel more comfortable (P9).
Family support means a lot even though they are sometimes anxious, so collaboration is key in providing maximum support (P7).
Health workers help with medical information and ways to manage physical symptoms, supporting psychosocial assistance (P8).
Health workers play a role in educating patients about their condition and how to deal with it (P10).
Collaboration with medical personnel is important to harmonize physical and psychosocial care so that patients receive comprehensive support (P5).
The support of health workers gives me more knowledge about the patient's condition, so that psychosocial assistance is more appropriate (P4).

Theme 4. Strategies and development of psychosocial assistance

I use a personalized and empathic approach to overcome barriers in mentoring (P1)
I build trust with patients so that they are more open to support (P9)
I engage patients in slow conversations to overcome barriers and make them comfortable (P5)
I maintain open communication with patients and families to enhance psychosocial support (P10)
I approach the patient patiently and involve the family to better support the mentoring process (P4)
I provide space for patients to talk without pressure and assist them in their daily activities (P3)
I feel the need for further training to improve the effectiveness of mentoring (P8)
More coordination is needed with health workers and families to make the assistance more holistic (P12).

DISCUSSION

Theme 1. Forms of psychosocial assistance by lay workers

A caring presence in psychosocial support has been shown to reduce anxiety and provide a sense of security for patients facing emotional challenges (Karmadi et al., 2023). P1 emphasized that “just by listening, patients feel calmer,” showing how important the role of the companion is in providing emotional support. This approach not only builds a stronger relationship between the caregiver and the patient, but also helps to reduce the loneliness that cancer patients often experience. Thus, psychosocial assistance by lay workers must prioritize empathy and active involvement so that patients feel heard, understood, and get optimal support in dealing with their condition.

Relaxation techniques, such as deep breathing, have been shown to be effective in lowering anxiety levels and reducing physical tension in patients (Nurmawati & Gati, 2023). P9 mentioned that these methods are used to calm patients, demonstrating their effectiveness in creating a sense of comfort and control over their condition. Patients experiencing treatment-related anxiety can directly benefit from this technique, which helps them relax more in the face of treatment. Therefore, companions trained in relaxation techniques can provide more optimal support, not only in psychosocial aspects but also in improving the overall quality of life of patients.

Moral support provided in a positive manner has been shown to strengthen the patient's mentality, give hope, and increase resilience in the face of illness (Aseren, 2019). P5 stated that reminding patients to keep thinking positively by modelling the stories of others who succeed can provide additional motivation. This approach helps patients feel more optimistic and see the future with a better perspective. With consistent moral support, patients are more motivated to continue struggling in undergoing treatment, so that their quality of life can be significantly improved.

Education about medical conditions and treatment is essential in providing holistic psychosocial support (Afifah et al., 2023). P8 explained that providing information to patients about treatment and how to manage pain helps them feel better prepared and reduces anxiety. Proper education can improve patients' understanding of medical treatment in patients, leading to better compliance and more effective pain management (Rossa et al., 2024). Caregivers who are able to provide clear and precise information help patients feel more in control of their condition. This education increases patients' self-confidence and minimizes uncertainty regarding their medical treatment.

Theme 2. Challenges in psychosocial assistance

Challenges in psychosocial support for cancer patients are strongly influenced by the anxiety and fear that patients experience about future conditions (Tumanggor et al., 2023). P1 emphasized that patients who feel anxious and fearful about their future often find it difficult to be reassured. Deep anxiety can hinder the mentoring process as patients feel hopeless, leading to resistance to the support provided (Hasanah et al., 2023). To overcome this, caregivers should be able to offer a sense of security and manage patients' anxiety with a more personalized and empathic approach. Assistance that involves relaxation techniques and attentive communication can help reduce the anxiety experienced by patients.

Open and honest communication plays an important role in reducing anxiety and strengthening the emotional bond between patients and caregivers (Hamdana & Nurhidayah, 2022). P9 revealed that patients are often reluctant to express their feelings, making it difficult for caregivers to provide appropriate support. When patients feel heard and understood, they are more open to receiving the help provided. Therefore, caregivers should create an environment that supports openness, builds trust, and reduces patients' fear of expressing their feelings. Patients who experience loneliness are more prone to depression and anxiety, which can worsen their psychosocial conditions (Sanjiwani & Dewi, 2022). P6 mentioned that patients who feel lonely and anxious often find it difficult to receive support from caregivers. In this condition, a caring and empathetic approach is key so that patients feel valued and accepted. Caregivers who are able to build strong relationships with patients can help reduce feelings of isolation, so that they are more open to the support provided and are able to cope better with their condition.

