



The Influence of Palliative Care Guidance in Physical Aspects in Families on Level of Independence Post-Stroke Patients' Families in Garut Regency

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Abstract: Physical complications due to stroke result in a decrease in the patient's level of independence to meet their daily needs, so it is necessary to carry out rehabilitation measures to increase independence through providing palliative care guidance at home. The aim of this research is to determine effect of palliative care guidance in physical aspect on the level of independence of families of post-stroke patients in Garut Regency. This research method is quasi experimental with one group pre-test and post-test design. The research sample was families who had family members with stroke infarction, 20 respondents in intervention group, sampling technique used purposive sampling. Data collection used standard nursing operational procedures from PPNI and family independence level instruments. Data analysis used Wilcoxon. The results of the research before being given palliative care guidance in the physical aspect, most families (55%) were at level 2 of independence and after providing palliative care guidance most of the families (55%) were at level 3 of independence. There was an influence of palliative care guidance in the physical aspect on level of independence of post-stroke patients' families with p value of 0.00. Providing information and skills through palliative care guidance can increase family understanding and independence in caring for family members who have experienced a stroke, so that palliative services can be used as one of the health center's work programs to improve quality of life for stroke infarction patients.

Keywords: Infarction stroke; Level of independence; Palliative care

Introduction

According to the WHO, a stroke is "the sudden onset of clinical signs and symptoms of a focal neurological disturbance lasting >24 hours or resulting in death with no other apparent cause other than the vascular origin. According to Langhorne et al. (2012), Stroke treatment mostly entails thrombolysis and secondary prophylaxis. Stroke mortality has decreased as a result of the establishment of established stroke units in developed nations. However, a lack of resources in low- and middle-income nation's results in insufficiently coordinated care for stroke patients.

Stroke care is impacted by choices that are clinically difficult, emotionally draining, and ethically complex

(Mazzocato et al., 2010). Most stroke victims seek comfort from their suffering, a sense of control, and a reduction in the load on their families during their hospitalization and recovery. According to Holloway et al. (2014), Palliative care seeks to improve the quality of life of patients and families through the identification, prevention, and relief of pain and suffering in body, mind, and spirit. However, the palliative needs of stroke patients are often poorly investigated.

According to Salins (2014), Clinicians must be aware of the palliative needs of stroke survivors because many of them are frequently unable to express and describe their needs and concerns. According to studies, the ordinary Indian patient suffering from an illness that causes moderate to severe pain is unaware that there are

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effective treatments to treat it. Long after the stroke began, many patients still struggle with poor symptom control and unmet palliative needs (Frontera et al., 2015).

Previous research has revealed that among stroke patients, prevalent palliative needs include pain, dyspnea, anxiety, depression, agitation, incontinence, exhaustion, poststroke seizures, sexual dysfunction, and sleep-disordered breathing (Colby et al., 2010). According to Ntlholang et al. (2016), extensive palliative care is the primary emphasis and objective for stroke patients with chronic comorbidities for the rest of their lives. Few professionals and patients are aware of the full breadth of palliative care, and little data is available on the proportion of stroke patients who received this type of treatment (Mani et al., 2012).

The impacts that occur due to stroke infarction can occur in physical, psychological, social and spiritual aspects. The impact that occurs on the physical aspect can cause physical limitations, resulting in a decrease in level of independence, requiring rehabilitation efforts when the patient returns from the hospital (Brewer et al., 2013). One of the goals of stroke rehabilitation is to increase the patient's level of independence in meeting basic needs so that they can achieve life goals and well-being of the patient and family, which can be done by providing palliative care (Badaru et al., 2015).

Palliative care is care that is patient and family centered with the main aim of improving the quality of life patients and families in dealing with disease experienced by the patient (Steele et al., 2016). The palliative care process is a specialized care process in health sector involving doctors, nurses, health care experts and other specialists who have mutual roles and responsibilities in providing care and providing support to patients and their families. Through the palliative care process, patients and their families can communicate with doctors about hopes, goals of care, symptom management, and action decisions to overcome physical complaints. Physical problems that often arise are limitations in carrying out daily activities, maintaining personal hygiene, consuming foods that contain nutrients, carrying out movement, elimination, bathing and other activities (Curie, 2019).

Accuracy in providing palliative care to post-stroke patients will be able to lighten the sufferer's burden, minimize emotional physical disability, anxiety and stress so that it will reduce dependence on other people and patient's level of independence will increase (Chapman & Bogle, 2014). Family involvement in palliative care process for post-stroke patients plays an important role in terms of attitudes, actions and acceptance of each family member. This is because family has a health care function which requires family to be able to provide care to sick family members, be able

to maintain/create a healthy family system, and be able to make appropriate health action decisions (Friedman et al., 2014).

