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Family Support and Meaning of Life among Palliative Patients

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Abstract Introduction: Palliative patients who receive palliative care are only 14% of over 40 million around the world. Palliative patients who find meaning in their lives also find purpose despite their illness. Family support is one of the factors that help palliative patients find meaning in life. It can be in the form of emotional support, instrumental support, informational support, appraisal and appreciation from others. The past and present life experiences such as, the disease suffered, can also influence the meaning of life. This study aims to study the relationship between family support and the meaning of life in palliative patients. This study adopted a quantitative-correlational method with data collection techniques using purposive sampling. The number of respondents was 107 people. The questionnaire used the Family Support scale and the Meaningfulness of Life questionnaire. Data analysis utilized Kendall's Tau and Kruskal Wallis tests. Results: Family support obtained an average of 100.63 with a standard deviation of 14.150. Meaningfulness of life obtained an average of 76.96 and a standard deviation of 14.540. The result is that there is a correlation between family support and meaningfulness of life, with a p-value of 0.012. When viewed from the coefficient correlation (r) value = 0.173, there is a correlation between family support and meaningfulness of life in palliative patients. The level of family support between different types of caregivers had a p-value of 0.0005. Husbands had the highest mean family support scores. Conclusion: Families should pay more attention and provide support during treatment, and palliative patients should be more active in activities to foster a sense of meaning in life.

Keywords Family Support, Meaning of Life, Palliative Patients

1. Introduction

Chronically ill and palliative care patients require high healthcare resources, family support, and physical or psychological support. Individuals may survive for many years before passing away if they have one or more chronic illnesses. Patients are described as experiencing a stable phase of life in the immediate aftermath of a diagnosis, which is followed by a brief and predictable period of functional and clinical decline. Months to years of physical and psychological problems, increasing functional dependence, weakness, and significant family support needs can also be characteristics of the period after diagnosis [1]. Chronic non-cancer diseases are prevalent and linked to a lower quality of life (QOL), a high burden of symptoms, impairment, and increased healthcare utilization. Palliative care aims to help patients and their caregivers make decisions, lessen pain, and enhance

quality of life [2].

Palliative care is an approach to improving the QOL of patients and families facing life-threatening illnesses by alleviating pain and providing physical, psychosocial and spiritual support from the time of initial diagnosis to the end of the patient's life [3]. The family helps the patient with daily activities, accompanying the patient to medical appointments and ordinary life tasks. They are responsible for acquiring health-related information and communicating it to other family members. These are instrumental tasks, and the family needs to support the patient emotionally [4].

Palliative, non-cancer care is someone who is diagnosed with Heart Failure (HF), Chronic Obstructive Pulmonary Disease (COPD), kidney failure, dementia, cirrhosis, or stroke [2]. Some other diseases included are cardiovascular disease with a prevalence of 38.5%, cancer 34%, chronic respiratory disease 10.3%, Human Immunodeficiency Virus (HIV) /Acquired Immunodeficiency Syndrome (AIDS) 5.7% and diabetes 4.6% [5]. The average age range that requires palliative care is the elderly age group, namely 60 years and over 60%, while adults aged 15-59 reach 25% and those aged 0-14 years are 6% [6].

“Meaning of life” is a person's ability to understand their life circumstances, recognition of motivation, life goals, and a sense that life is worthwhile [7]. The meaning of life is essential for someone to understand the nature and purpose of a person's life in the world [8]. Several researchers have presented results on patients with palliative illnesses in finding life's meaning. The meaning of life is crucial to achieving the personal well-being of people with palliative illnesses. It is also a critical factor for ensuring mental health and quality of life, which is a protective buffer for patients, relieving depression, reducing despair, and avoiding accelerating death [9]. Purposefulness in life and social support are associated with a significant reduction in the level of disease symptoms. Psychological support can also significantly improve distress caused by disease [10].

