Pastoral Care in End-of-Life: Can you be Healed when there is No Cure?

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Abstract: When death is coming for sure, the terminally ill patients will be in sorrow. For them who do not have hope of being medically cured, do having joy and feeling serene become a possibility? Can they be healed at some point? This research aims to describe the existential experiences of the terminally illness patients' family receiving a pastoral care. While the patients deteriorate because of illness, what type and kind of care they found most helpful? This research was a qualitative study with a phenomenology method. This paper is part of a bigger case study conducted in a Catholic hospital in Indonesia. The subjects for this research were the families of terminally ill patients. They were interviewed whether they have received pastoral care and the significance of it. The presence of pastoral care staffs and their visits were significant for the families and the patients. They feel strengthened in facing this difficult times. In particular, the spirit of the patients uplifted, they no longer feel angry with their condition and are in process of accepting the death coming their way. They found prayers as powerful resources. All the participants agreed that the pastoral care is important part for the patients' healing. Catholic hospitals in Indonesia should be aware to provide a holistic healing. Pastoral care is one of key factors to maintain the spirit of institutions. It is the way to humanize the patients and families in their end-of-life care.

Keywords: Spiritual accompaniment, pastoral care, end-of-life care, palliative, phenomenology.

BACKGROUND

At the end of life, the terminally ill patients experience fear, worries, and stress. They are afraid to face death. The terminal illness makes them be dying soon. The term 'terminal' comes from the Latin, 'terminus.' It means a boundary, a limit, or an end. The terminal illness puts the patients at the end of life. They will die in a short time. The patients will be dead soon because of their terminal illness. He does not have any long expectancy for life (Stevens, 2011; Bay, Beckman, Trippi, Gunderman, Terry 2008).

Because of the death, they will be separated from the loved ones, either their spouses, parents, children, relatives, and friends. They cannot do their activities regularly. Above all, their presence in the world will be perish and disappear. One of the fears that humans should face is to be death. To die means to separate from the loved ones. The terminal illness demolishes physically and also psychosocially (Addington-Hall, Clark, Corner 2001).

The fear, worries, and stress are also experienced by their family (Bay, Beckman, Trippi, Gunderman and Terry 2008). The family of the terminally ill patients will feel and experience the same. The family cannot have their members in life because of death. They cannot see each other again. Also, they cannot have any relationship anymore. Death makes them separated. Not only from the psychosocial side but also the family experiences the economic ones. They have expensed millions of rupiahs to cure the patients. They try to do their best to save the lives of patients (La Kahija 2017).

In the crisis facing by the terminally ill patients and their families, pastoral care in Catholic hospital can give its contributions, assistances, helps and supports. Pastoral care is an effort to help and support the fellowship who is in crisis because of the changing situation (Community Church Hongkong, 2016). In the hospital, pastoral care becomes an integral part of healthcare service in giving moral and spiritual assistance and support for the patients and families. World Health Organization (WHO) acknowledges that a spirituality-which is part of pastoral care- is an important aspect for the patient's quality of life. In facing death, a spiritual carer regards the patients as a human and care for them emotionally (Ando, Kawamura, Morita, Hirai, Miyashita, Okamoto and Shima 2010)

Relating to the crisis at the end of life, there is no preference or option to have euthanasia or assisted dying in Indonesia. They are counted as criminal actions. There are Indonesian laws rule about it. The

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laws-pasal 344 dan 345 Kitab Undang-Undang Hukum Pidana (KUHP)-says, "Anyone who takes the life of another person at the request of that person himself, whom he mentions clearly and sincerely, is sentenced to prison for up to 12 years; Anyone who deliberately encourages others to commit suicide, helps him in the act, or gives him the means to do so, is threatened with a maximum sentence of four years if that person commits suicide." The Indonesian doctor should not involve in euthanasia or assisted suicide. The regulation is in Kode Etik Kedokteran Indonesia Tahun 2012 pasal 11. It says, “Every doctor is obliged to always remember his obligation to protect human beings.”