Health education and improving family skills in providing health care to sick family members need to be provided, this is in accordance with the results of research conducted by Zaenal et al. (2022) which revealed that there was an influence of providing health education on the level of independence in Activity Daily Living (ADL) of patients who experienced a stroke. The increasing knowledge (cognitive) of Activity Daily Living (ADL) in stroke patients will have a positive impact in maintaining the fulfillment of basic needs and improving the quality of life and level of independence of stroke patients.

Providing health education and family support has a positive effect on fulfilling Activity Daily Living (ADL). Health education can overcome disease without waiting until the disease gets worse and create a calm situation so that it can increase patient independence (Firawati et al., 2021). In addition, there is a relationship between palliative care and quality of life in breast cancer patients (Ibrahim et al., 2021). The number of stroke survivors with ongoing disability and impairment has increased along with the drop in stroke patient death. Following a stroke, these impairments reduce quality of life (Sarti et al., 2000).

Based on Hong et al. (2017) Studies have revealed a correlation between physical inactivity and post-stroke depression prevalence and that the prevalence of disability among stroke patients ranges from 24% to 54%. Liu et al. (2014) cited physiatrists who said that pain frequently impedes the rehabilitation process, leading to discontinuation and unsatisfactory results. According to studies, early rehabilitation after a stroke is necessary for a better functional prognosis. According to Hu et al. (2000), pain management should be implemented from the start of treatment for stroke patients in order to achieve a better result.

According to van Almenkerk et al. (2015), pain is linked to higher levels of agitation, anxiety, and depression in stroke patients. Although clinicians are aware of the psychological component of pain, the steps taken to address it are insufficient. The main psychological problems that develop include PSD, poststroke anxiety, poststroke fatigue, poststroke anger propensity, and poststroke emotional liability (Kim, 2016). PSD was the most often mentioned psychological condition in our investigation.

Male gender, marriage, and nuclear family status are significantly correlated with PSD (Volz et al., 2016). Depression is thought to have the biggest impact on the poor quality of life of stroke survivors. Additionally, studies have linked PSD to worse rehabilitation results,

cognitive decline, increased disability and fall risk, as well as higher mortality. Additionally, PSD has been connected to a less effective use of rehabilitation programs.

The results of an empirical study in the Bayongbong Community Health Center working area showed that the majority of families asked for help from health workers in providing care for family members who had suffered stroke infarction, this was because families had never received information about treating stroke patients with infarction at home, families only learned from habits of other people who have carried out palliative care or only get information from online media. The objective of this study was to determine effect of palliative care guidance in the physical aspect of the family on level of independence of families of stroke infarction patients in Bayongbong District, Garut Regency.

Method

This research method is quasi experimental with one group pre-test and post-test design. The research sample was families who had family members with stroke infarction, 20 respondents in intervention group, sampling technique used purposive sampling. Data collection used standard nursing operational procedures from PPNI and family independence level instruments. Data analysis used Wilcoxon and the results were presented in tabular form. This research has been done in the Bayongbong Community Health Center working area for 1 month in June 2023. This research has been subjected to ethical due diligence by the research ethics committee of 'Aisyiyah University Bandung and obtained an ethical approval letter Number: 167/KEP.01/UNISA-BANDUNG/V/2023.

Result and Discussion

Level of Family Independence before Being Given Palliative Care Guidance in Physical Aspects

Palliative care is an integrated care system to improve quality of life by alleviating pain and other aches, providing spiritual and psychosocial support and providing support to patient's family (Leuna & Rantung, 2019). Palliative care is provided for all patients suffering from chronic illnesses with life-limiting or life-threatening conditions as well as conditions for patients who receive interventions to prolong life span (Muntamah, 2020). Providing appropriate palliative care to post-stroke patients will minimize physical and psychological disability and reduce dependence on other people so that they are able to be independent and

able to increase their independence (Chapman & Bogle, 2014).

According to this research, before being given palliative care guidance, the patient's level of independence was at level II independence. Providing palliative nursing guidance as an effort to prevent and alleviate suffering to maintain and improve quality of life patients and families in dealing with various disease problems suffered through efforts to treat pain and other problems both physical, psychological, spiritual, social support and family support to patients during times of illness and grief (Campbell, 2014).

Palliative care is multidimensional in nature which aims to treat symptoms, communicate and decide on actions with patients and families in dealing with physical complaints that often arise in maintaining personal hygiene, nutritional intake, mobilization, elimination, personal hygiene and other activities (Curie, 2019). The results of research on level of family independence before being given palliative care guidance in physical aspects can be seen in Table 1.

Table 1. Level of Family Independence before Being Given Palliative Care Guidance in Physical Aspects

Level of Family Independence	n	%
I	9	45.0
II	11	55.0
Total	20	100

Based on Tabel 1, it is known that the level of family independence before being given palliative care is mostly (55.0%) in the level II and nearly half (45.0%) are in the level I.