The results of research on the meaning of life in cancer patients carried out at the Wangaya Denpasar Hospital, Indonesia conclude that the majority are in the high category, as many as 14 respondents (60.9%). High meaning of life is found mostly in female respondents, as many as ten (43.4%). High meaning of life dominates the respondents in the adult stage as many as ten respondents (43.4%). High meaning of life is also found in respondents with secondary education, as many as eight respondents (34.7) and in cancer patients based on as many as 15 (65.2%); the results of this study are in accordance with Santrock's theory (2008) that, because education increases knowledge, one can better develop constructive coping in dealing with stressors. High meaning of life dominates the respondents who work, as many as 11 (47.8%) [11].

The results of previous studies indicate that social support provided by close relatives has a more significant and more profound influence on the meaning of life of cancer patients. However, research related to social support and the meaning of life of palliative patients associated with kinship types is still needed, especially for communities with socio-cultures that have a parental kinship system. Therefore, the researchers studied social support with the meaning of life of palliative patients to see the kinship relationship between patients and caregivers.

2. Method

The method used in this study is quantitative-correlational with purposive sampling, and the number of respondents is 107 from Bandung, West Java. Age, gender, and diagnoses were among the demographic information gathered. The Meaning of Life questionnaire and the Family Support scale are the surveys utilized. The family support tool has 29 items, with options 1 = never, 2 = sometimes, 3 = often, and 4 = always. The results of the questionnaire validity test are > 0.374, and the Cronbach alpha value reliability test results are 0.909. The meaningfulness of life instrument consists of 30 items with options 0 = never, 1 = rarely, 2 = sometimes, and 3 = often. The validity test is > 0.374, and the Cronbach alpha value reliability test is 0.956.

The surveys were distributed directly using an e-form filled out by respondents who had signed the research consent form without coercion. Data analysis: the descriptive data displayed were frequency, percentage, mean, and standard deviation (SD). Since the data was abnormal, correlation analysis utilizing Kendall's Tau and Kruskal Wallis tests was employed to compare social support levels between two or more groups (caregivers, for example). The threshold for statistical significance was $p<0.05$.

3. Results

The age of most respondents is 60 years old and older, as many as 31 respondents, with a percentage of 28.7%; 67% of respondents are male. The highest reported level of education is a bachelor's degree, as many as 43%. The highest reported disease is diabetes mellitus, as many as 21.5%. The highest reported caregiver is one’s child (39.3%). Family support was obtained on average 100.63, considering a standard deviation value of 14.15. The minimum value was 63, and the maximum value was 118. Meaningfulness of life was obtained on average at 76.96 with a standard deviation value of 14.54. The minimum value was 29, and the maximum value was 90 (Table 1).

A p-value of 0.012 and a coefficient correlation (r) value of 0.173 indicate a relationship between family support and the meaning of life in palliative patients (Table 2).

The degree of family support varied significantly

depending on the type of caregiver. The participants with the highest mean family support scores were spouses. According to post-hoc tests (Table 3), the mean family support scores of the husband (p=.000) were higher than those of the wife (p=.052), parent (p=1.000), grandchild (p=1.000), child (p=.000), and sibling (p=.666).

Table 1. Demographic data

Characteristic	n	%	mean	SD	min-max	SE
Age (year)						
20-29	2	2.0				
30-39	22	20.6				
40-49	25	23.4				
50-59	27	25.0				
>60	31	29.0				
Gender						
Man	61	57				
Women	46	43				
Education Level						
Elementary School	6	5.6				
Junior High School	5	4.7				
Senior High School	20	18.6				
Diploma	16	15.0				
Undergraduate	46	43.0				
Post-graduate	14	13.1				
Diagnosa						
Diabetes mellitus	23	21.5				
Cardiovascular disease	20	18.7				
Stroke	21	19.6				
Mammae cancer	22	20.6				
HIV	21	19.6				
Caregiver						
Child	42	39.3				
Husband	16	15				
Wife	19	17.8				
Parent	7	6.5				
Sibling	19	17.8				
Grandchild	4	3.7				
Family Support			100.63	14.15	63 - 118	1.40
Meaning of Life			76.96	14.54	29-90	1.41

n: frequency; SD: standard deviation; SE: standard error

Table 2. Correlation family support with meaning of life

Kendall's Tau Correlation			
		Family Support	Meaning of Life
Family Support	Correlation Coefficient	1.000	.173*
	Sig. (2-tailed)	.	.012
	n	107	107
Meaning of Life	Correlation Coefficient	.173*	1.000
	Sig. (2-tailed)	.012	.
	n	107	107