OBJECTIVES AND METHODS

This research aims to describe the existential experiences of the terminal ill patients receiving care from the pastoral staff. The researchers think that those experiences are very advantageous and profitable to develop the healthcare service at the end of life situation. In the terminal ill condition, the cure is impossible but the care is still possible to be done. While the patients worsen because of illness, what kind of care they found benevolent? For them who do not have a hope of being medically cured, do having joy and feeling serene become a possibility? Can they be healed at some point in a way of pastoral care setting?

This paper is a component of a bigger case study organized in a Catholic hospital in Indonesia. The location is in one of a Catholic hospital in Yogyakarta Province, Indonesia. The research is still on-going. The interview has been conducted with 10 people. There will be more participants interviewed. The hospital has applied pastoral care in their healthcare service. The subjects for this research were the families of terminally ill patients. They were interviewed for the topics of pastoral care received and the impact of it. The interview is useful to explore the individual experience.

To find and interpret the existential experiences of the terminal ill patients, the researchers used phenomenology method to find the meaning and significance of the human experience. The researchers choose the family of the patients because of the vulnerabilities of the patients. They have a problem to communicate, talk, or respond during the interview because of the illness. The patients are vulnerable physically and mentally.

The researchers involved 10 participants in the research. In the phenomenological setting, the sample is purposive and needs a little number. The inclusion criteria are the family and the terminal ill patients (the participants) who have been in the hospital for more than 3 days; the participants who have been out of the hospital and left it less than six months; and the participants who are willing to join the research. The exclusion criteria are the participants who are difficult to communicate, either because of the sickness or the emotional impact of losing the loved ones.

The data were analyzed using thematic analysis. The themes are the pastoral care practices, the acceptance of death, the prayer and rites, and the significant pastoral care for the families.

RESULTS

The study participants comprised of 5 women and 5 men who are family members of 8 patients. The average age was 40, ranging from 37 to 64 years old. All patients could not talk and communicate anymore to the researchers because of the illness. Amid during in the acute situation, the family agreed to be interviewed. The interviews were held at the different rooms so that the patients would not feel disturbed.

The Hospital Setting

The hospital has 6 pastoral care staff. Five of them are laypeople and 1 of them is a religious sister. There are 2 staff who have worked for more than 10 years. Three of them are still below than 5 years. The pastoral care staff are under the nursing division. They have own office in one section of the hospital area. They work for 16 hours service, divided into 2 shifts, morning and afternoon.

The pastoral care service involves the religious leaders who have a connection to the hospital or a part of the state ministry of religious affairs. The non-Catholic patients and families have possibilities to accept the service from their religion, such as Islam, Christian, Hindu, Buddha, and Confucian. The pastoral care staff will be a facilitator to call the Catholic and non-Catholic religious leaders. The hospital offers the possibilities also to the faith groups or activists to give any spiritual or religious service to the patients and families. The service which is provided by the faith groups or activists (and not from the pastoral care staff) should have permission from the hospital management.

The Pastoral Care Practices

Six pastoral care staff do the pastoral care service every day in the hospital. They work as a team. A

coordinator becomes a leader for this team. He is responsible for the teamwork and directly under the supervision of the director of the nursing division. There is a daily meeting to make coordination between the pastoral care staff members.

In their service, pastoral care staffs do pray and visit for the patients and families in the patient's room; provide the sacramental service for Catholics such as: baptizing, First Friday Mass, giving the Holy Communion, anointing of the sick, and reconciliation; organize the religious songs and prayers from the central audio of hospital; become an intermediary to the religious leaders.

From the interviews, we found that pastoral care staff from the hospital regularly visited the patient for about 10-20 minutes. They chatted each other between pastoral care staff, patients, and families. Even though pastoral care staff does not know who the patients and families, they were willingly doing the service. One family member who is Moslem even touched by the visit.