Level of Family Independence after Being Given Palliative Care Guidance in Physical Aspects

After being given palliative care guidance, the family's level of independence largely changed from level II independence to level III independence. This increase in independence is influenced by the level of family education, most families have a senior high school education level, making it easier to provide information and understanding about palliative care guidance in caring for family members who experience post-infarction stroke. The level of individual knowledge is influenced by level of education, attitudes and behavior as well as information obtained by the individual. An individual's level of education and experience will influence their response to information. People who are highly educated will respond more rationally to the information obtained and will think about the usefulness of the idea (Sukmadinata, 2013).

The level of individual knowledge and education influences family's ability to receive and understand information about guidance on palliative care on

physical aspects for family members who have experienced stroke infarction. Increasing family's ability to care for patients will minimize costs and energy that must be spent by family for process of treating patients to hospital, so that the treatment process can be carried out at home. Another factor that influences the increase in level of family independence after being given palliative care guidance in physical aspect is the age of family caring for the patient at home. Almost half of families are in young adult age category (25 to 35 years), so this will provide strong motivation to be independent in caring for family members who experience stroke infarction. Age is strongly related to family knowledge in palliative care, families are enthusiastic and strong in receiving information in carrying out palliative care at home (Widowati et al., 2020).

The level of family independence is family's behavior in carrying out nursing actions independently at home. Palliative care guidance is very important to provide to families and stroke infarction patients at home, because it can increase family's ability to take action according to patient's needs. The results of research on level of family independence after being given palliative care guidance in physical aspects can be seen in Table 2.

Table 2. Level of Family Independence after Being Given Palliative Care Guidance in Physical Aspects

Level of Family Independence	n	%
I	3	15.0
II	6	30.0
III	11	55.0
Total	20	100

Based on Tabel 2, it is known that level of family independence after being given palliative care is mostly (55.0%) in the level III, small portion (30% and 15%) in the level II and I.

Effect of Palliative Care Guidance in Physical Aspects on the Level of Independence Families of Post-Infarction Stroke Patients

After providing palliative care guidance to families of post-stroke patients, none of families experienced a decrease in their level of independence, 15 families experienced an increase in their level of independence, and 5 families experienced no change in their level of independence. The aim of rehabilitation efforts and palliative care services for stroke infarction patients is to increase level of independence of patients and their families regarding health problems they experience, so that they can achieve optimal life goals and well-being (Badaru et al., 2015).

Caring for post-stroke patients requires family involvement. Family involvement is manifested in

attitudes, actions and acceptance of each family member towards health problems experienced by one of family members. This is done by providing emotional, energy, thought and financial support to improve physical, mental, emotional and social development of each family member to improve quality of life of patient and family (Mahmuddin et al., 2020). Palliative care is a form of integrated health service that is needed to improve quality of life by alleviating complaints, providing spiritual and psychosocial support from the time diagnosis made until death.

The results of research on Effect of Palliative Care Guidance in Physical Aspects on the Level of Independence Families of Post-Infarction Stroke Patients can be seen in Table 3.

Table 3. Effect of Palliative Care Guidance in Physical Aspects on the Level of Independence Families of Post-Infarction Stroke Patients

Level of Family Independence	n	Negatif Rank	Positif Rank	No Change	p value
Pre-Post	20	0	15	5	0.00

Based on Tabel 2, it is known that after providing palliative care guidance to families of post-stroke patients, not a single family experienced a decrease in their level of independence, 15 families experienced an increase in their level of independence and 5 families experienced no change in their level of independence. The results of the Wilcoxon test obtained p value of 0.00 (< 0.05), which means that there is an influence of palliative care guidance on physical aspects on level of independence of post-stroke patient's family.

Conclusion

Most of levels independence of families' post-stroke patients before being given palliative care guidance in physical aspects is at level II. Most of levels independence of families' post-stroke patients after being given palliative care guidance in physical aspects is at level III. There is an influence of palliative care guidance in physical aspect on level independence of families' post-stroke patients in Bayongbong District, Garut Regency.

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Author Contributions

Each author has contributed to this research process. The process of conceptualizing research theory and methods, obtaining research permits, data collection, data analysis, and supervision was carried out by Zahara Farhan as the corresponding author. The process of data collection, data validation, data analysis, and preparation of publication manuscripts was assisted by Rudi Alfiansyah, Devi Ratnasari, and Debi Mutiara Suci as research members.

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Conflicts of Interest

During the research process and preparation of this research report, there was no conflict of personal interest that influenced the research results, either in data collection, data presentation or interpretation of research data. Each author has agreed to publish the results of this research at their own expense so that no one can interfere with the process of publishing on this research.

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