Characteristics of Palliative Patients, Insights of Patients and Families, and the Impact of Estimated Survival Time on Therapy Decisions

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ABSTRAK

Latar belakang: *penyakit kronis dan terminal membutuhkan terapi holistik yang mencakup aspek biopsikososial, dan dapat ditemukan dalam terapi paliatif. Pasien yang menerima terapi paliatif menunjukkan profil yang sangat beragam. Oleh karena itu, peneliti ingin melihat karakteristik umum pasien paliatif. Selain itu, peneliti juga akan menilai tilikan pasien dan keluarga yang mempengaruhi keberhasilan terapi dan pengaruh perkiraan waktu bertahan hidup dalam membuat keputusan pengobatan.* ***Metode:*** *penelitian ini menggunakan studi analitik deskriptif potong lintang dan data sekunder dari 300 pasien paliatif yang berkonsultasi dengan Tim Paliatif Psikosomatik di Rumah Sakit Dr. Cipto Mangunkusumo. Data diproses menggunakan SPSS versi 25. Data yang diproses termasuk karakteristik sosiodemografi, lama tinggal, kejadian kematian di rumah sakit, kasus DNR, tilikan pasien dan keluarga, dan pengaruh perkiraan waktu bertahan hidup terhadap jenis pengobatan yang dipilih.* ***Hasil:*** *sebagian besar pasien paliatif adalah wanita (52,0%) berusia 51 - 60 tahun (27,0%), tidak bekerja (29,0%), dan menderita kanker (55,3%). Selain itu, pasien umumnya dirawat kurang dari 1 bulan (83,6%), meninggal di rumah sakit (37,3%), dan menyetujui DNR (36,7%). Kasus-kasus DNR ini sangat berkorelasi dengan pemahaman keluarga mengenai prognosis kondisi pasien (p = 0,022). Pemahaman keluarga tentang diagnosis, prognosis, dan tujuan pengobatan (92,3%, 81,3%, dan 87,7%) lebih baik daripada pasien (79,0%, 64,0%, dan 69,7%). Lebih lanjut, tidak ada hubungan yang ditemukan antara pilihan terapi (optimal, pembatasan, dan pengurangan terapi) dengan perkiraan waktu kelangsungan hidup pasien (p=0,174).* ***Kesimpulan:*** *pasien wanita, lansia, dan kanker paling sering mendapatkan terapi paliatif. Persetujuan untuk DNR pada pasien paliatif sangat sering. Saat ini, tilikan keluarga jauh lebih baik daripada pasien, yang berarti bahwa penyedia layanan kesehatan perlu meningkatkan pendidikan dan informasi ke pasien. Selain itu, pasien dan keluarga umumnya masih memilih terapi yang optimal meskipun waktu perkiraan bertahan hidup yang rendah.*

Kata kunci: *karakteristik, do not resuscitate (DNR), tilikan, paliatif, pilihan terapi.*

ABSTRACT

Background: *chronic and terminal diseases require holistic therapy that covers the biopsychosocial aspect, and it can be found in palliative therapy. Patients who receive palliative therapy exhibit very diverse profiles. As such, researchers are keen to study the general characteristics of palliative patients. In addition, researchers will also assess the patient's and their family's insight that influences the success of the therapy and the impact of estimated survival time in making treatment decisions.* ***Methods:*** *this research used cross-sectional descriptive analytic study and secondary data of 300 palliative patients who consult to Psychosomatic Palliative Team at Dr.*

Cipto Mangunkusumo Hospital. The data were processed using SPSS version 25. The data processed included: sociodemographic characteristics, length of stay, incidence of death in hospital, DNR cases, the patient's and their family's insight, and the impact of estimated survival time on treatment decisions. ***Results:*** *most palliative patients were women (52.0%) aged 51 - 60 years (27.0%), unemployed (29.0%), and suffered from cancer (55.3%). In addition, the patients were generally treated for less than 1 month (83.6%), died in the hospital (37.3%), and consented to DNR orders (36.7%). These DNR cases are highly correlated to the family's understanding regarding the prognosis of the patient's condition (p = 0.022). The family's understanding of the diagnosis, prognosis, and treatment goals (92.3%, 81.3%, and 87.7%) was better than the patient's (79.0%, 64.0%, and 69.7%). Furthermore, no link was found between the therapy choice (optimal, withholding, and withdrawing therapies) with the patient's estimated survival time (p = 0.174).* ***Conclusion:*** *female, elderly, and cancer patients most often get palliative therapy. The consent for DNR orders to palliative patient is notably frequent. Currently, the family's insight is much better than the patient's, which means that health care providers need to improve patient education and information. In addition, patients and families generally still opt for optimal therapy despite low estimated survival time.*