The pastoral care staff visited a patient (Mrs. S), about once every 3 days. "[The pastoral care staff visited] at least, once every 3 days (Mrs. E, the daughter of the patient)." Each visit took 15-20 minutes. For Mrs. F, the pastoral care staff of the hospital regularly visited around 10 minutes. "Yes, it is around 10 minutes being there (Ms. D, the sister of the patient)."

The patients feel strengthened in facing difficult times. Mrs. S felt happy after the pastoral care staff visited her and she was grateful to the staff. During the visit for patients, pastoral care staff offered support by talking to Mrs. F and gave motivation for the patient to get stronger. She motivated the patient for not giving up in facing cancer. "She felt happy, grateful, and enthusiastic, there was attention, there were many good people around her, that is, she was not alone, so there were people who still cared, who wanted to encourage. (Ms. D, the sister of the patient)"

Pastoral care staff chatted about daily lives and exchanging stories, like old friends. "Yeah, chatting like friends, friends for a long time (Ms. D, the sister of the patient)." She (the pastoral care staff) talked about children or chit-chatting light topics to make the patient cheerful and happy.

Mr. H as the husband of the patient felt glad and think that he is being helped greatly by the pastoral care visits. He thinks even though they are not family members, relatives or friend but they care a lot, to visit and pray for his wife. "Happy, happy, happy, it turns out there are people who want to pray, who want to encourage, even though that means, from someone who has no relation to us, who can still encourage, hope to patients and families facing trials well (Mr. H)."

The Acceptance of Death

Most of the family members interviewed said that the spirit of the patients uplifted, they no longer feel angry with their condition after the patients did pray. They are in the process of accepting the death coming their way as the pastoral care staff visited them regularly. Family members said that the patient has been calmer and ready to embrace her death; while another patient has been surrendered herself to God. "…. after the prayer, my mom has been calmer and more or less ready to embrace her time [to death] (Mrs. E, the daughter of the patient)." "Mom has surrendered herself to God, like that, so maybe what, for the way, more is more, becomes better ... (Mrs. E, the daughter of the patient)." After the family was informed of Mrs. S condition that is worsening, they told themselves they have to be ready for anything, should she die anytime, even though they believe and hope for a miracle. Towards the end of her last days, her daughters felt Mrs. S perhaps has accepted her faith that she will die soon.

The pastoral care staff prepared the family for the death faced by the patient. The family was ready for death because of the presence and advice from the pastoral care staff. "I like it, here is a non-Muslim hospital, even though it is Catholic, but they also think, while the patient is not, not Catholic, you know… if the family is ready at the worst point, that's must, sincerely, whatever the conditions may be, the family must be ready… (Mrs. Su)."

We found that pastoral care staff prepared the patients and families for death. Pastoral care staff indicated death as an immediate fact to the patients and families. They do not hide the fact, but they help the patients and families to accept death either by advice or prayer.

The Prayer and Rites

From the data, pastoral care staff prayed for the patient at the request of the patient even though the patient was from a different faith. The different perspectives of faith did not make any barrier to the

patients and pastoral care staff. Mrs. F asked the pastoral care staff to pray for her. “Mrs. F is a Moslem. Yesterday, Mrs. M (the pastoral care staff) came. Then F asked, Ma’am, why don’t you pray for me? After that, she was prayed for (Mrs. D, the sister of the patient).” After prayer, she felt spiritually uplifted and not alone in facing this difficult time. Mrs. S received Holy Communion and the sacrament of anointing for the sick, with the help of pastoral care who called the priest. The service fulfilled the need of the patient. “Just asking for the anointing for the sick like that, which I did ask the hospital (Mrs. E, the daughter of the patient).”

The data showed that prayer and rites are part of pastoral care service. Prayer and rites were available for all people whatever the religion was. Pastoral care staff would provide the prayer service whenever the patients need.

