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The importance of providing palliative care for patients with severe COVID-19 in Indonesia

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Abstract

Patients with Coronavirus Disease 2019 (COVID-19), particularly those with a severe condition, might not survive. Pandemic situation challenges the healthcare providers in addressing palliative care to the patients. This paper aimed to describe the importance of providing palliative care for patients with severe COVID-19 in Indonesia. We used a case scenario to illustrate the common condition experienced by a patient with severe COVID-19. Healthcare providers in Indonesia could address palliative care for patients with COVID-19 by focusing on controlling the symptoms, avoiding futile intervention, and connecting the patients and their families. Nurses need to consider the patients' needs for family supports, even though not in physical or psychosocial support, and help the patients who need end-of-life care to be dying with dignity. Communication technology must be utilized optimally by healthcare providers to realize the communication among the patients, families, and health workers.

Keywords

COVID-19; palliative care; end-of-life care; terminal care; patient-centered care; nursing; Indonesia

The world has been suffering due to the COVID-19 pandemic. This causes stress and anxiety amongst people around the world and seriously contributes to the instability of social and economic conditions (Bong et al., 2020). Therefore, health service organizations have to prioritize efforts to reduce the risk of diseases, complications, and suffering (Ting et al., 2020). Furthermore, patients with severe COVID-19 may experience distressing symptoms, and these can escalate rapidly, including breathlessness and agitation, in which they will feel they have life-threatening risks and are in uncertain situations. Accordingly, healthcare providers should address the best approach for the palliation of these symptoms (Ting et al., 2020).

In Indonesia, as in other countries, during the COVID-19 pandemic (<http://covid19.go.id>), family members are not allowed to assist the patients at their bedside in order to prevent the spread of the virus (NHS Education for

Scotland, 2020). This isolation gives a heavy burden for the family since, in Indonesia, they are used to assisting during most hospitalizations for even 24 hours a day and seven days a week (Effendy et al., 2015). Many patients and families suffer from numerous miserable conditions in this current situation, both physically and emotionally. In this context, the role of the healthcare providers to give adequate and qualified service needs to be doubled compared to the normal condition (without the pandemic). Healthcare providers can (and should) assist the patients to not feel lonely or isolated during their severe illness because it can lead to death (Ting et al., 2020).

Palliative Care and Its Roles in COVID-19 Pandemic in Indonesia

Palliative care as a basic need of patients with serious illness has been underused in caring for those with severe COVID-19. Palliative care involves therapy and caring and

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support for people with certain diseases that limit their lives, families, and social network. This is also categorized as supportive care. With its bio-psycho-socio-spiritual approaches, palliative care focuses on improving the patients' life quality with serious suffering related to their health and families (World Health Organization, 2020). This includes controlling the symptoms, therapeutic communication and empathetic attitude, psychosocial support, loss, grief, and end-of-life care (Hui et al., 2013).

One of the significant factors in giving palliative care is the involvement of the family caregivers as a support system. Taking care of sick family members as a family duty is one of the cultures in Indonesia (Effendy et al., 2015; Kristanti et al., 2017; Kristanti et al., 2021). that is highly respected by Indonesian society at any ethnic level. However, the present condition challenges the patients, families, and health care professionals. Ideally, palliative care is conducted by using the patient-centered care approach (Lavoie et al., 2013), and families are the crucial parts that always collaborate with the medical team who takes care of the patients. For the health workers, particularly nurses, providing palliative care for these patients is challenging due to several reasons (Giorgi et al., 2020). In Indonesia, the absence of the family members' attendance during the hospitalization or patient's isolation could be the main challenge in caring for the patient.

In this pandemic condition, nurses and healthcare providers must be creative and innovative in realizing the expected nursing objectives, which is, in this case, palliative care. In addition, the other challenges such as workload, society stigma, limited facilities, and uncertain patients' conditions as well as human resources must be handled well to help the patients to get qualified service and to uphold the patients' quality of life according to their conditions or so that the patients can pass away with dignity (Giorgi et al., 2020).

In this situation, it can be understood that the families get panic and worry if one of the family members tests positive for COVID-19 because it is impossible for the families to assist the patients anymore (Prime et al., 2020). In Indonesia, families are actively involved in taking care of the patients and have great roles in decision making related to the patients both about medication/therapy and other decisions related to the patients' treatment. In Indonesia, autonomy in decision-making is generally not in individuals but families (Effendy et al., 2015).