Keywords: *characteristics,* do not resuscitate (*DNR), insight, palliative, therapy decisions.*

INTRODUCTION

The incidence of chronic progressive diseases including cancer is increasing in various developing countries, from 18.7% in 1990 to 25% in 2000, and is even expected to increase to 36.6% by 2020.[1] Chronic diseases could deteriorate into terminal diseases that often decrease the patients' quality of life, causing not only somatic but also psychosocial disorders,[2] and country's economic burden.[3] This can be caused by the various unpleasant symptoms experienced[4] or can be due to the feelings of despair and uselessness.[5,6] As a result, palliative therapy is now being implemented and is considered a useful and holistic solution for the patients as stated by World Health Organization (WHO) and the Worldwide Palliative Care Alliance.[7]

According to the WHO[8], palliative therapy is an approach that improves the quality of life of patients and families facing the challenges associated with life-threatening illnesses, through the prevention and relief of sufferings by means of early identification and careful assessment and treatment of pain and other problems, either physical, psychosocial, or spiritual. In palliative therapy, in addition to handling symptoms, good communication regarding the diagnosis and prognosis of the disease to the patients and their families is also needed.[9]

Consequently, researchers would like to assess whether health care providers have been providing comprehensive information to the patients and their family, so they will have a good insight. Researchers will also assess the impact of estimated survival time in making treatment decisions. However, researchers will first observe the characteristics of palliative patients in general.

METHODS

This research used a cross-sectional descriptive analytic study design and was carried out based on the medical records data of palliative patients at Cipto Mangunkusumo Hospital, which is a national tertiary referral hospital. The data were taken from 300 patients who consulted to Psychosomatic Palliative Team during 2016 to 2018, using all sample recorded. The data were then processed using SPSS version 25.

Based on these data, the characteristics of palliative patients could be observed in general, based on sociodemographic characteristics. Subsequently, the patient's understanding of the illness would be observed. In addition, the family's insight would also be assessed. This would be a reference to determine whether the communication from the medical teams to the patients and their families was good enough or needed to be improved. The family's understanding on the patient's prognosis would then be assessed in terms of its relationship to the occurrence of Do Not Resuscitate (DNR) cases.

The estimated survival time of palliative care patients was assessed using the Palliative

Prognostic Index (PPI), where a score of $\leq$ 4 means an estimated survival time of > 6 weeks; a score of > 4 means an estimated survival time of 3-6 weeks; and a score > 6 means an estimated survival time of < 3 weeks. Based on the estimated survival time data, it would be apparent how they affect the therapy choice made by the patients or their families. The relationship will be analyzed using chi-square test. The p value less than 0.05 will be meaningful significantly.

Table 1. Basic characteristics of palliative patients study in tertiary hospital

Variables	Frequency (n=300)	Percentage (%)
Gender		
- Male	144	48.0
- Female	156	52.0
Age, y.o		
- 11-20	3	1.0
- 21-30	19	6.3
- 31-40	44	14.7
- 41-50	60	20.0
- 51-60	81	27.0
- 61-70	50	16.7
- 71-80	37	12.3
- 81-90	5	1.7
- 91-100	1	0.3
Occupation		
- Unemployed	87	29.0
- Government Employee	15	5.0
- Private Employee	32	10.7
- Retired	19	6.3
- Housewife	25	8.3
- Student	6	2.0
- Entrepreneur/ Businessman/Laborer/ Fishermen	43	14.3
- Others	73	24.3
Disease		
- Cancer	166	55.3
- Non-cancer	134	44.7
Length of Stay (Days)		
- 0 – 30	239	83.6
- 31 – 60	39	13.6
- 61 – 90	6	2.1
- 91 – 120	1	0.3
- 121 – 150	0	0.0
- 151 – 180	0	0.0
- 181 – 210	0	0.0
- 211 – 240	0	0.0
- 241 – 270	0	0.0
- 271 – 300	1	0.3
Died in Hospital		
- Yes	112	37.3
- No	188	62.7
DNR Cases		
- Yes	110	36.7
- No	190	63.3

RESULTS

Palliative patients at Dr. Cipto Mangunkusumo Hospital were very diverse. Various sociodemographic characteristics such as gender, age, occupation, and the type of diseases experienced by palliative patients are presented in **Table 1**. In **Table 1**, we will also observe the length of stay, incidence of death in hospital, and DNR cases among palliative patients. In addition, the symptoms exhibited also varied greatly, from gastrointestinal, neurological to psychological symptoms. Graph 1 presents the most common symptoms experienced by palliative patients, which are loss of appetite, weight loss, pain, dyspnea, loss of consciousness, nausea, and coughing. These characteristics were analyzed from 300 palliative patients.