Table 3. Mean average family support based on caregiver

Variable	Mean	SD	95% CI	P-value
Caregiver				
Child	97.14	12.99	93.09-101.19	
Husband	113.56	6.00	110-116.76	0.0005*
Wife	107.58	10.66	102.44-112.72	
Parent	98.71	18.49	81.61-115.82	
Sibling	90.05	14.72	82.96-97.15	
Grandchild	98.50	13.72	97.57-103.13	

SD: Standard deviation, CI: confidence Interval

* Kruskal Wallis tests

4. Discussion

Family support ranges from a minimum of 63 to a maximum of 118, with an average of 100.63 and a standard deviation of 14.150. Family support for palliative patients is high. This result is similar to the study about family support for type-2 diabetes mellitus patients [12], which found that family support for diabetes mellitus patients is high and good. In another study on patients with heart disease (CHF), they also received good family support [13]. Family health correlates favorably with the number of close friends and family members and perceived social support [14]. We see that family support for sick family members is exemplary. Family support in society is separable from the kinship system as one of the essential aspects of culture. One of the kinship systems widely found in Indonesia, especially in Javanese society, is the parental kinship system. This kinship system includes joint rules that apply to families and relatives. Families who are members of relatives will have a feeling of closeness and responsibility.

With an average meaningfulness of life score of 76.96, a standard deviation of 14.54, a minimum score of 29, and a maximum score of 90, palliative patients have incredibly high meaningfulness of life. The meaning of life is something that individuals must find—patients who experience pain due to terminal illness that cannot be treated can reduce their pain if they have a positive psychology and meaning in life. While long-term illness is a negative life condition, one example of meaning is religion and belief in God such that patients find spiritual values that ultimately provide meaning to life for themselves in connection with their illness. The meaning of life can prevent despair, playing an essential role in allowing patients to prepare themselves for death and welcome it with dignity. Due to its massive role in the death process, the meaning of life must be considered in palliative care [15]. The results of the current study indicate that patients have had a high meaning in life. It implies that they have a good spirituality.

The correlation between family support and meaningfulness of life is strong, with a p-value of 0.012 and a coefficient correlation (r) of 0.173. Family support contributes to the meaning of life [16]. The meaning of life with the health conditions of each individual can depend on the individual's condition, which is influenced by past and present life experiences. The health situation of patients can be synthesised by new individual values, lifestyles and the environment related to health. Family support makes individuals feel loved, appreciated and helped. This helps individuals gain the strength to accept their illness. Individuals who can tolerate their illness will still feel psychologically comfortable even though the disease cannot be cured.

However, there were notable variations in the degree of family support among the various caregiver categories. Participants who were husbands had the highest mean family support scores. Partner support can play a key role in adjusting to serious stressors such as illness and has the potential to protect against the effects of stress [17]. Family members other than spouses may have their own lives and responsibilities to take care of. For example, palliative patients' children, grandchildren, and siblings, although they provide family support, will not be as much as the family support provided by the spouse in all aspects. Family support consists of four factors: emotional support, appreciation, instrumental support, and information support [18]. Partner support could be informational, tangible, and emotional [19]. Support from a partner is a form of loyalty from the love that a partner has. The feeling of love for a partner will make the partner try to provide support in all factors.

5. Conclusions and Recommendation

There is a correlation between family support and the meaning of life in palliative patients. This shows that family involvement is needed in every palliative care effort so that palliative patients can better find meaning in life and that, even in their condition, they still have psychological well-being. In addition to family support, the spiritual values of palliative patients are essential for making life meaningful, and they can be the variable of future research.

There is a difference in the average amount of family support based on familial relationships. This study shows

that palliative patients very much need the involvement of partners such that the handling of palliative conditions is centred on the patient and the family, especially the partner. Partners or families of palliative patients should receive psycho-education and psychological management for themselves because partners of palliative patients are also susceptible to psychological problems, burnout or compassion fatigue that can affect the quality of family support provided.

The study's limitation is that generalizations cannot be made because it used a small sample and a cross-sectional design. Further research is needed with a larger sample size.

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