Health care systems and their workers can suffer more when the number of COVID-19 patients is constantly increasing (Margaretha et al., 2020). Several hospitals even experience a lack of healthcare providers (Bong et al., 2020). On any occasion, the health care providers, especially the nurses, should maintain effective communication with the patients' families. Communication between the patients' families and the healthcare providers will facilitate peace for the families and the patients (Ting et al., 2020). There are several aspects that nurses and other healthcare providers can provide for the patients and families during separation due to the COVID-19 protocol

(Feder et al., 2020). For example, an illustration of a case, as follows:

A Case Scenario

Mr. SN (52 years old) is an employee being hospitalized due to COVID-19. On day 6, he is still conscious, with complaints of suffocation, cough, and fever. The laboratory results are getting worse. The medical team predicts that Mr. SN might not be able to survive. All members of the medical team feel concerned with his condition. They try hard to give the best treatment for Mr. SN by not letting him feel pain and suffocated by giving him painkillers and applying respiratory aids. On the 11th day of the treatment, Mr. SN can no longer communicate, and his condition is getting worse. All medical workers are busy and focused on the physical condition of the patients. The problems that might arise in that case are as follows:

- 1. Physical problems: pain, suffocation, self-care problems, daily activities problems.*
- 2. Psychological problems: afraid and anxious due to the progress of the illness, depression, and loneliness.*
- 3. Social problems: feeling lonely, lack of communication, lack of knowledge, and far away from family.*
- 4. Spiritual problems: afraid of death, feeling that the disease is a punishment from God.*
- 5. Lack of information about the disease and its progress.*

In Mr. SN's situation, healthcare providers are able to provide palliative care to the patient. It means that medical team members take care of the patients regarding their physical condition and psychological, social, and spiritual problems. Of course, the medical team should consider the best solutions to realize palliative care for the patients.

Recommendation of Palliative Care in Caring for Patients with Severe COVID-19

Basically, the main goal of palliative care is to facilitate patients to handle the problems such as physical, psychological, social, and spiritual problems that eventually will help the patients feel comfortable and improve their well-being (The Lancet, 2020). In the situation where the patients' conditions are getting worse, the implementation of palliative care is expected to help and assist the patients in going through their life journey reflection, and eventually, they can die with dignity (Hui et al., 2013).

Generally, the medical team will feel that they do not have the skills in palliative care. This can be understood since, based on the prior research, in most of the hospitals in Indonesia, the active healthcare providers have never joined palliative care training, and only less than 10% have joined palliative care training (Effendy et al., 2015). However, this does not matter since the healthcare providers have conducted the basics of palliative care without realizing it, as long as they have paid enough attention to the physical, psychological, social, and spiritual aspects and have avoided futile actions since those are in line with the basic palliative care (Quill & Abernethy, 2013). Or, when health care professionals realize that they need to apply palliative care, they then make extra effort to get more information on this topic to enhance their own knowledge and learn about new skills (Fadul et al., 2021).

In the situation when there are no palliative specialists, primary palliative care is the responsibility of every healthcare provider caring for a seriously ill patient (Quill & Abernethy, 2013), including patients with severe COVID-19 (Powell & Silveira, 2020).

Several approaches might be able to be performed under challenging situations for health care professionals with no palliative care training certifications:

1. Providing comfort for the patients (no pain, no suffocating, no other physical complaints). This can be done by administering pain killer medications, giving oxygenation according to the patients' needs (referring to the lab results and oxygen saturation), and providing respiratory aids (if needed) (Ballentine, 2020).
2. Maintaining good communication among the families, patients, and medical team (using phone calls or video calls, whispering to patients' ears, holding the mobile phone when families communicate with the health workers) (Goodman, 2020).
3. Avoiding futility intervention. For patients with worsening conditions, futile supporting examination intervention should be avoided. This is to prevent the patients from feeling more suffered for something that is less advantageous. For example, CT scan, repeated COVID-19 tests, and so on. Besides, this is also to reduce more expenses for patients not covered by health insurance (Feder et al., 2020).
4. Helping the patients to find self-peace by assisting the patients in praying or praying for patients or letting the patients listen to some prayers (for those who are unable to communicate anymore). It is essential to keep in mind that even though the patients are not conscious anymore, patients still can hear or feel what is done to and for them (Ferrell et al., 2020).
5. Giving a chance for the patients to be close to their favorite belongings, like family or friends' pictures or others. This can be done by cooperating with the patient's family. Besides giving positive effects for the patients, it will also make the families feel calm and close to the patients even though they are physically separated. This could help the patients feel as if they are not dying alone (Wakam et al., 2020).
6. Always giving information related to the patients' progress for the families (because palliative care is not only meant for improving patients' life quality but also families' life quality).
7. Communicating with the patients about what they want during hospitalization and their whole lives and wishes (Goodman, 2020). It is important to ask about the patients' wants (preference) while it is still possible to ask them (still conscious). This might be a huge burden for most health care providers because they already feel overloaded and overwhelmed with the duties and daily activities (Margaretha et al., 2020). However, suppose it is planned well, for example. In that case, nurses can use their time when helping the patients bathe or do other interventions while establishing a mutual relationship with the patients by giving them

more time (a couple of minutes to chat with the patients). Besides serving as essential data for the medical team for the consideration in decision making related to the therapy and patients' illness, this is also beneficial in handling psychology problems of the patients if the patients feel lonely and far from their families. It is essential to believe that this action is very meaningful for the patients. Nurses can be excellent listeners.