The Significant Pastoral Care for Families

Most of the families felt satisfied with the pastoral care service. They were advised to keep healthy, felt supported, and had been helped. Even so, there was a fact that one family expressed her discontent. She felt the pastoral care service as a routine and needs to be enhanced. “Good too, because so that we are also the ones who maintain the health, keep the condition so that we don't feel it, we must be patient in facing and also supporting like that (Mr. H, the husband of the patient).” “Yes, he (pastoral care staff) is very familiar, he also greets us, as a family and always greets and pray for our families and those who are sick are also prayed for, who keep praying for us, we are very happy (Mrs. M, the sister in law of the patient).

One family expected the service from pastoral care staff. The pastoral care service should be improved for the families of patients. Mrs. E expected guidance and support from pastoral care staff during the critical time. “Like me who is experiencing, hm, I have to decide on something [on operation], I have to convince… (Mrs. E, the daughter of the patient).” The family had to decide on the operation of Mrs. S, however, she didn’t get any support or guidance from pastoral care. She felt pastoral care staff were not sensitive to what the families need because during their visit to the patients the time is too short in time. “Today there are so many patients, she (the pastoral care staff) visited this patient, this, this, that’s all, …I (the daughter) just feel, for example, she visited my mother's room, like that, it seems like that's all, routine there” (Mrs. E, the daughter of the patient). The routine became a problem. One family saw the pastoral care service as a routine from the staff. Because of the routine, the family did not feel taken care of. The family thought that the pastoral care staff did a “checklist.”

DISCUSSION

The finding of this research as well as in other parts of the world have discovered issues about the importance of religious care. The value is so high and crucial for the patients. Ando (2010) showed that the patients felt the inner peace when they were in religious care facing cancer illness. They were relieved (Ando, Kawamura, Morita, Hirai, Miyashita, Okamoto, Shima 2010; Stevens and Kenneth 2011). These findings are consistent with much of the international literature. Van Aalst (2013), researched the religious service in the hospital for the acute cancer illness. Eighty-five percent of the respondents agreed that spirituality and religiosity play a big and important role in their healing.

Our findings show that pastoral care service in one of the Catholic hospitals is not only about prayer and sacramental services, but also chatting and greetings during visits. These simple actions, such as chit-chatting make the patients happy and the short visits make them not feel alone. In his study, Aldridge (2005) found that spiritual services helped the patients to overcome their sufferings. The patients were aware that they were not alone, they were more hopeful, and where having friends beside them.

It was clear from our findings that pastoral care is significant for patients and families. Both of them need accompaniment, guidance, and service from pastoral care during hospitalization. Nevertheless, our study findings point more to the service for the families. The pastoral care staff still put more effort into the patients but not for the families. The pastoral care staff should be aware that the terminal illness impacts the families also. The families need to be accompanied, encouraged, and guided when they are beside the patients. All the burdens and problems must be seen in the context of patients’ condition. Rayburn (2008) wrote that the families of patients often have feelings of guilt, sadness, anger, and fear. The feelings arise because they will say goodbye to the loved ones.

CONCLUSION

Catholic hospitals in Indonesia should be aware to provide holistic healing. The results of this study

indicate that healing is not just mainly about physical but also embraces the whole aspect and human needs such as psychosocial and religious. It could be helpful to the patients and families that the hospital management put special attention to the pastoral care service. The pastoral care service is not a routine. The pastoral care is a must to maintain the characteristics of a catholic hospital.

Pastoral care is one of the key factors to maintain the spirit of institutions. It is the way to help and care the patients and families in their end-of-life care. Therefore, it is important that care is possible to be given to the terminal ill patients and families. The patients will not be possible to have a cure anymore but they will be taken care of as humans. Moreover, families should be taken care of. The families are part of a terminally ill patient who needs support. Pastoral care service needs to pay attention to the families of the patient. If they cannot handle the problems, pastoral care staff can be an intermediary to the other people, such as social worker.

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