Based on the general characteristics of palliative patients, the patient's and family's insight of the disease will be assessed. There are three points that will be assessed, which are the patient's and family's understanding of the diagnosis, prognosis, and treatment goals. **Table 1** presented the occurrence of DNR cases among palliative care patients. The DNR cases are quite high, at 36.7% (about one third of palliative care patients). For this reason, it will be assessed whether the frequency of DNR cases relates to the family's understanding of the prognosis of the patient's disease. The relationship will be analyzed using a 2x2 table with bivariate chi-square method.

In addition to DNR orders, patients and their families were given the opportunity to decide on which therapy to be received, namely optimal therapy (increase therapy if needed), withholding therapy (therapy was maintained as given at the time), and withdrawing therapy (therapy was reduced from current therapy). The researcher wanted to see whether therapy choice

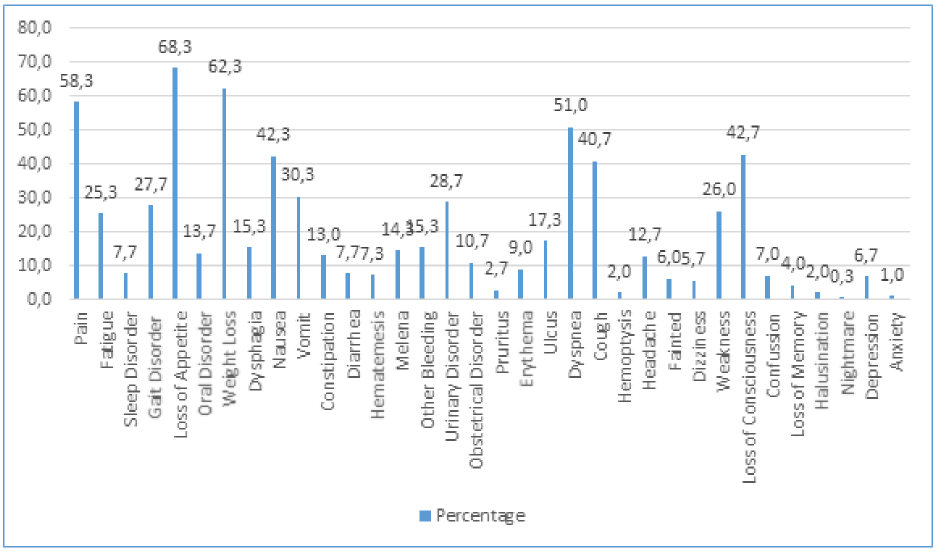

Figure 1. Symptoms experienced by patients in the hospital.

Table 2. Patient's and family's insight of the disease suffered

Variables	Frequency (n=300)	Percentage (%)
Patient's Knowledge		
- Understanding of the diagnosis	237	79.0
- Understanding of the prognosis	192	64.0
- Understanding of the treatment goal	209	69.7
Family's Knowledge		
- Understanding of the diagnosis	277	92.3
- Understanding of the prognosis	244	81.3
- Understanding of the treatment goal	263	87.7

Table 3. Relationship between family's insight and occurrence of DNR cases

	No. of DNR Cases		P value*
	Yes	No	
Families' Understanding of the Prognosis			
- Yes	82	162	0.022
- No	28	28	

* Chi-square test

was influenced by the survival time based on PPI as seen in **Table 4**. However, because there were 44.4% of respondents with the expected count of fewer than 5, patients receiving withholding and withdrawing therapies were combined under non-optimal therapy, and analyzed with bivariate chi-square method (**Table 5**).

Table 4. Percentage of therapy choices based on estimated survival time

Survival time (weeks)	Therapy Choices		
	Optimal n (%)	Withholding n (%)	Withdrawing n (%)
- <3 weeks	45 (76.3)	12 (20.3)	2 (3.4)
- 3-6 weeks	18 (94.7)	1 (5.3)	0 (0.0)
- >6 weeks	36 (75.0)	12 (25.0)	0 (0.0)

Table 5. Relationship between estimated survival time and therapy choices based on PPI

Estimated survival time (weeks)	Therapy		P value*
	Optimal (%)	Non-Optimal (%)	
- <3 weeks	45 (76.3)	14 (23.7)	0.174
- 3-6 weeks	18 (94.7)	1 (5.3)	
- >6 weeks	36 (75.0)	12 (25.0)	

*chi-square test

DISCUSSION

Based on sociodemographic characteristics, palliative care patients were more frequently women (52.0%), aged 51 - 60 years (27.0%), unemployed (29.0%), and suffering from cancer (55.3%). In this study, it was observed that the number of female and male patients suffering from chronic or terminal illnesses did not differ significantly, only 4%. This is as mentioned by Goodwin K,[10] where 38% of women suffered from chronic diseases and only 30% of men did. However, the difference was insignificant, only 8%. Women are established to be more susceptible to chronic diseases with more women than men experiencing endocrine, nutritional, and metabolic related diseases, which is one of the etiologies of chronic diseases.[11,12]