8. Making families the source of information that can be useful in helping the patients to get anything they want or to make patients' habits optimally so that the patients can be "themselves" (Bajwah et al., 2020).
9. Trying hard so that the patients will experience their last moment with dignity. Medical team members, especially nurses whose job is to assist the patients for 24 hours, can help them realize their dreams and convey the family's messages to their patients. For example, the patients mention their wish for their children if they have a chance, they will give something, or the patients wish to be buried in their hometown or near their parents' grave, and so on. Therefore, it is vital to communicate and listen to the patients while they are still able to say their wishes. If the patients are already in an unconscious condition, then realizing the patients' wishes based on what is stated by their families is a crucial task to do. Maybe, their families did not know that the patients have certain desires, so the medical team should remind their families to realize the patients' wishes so that they can die peacefully.
10. Health care professionals can also offer a more memorable touch for the family. For example, when possible, ask if the family would like to get the patient's video. This may become the family's last moment with their loved ones.

Discussion

Palliative care is a treatment with a patient-centered care approach (Lavoie et al., 2013). Patients have different problems and needs from each other. Therefore, they must be treated personally by focusing on the patients' conditions and needs by considering numerous aspects such as norms and culture, patients' wants, beliefs/religion, and support system involved in patient care.

Based on the concept of patient-centered care, the medical team must focus on the problems and the needs of the patients personally (Lavoie et al., 2013). For example, even though the patients are hospitalized due to the same disease, COVID-19, the patients have a different medical history, personal and cultural issues, and religions. Therefore, medical team members must treat the patients by focusing specifically on the patients' problems and needs.

In handling the worsening condition of COVID-19 patients, the medical team should refer to the general local, regional, or national guidelines. In Indonesia, healthcare providers address palliative care based on the Decree of

the Minister of Health No. 812/Menkes/SK/VII/2017 about Palliative Care Policy as the national regulation. In caring for patients with severe COVID-19 who need palliative care, healthcare providers should adapt to the pandemic situation within various existing constraints.

Generally, in Indonesia, patients do not have autonomy in decision-making since it is mainly done by their families (Effendy et al., 2015). Therefore, families have a role in decision-making for every decision related to therapy and the patients' illness (Effendy et al., 2015). This is such a challenge for the healthcare providers in this pandemic condition because this is when the families cannot physically support the patients. Therefore, communication must be maintained very well by utilizing technologies to support the communication between the healthcare providers and the families and between the patients and the families (Fadul et al., 2021; Wittenberg et al., 2021).

For those who have family members with concerning conditions of serious chronic diseases, the families must have high anxiety and fears and have many questions related to how to support the patients to get better condition, safe, and not be infected by COVID-19 during this pandemic (Bajwah et al., 2020). In this situation, families need accurate and complete information about patient management, available services, and what must be done if the loved ones get worse and in a life-and-death situation. Therefore, it is essential to educate the families through various social media and using the roles of the village officials, public figures, and religious figures. Furthermore, it is irrefutable that family support is a crucial factor in the treatment process for the patients (Radbruch et al., 2020).

Healthcare providers must make sure that the patients being hospitalized with severe COVID-19 receive palliative care (Ballentine, 2020) not only for physical needs such as suffocation, cough, fever, and delirium but also for psychosocial and spiritual needs, as well as for the communication to their families, even from a distance. The medical team must not do a futile intervention and conduct the treatment effectively since the progress of the disease is rapid with sometimes only provides a short time to survive (NHS Education for Scotland, 2020). In facing a more severe condition, the medical team must anticipate this inevitable outcome with life-long care until the end (Fadul et al., 2021).

Implication for Nursing Practice

Nurses always have direct and frequent contact with patients and their families. In this pandemic condition, nurses must be creative and innovative in realizing the expected nursing objectives, particularly caring for patients with COVID-19. Nurses have an essential role in addressing palliative care. The use of technology can be optimally used to connect the patients and their families. In order to provide good palliative care for patients with severe COVID-19 and to enhance the quality of life of the patients as well as help the patients dying with dignity, we

have recommended 10 points in practically apply palliative care for the COVID-19 patients, especially those who suffer from separation with their families during isolation.

Conclusion

In this pandemic situation, both health care providers and patients' families are challenged to provide palliative care. Health care providers must prepare themselves to manage their time effectively and efficiently in giving treatment for the patients. Palliative care must be applied for COVID-19 patients by considering the patients' needs for family supports, even though not in the form of physical support. Communication technology must be utilized optimally by healthcare providers to realize the communication among the patients, families, and health workers. This is particularly intended for the patients so that they will not feel lonely and may eventually die without their families to share in their last breath.

Declaration of Conflicting Interest

None declared.

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Authors' Contributions

CE was responsible for design the work, drafting the concept and writing the manuscript; MSK contributed to revising it critically for important intellectual content. Both authors have provided final approval of the version to be published and agreement to be accountable for all aspects on the work regarding to content.

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