Lack of family support can worsen cancer patients' quality of life and increase the psychosocial challenges they face (Irma et al., 2022). P7 revealed that some families felt it was enough to provide physical care, but lacked in providing emotional support. In accordance with this condition, assistants need to involve families in the assistance process and provide education on the importance of emotional support for patients. Through more active family involvement, the support system formed becomes more holistic, so that patients get more comprehensive attention in physical and psychosocial aspects.

Theme 3. Support and collaboration during assistance

Support and collaboration between lay workers, health workers, and families are essential in effective psychosocial assistance for cancer patients (Putri & Suryanto, 2020). P1 emphasized that the support of health workers, especially in providing clear medical information, makes it easier for lay workers to carry out their role. Open communication between health workers and companions contributes to a better understanding of the patient's condition. With accurate medical information, caregivers can help patients manage anxiety and provide support that better suits their needs, thus improving the overall quality of caregiving.

The integration of physical and psychosocial care has been shown to improve the quality of life of cancer patients (Nurhikmah et al., 2018). P9 mentioned that support from health professionals is crucial in ensuring patients receive appropriate care. Collaboration between health professionals and caregivers not only strengthens understanding of the patient's condition, but also ensures the support provided is holistic. By combining medical care and emotional support, patients get a more holistic approach, which helps them better cope with the challenges of the disease.

Family support plays an important role in assisting cancer patients, as it can contribute to patients' emotional recovery by making them feel more accepted and valued. However, families often experience anxiety and emotional burden in dealing with the patient's condition (Pristiwati et al., 2018). P7 highlighted that although families provide significant emotional support, they also often feel overwhelmed. Therefore, lay workers need to involve families in every stage of care and provide education on effective psychosocial support. With a balance between physical and emotional care, families can be a more optimal source of support for patients.

Collaboration between health professionals, lay workers and families plays an important role in ensuring cancer patients receive comprehensive care. Effective collaboration can improve patients' quality of life by integrating physical care and emotional support (Rokhmah & Anggorowati, 2017). P5 and P8 noted that this synergy helps align medical and psychosocial care, so that patients not only get the right therapy, but also feel more emotionally supported. Through a supportive environment, patients can cope better with the treatment process, both physically and psychologically.

Theme 4. Strategies and development of psychosocial assistance

The approach used by the companion is very influential in the effectiveness of psychosocial assistance for cancer patients. An empathic approach has been shown to reduce patients' anxiety and increase their acceptance of treatment(Fanny, 2024). P1 emphasizes that building a personal and empathic relationship helps to overcome barriers in mentoring, allowing patients to be more open to the support provided. Through a strong bond, the mentor can accelerate the patient's adaptation process to their condition, making the mentoring more effective in improving the patient's psychosocial well-being.

Building trust with patients is an important strategy in psychosocial support. A relationship based on trust allows patients to feel safer and more open in expressing their feelings without fear of being judged (Wijayanti & Astuti, 2023). P9 stated that well-established trust makes patients more receptive to the support provided. Through trust, patients find it easier to express their concerns about their illness and treatment, which ultimately helps reduce emotional stress and increase the effectiveness of support.

Open communication plays an important role in psychosocial support, especially in maintaining coordination between patients, families, and lay workers. Effective communication with families helps ensure that patients receive optimal support, as families are often the primary source of emotional support (Kharunia & Indrawati, 2024). P10 emphasized that maintaining good communication with patients and families can improve understanding of the patient's condition and the support needs required. Family involvement in support not only strengthens the emotional support network but also helps reduce the loneliness and uncertainty that cancer patients often experience.

Improving skills other than communication in lay workers through training is also an important factor in the effectiveness of psychosocial assistance. Continuous training allows lay workers to gain new knowledge about more effective techniques in managing patient stress and anxiety (Zendrato et al., 2022). P8 said that further training would be very useful in dealing with patient psychosocial challenges. Through better skills, lay workers can provide more targeted support and handle more complex situations more confidently and effectively.

CONCLUSION

The conclusion of this study shows that psychosocial support by lay workers for cancer patients involves a highly empathetic approach and is based on attention to the patient's emotional condition. Lay workers use various methods, such as emotional presence, relaxation techniques, moral support, and medical education to help patients manage the psychosocial challenges they face. Collaboration with health workers and support from families is also very important in creating an environment that supports the patient's overall well-being. Lay workers focus on psychosocial aspects, such as anxiety, loneliness, and uncertainty of patients, which greatly affect their quality of life. A more personalized approach allows lay workers to provide deeper and more effective support to patients.

However, there are challenges in the mentoring process, such as difficulties in dealing with patients' deep anxiety and their inability to open up about their feelings. Some patients feel anxious and lonely, which complicates mentoring efforts. Less than optimal support from families also hinders the success of mentoring. Therefore, further training for lay workers is needed to improve skills in dealing with more complex psychological problems. Better coordination with health workers and families is needed so that mentoring can be more holistic and effective.

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