In terms of age, palliative care patients are generally elderly patients because the older they are, the more susceptible they become to the diseases.[4] The results obtained were identical to the research results of John P., et al.[13], which found that patients aged 51 - 60 years most often suffer from diseases needing palliative therapy. Furthermore, several studies also found that palliative therapy was most often given to cancer patients, as found by the study by Stiel S., et al.[14] and Bannon M., et al.[15]

A number of palliative patients have stopped working due to functional limitations caused by the disease, which caused the patients to lose their productivity.[5] This not only disrupts the psychological condition of the patient but also poses an additional burden to the family.[5,16]

Palliative care patients are commonly associated with long-term hospital care. It was observed that 16.4% of the patients were treated for more than 30 days, although there were more patients who were treated for less than 1 month (83.6%). The data from the National Hospital Morbidity Database (NHMD) in Australia showed that the average length of stay for palliative care patients is approximately 10.6 days, which is four times the average length of stay for all patients, which is only 2.8 days.[17] This is due to the severity of the illness. Moreover, palliative care patients are commonly cancer patients with immunodeficiency, which renders them susceptible to infection thus requiring longer treatment time.[18]

In addition to prolonged care, palliative care patients displayed a high mortality rate as they are patients with terminal illness.[19] Based on the available data, it is known that about one-third of patients died during treatment and about one third of these have signed DNR orders. DNR order is considered in palliative care patients because cardiac pulmonary resuscitation (CPR) actually only has a success rate of less than 1 percent and causes unpeaceful death. However, DNR orders uphold the principles of autonomy, so it must be in accordance with the desires of the patients and families. Therefore, DNR approval must be recorded and signed on an informed consent document.[20]

Palliative care patients often suffer from symptoms that interfere with and decrease their quality of life. The most common symptoms experienced by palliative care patients are loss of appetite, weight loss, pain, dyspnea, loss of consciousness, nausea, and coughing. Although rare, psychological symptoms such as depression and anxiety may also be experienced by the patients. However, several studies have found that psychological disorders such as depression and anxiety are quite often experienced by palliative care patients.[21,22] As such, management of palliative care patients is limited to controlling not only their somatic but also their psychological symptoms.

In palliative therapy, it is necessary to have good cooperation among the health care providers, patients, and families in order to promote good quality of life for the patients and their families.[23] For this reason, the patients and families need to fully understand the illnesses: the diagnosis, prognosis, and the goals of the treatment9. With a good understanding, the goals of palliative therapy can be achieved. Based on the findings, it turns out that the families have better knowledge on the illnesses than the patients, as demonstrated by a higher percentage.

A high incidence of DNR case was discussed previously and is considered as one of the ways for palliative care patients to feel calm near the end of their lives. A number of factors influence DNR decision, as this is not an easy decision. Long-term care in the intensive care unit is a common reason for the family to approve DNR for the patients.[24] However, it is also necessary to look at the link between the family's understanding of the patient's prognosis on DNR decision.[25] Generally, palliative care patients are terminal disease patients with poor prognosis, so the families often prefer DNR option. In assessing the relationship between the family's understanding of the prognosis of the patients' diseases and DNR cases, the results were statistically significant ($p=0.022$). However, it also shows that families who understand the prognosis of the disease are more likely to reject DNR for the patients. Based on the available data, DNR approval is observably the highest in patients with loss of consciousness (58.6%), whereas for patients who are still conscious, the family usually choose to do CPR.

DNR does not mean that the treatment provided is not optimal. The patients are still provided with the appropriate therapies. However, this will refer back to the principle of autonomy, where patients and families were explained about the therapy to be given. Subsequently, the patients and their families have the right to determine which type of therapy they want. For palliative care patients, there are three types of treatments, namely optimal and non-optimal therapies (withholding and withdrawing therapies). The determination of which therapy itself was not influenced by the survival time. The patients and their families still tend to choose optimal therapy.[20,26]

CONCLUSION

Female, elderly, and cancer patients most often get palliative therapy. Furthermore, palliative care patients generally experience limited functionality, which prevents a lot of patients from working.

Palliative patients are generally treated for less than 30 days but some need more than one month, and the consent to DNR is quite frequent. DNR decisions are influenced by the family's understanding of the patient's prognosis. For patients who are still conscious, the family prefer to continue with CPR.

Currently, the families have much better understanding than the patients on their diseases, which calls for health care providers to improve on educating and informing the patients. Patients and families generally still choose optimal therapy despite low estimated survival time.

Further research about factors affecting patients' insight and decision of therapy are needed, to improve palliative care program in hospital.

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