Bangladesh Journal of Bioethics

Published by: Bangladesh Bioethics Society
https://bjbio.bioethics.org.bd/index.php/BJBio
ISSN: p2226-9231 e 2078-1458
BJBio 2021; 12 (2): 20-24
Submitted:15.11.2020
Accepted: 12.03.2021
Published: 01.07.2020

Original Article

The Shift of Dignity in Terminally Ill Patients

Imanuel Eko Anggun Sugiyono[1], Puri Swastika Gusti Krisna Dewi[2] and Retna Siwi Padmawati [3].

https://doi.org/10.62865/bjbio.v12i2.3

Abstract: Objectives: When the illness becomes acute, the patient will be burdened physically and psychosocially. Three factors could affect their dignity: illness-related dignity, dignity conserving repertoire, and social dignity inventory. This research aims to describe the dignity shifting experiences of the terminally-ill patients based on their families' opinions. If the health care workers aware and realize this shifting, it will help them to give care to the terminally ill patients. Methods: This research was a phenomenological study as a part of a bigger study carried out in a Catholic hospital in Indonesia. The subjects for this research were the families of terminally ill patients. They were interviewed to know what kind of shifting happened in their family members. Result: Being sick and hospitalized was a shift of dignity. According to the families interviewed, being patients in the hospital everybody that they knew was visiting and watching them laying on the bed. Patients expressed their feelings that they were "such a performer"; not strong enough and ready to welcome guests because of the condition, or they felt uncomfortable and always wanted to go home. Other patients felt that she was very dependent and not used to being served by nurses in a hospital. The patient was strong before, but during the illness, she became and was so weak. In another case, one patient somehow kept her dignity by telling her sister to continue running the business. Every day she told

1. Graduate School of Bioethics, Universitas Gadjah Mada, Indonesia & School of Philosophy Driyarkara, Indonesia Email: imanuel.anggun@mail.ugm.ac.id Orcid ID https://orchid.org/0000-0001-8133-5037
2. Graduate School of Bioethics, Universitas Gadjah Mada, Indonesia ; Nursing Academy Yatna Yuana Lebak, Indonesia & Center for Bioethics and Medical Humanities, Universitas Gadjah Mada, Indonesia. Email: puri.gusti.dewi@mail.ugm.ac.id Orcid ID https://orchid.org/0000-0003-1328-6821
3. Graduate School of Bioethics, Universitas Gadjah Mada, Indonesia; Center for Bioethics and Medical Humanities, Universitas Gadjah Mada, Indonesia & Department of Health Behavior, Environment, and Social Medicines, Faculty of Medicine Public Health and Nursing, Universitas Gadjah Mada, Indonesia.
Email: rspadmawati@ugm.ac.id Orcid ID https://orchid.org/0000-0003-0744-5996

Corresponding Author: Imanuel Eko Anggun Sugiyono, Email: imanuel.anggun@mail.ugm.ac.id

her sister to do the job properly, like a business as usual, as if she did not want to lose her dignity. Conclusions: There are various stages and shifts happening during the illness. Some patients felt that the illness weaken their physical body and social relations. Some others tried to conserve their mental condition after the illness. The healthcare workers should be aware, paid attention and be trained to this dignity shifting. The care needs to be adapted and given considerably according to the patients.

Keywords: end-of-life care, phenomenology, dignity, palliative care

Introduction: The dignity is the term that universally acknowledged in our society. People are agreed to protect the dignity of one another. Either he is healthy or sick, his dignity as a human is still same. Whether she is rich or poor, she has the dignity which needs to be respected by others [1].

There is one of the bioethics principles, called a respect for dignity. To apply this principle is to protect the human dignity from the threat of technology, the mismanagement of health service, and the unawareness of health professionals to the patients' needs [1].

In 2005, the UNESCO Declaration continues to state human rights as a significant part of global bioethics principles [1,2,3]. The Declaration in article 2 has stated that the aim of declaration is to promote respect for human dignity by ensuring respect for the life of human beings. Men and women are self-worthy to be respected from the beginning until the end of their life [1].

There are a lot of the ethical issues raised by the rapid advances in science and the technological interventions [4,5]. The health practice is related to the needs of every patient as a human being. He or she has the physical and mental needs that should be taken care by the healthcare works, namely nurses and doctors 6 (Tronto, 1993)

While the dignity becomes the universal term, the understanding of it can be multi-facets. There are some research to investigate how the terminally ill patients view and understand their dignities [5,7,8,9,10]. Three factors could affect their dignity: illness-related concerns, dignity conserving repertoire, and social dignity inventory 9. First, illness-related concerns that influence dignity are coming from or are related to the illness itself, and threaten on the patient's sense of dignity. Second, dignity conserving repertoire can be seen from the internal qualities of patients that may be based on long standing personal characteristics, attributes, or an acquired world view; and also from the variety of personal approaches or techniques to maintain the sense of dignity. Third, social dignity inventory refers to social concerns or relationship dynamics that enhance or detract from the patient's sense of dignity.

The views and understandings of terminally ill patients on dignity were really important to improve the care for themselves. They bear the physics and mental burden during the terminal situation of the disease. By knowing what the patients' perspectives are, the healthcare workers can respond to the needs of patients correctly and efficiently in a significant way.

This research aims to describe the dignity shifting experiences of the terminally-ill patients based on their families' opinions. If the health care workers aware and realize this shifting, it will help them to give a good and personal care according to the needs for the terminal ill patients.

Methods The researchers made this study as a phenomenological study. It was a part of bigger study carried out in a Catholic hospital in Indonesia. The hospital was a B-type hospital. Research was done at Yogyakarta Province. We considered families of terminally ill patients only in this research as participants.

The research is still on-going. The interview was conducted on 24 families of terminally ill patients. The patients were not the first choice because of their illness situation. As the representative for the patients, we chose their families. They were interviewed to know what kind of shifting

happened in their families' members during the disease. The interview started on June 2019. There will be more people to be interviewed as a triangulation for the data. The place of interview was different from the bed of the patients. The location was separated so that the feelings and mental of patients not being disturbed.

The researchers used the phenomenology method to find the experiences of the patients. The sampling was purposive. The inclusion criteria were the family of the terminally ill patients who have been hospitalized at least three days; the participants who have left the hospital less than six months ago; and the participants who were agree to join the research and be interviewed. The exclusion criteria are the participants who rejected to be interviewed because of the sadness, anger, denial, or other negative feelings they had.

The data were analyzed using thematic analysis and Chochinov's model of dignity as a framework. Chochinov et. al developed the concept of dignity based on the subject experiences of the terminally ill patients [9].

Result: The study participants comprised of ten women and fourteen men. Their age were range between 47-64 years old. They were related to the patients as nucleus family, either the sister, the brother, the daughter, the son, the wife, the husband, or the mother, the wife of the patients. The age of the patients was between 30 -79 years old. The diseases of our participants were from diverse patients, a chronic diabetes, a cancer (ovary, lung, colon), and a brain tumor.

According to the families interviewed, being sick and hospitalized was a shift of dignity. They were feeling unhappy, stressed out, and angry with their condition. Some patients could handle the situation by doing their usual business while hospitalized, and some other patients just gave up with their sick condition.

The Illness-Related Concerns: Mrs. E as the daughter, felt that Mrs. Sb (68) was very independent and not used to be served by others. The patient was strong and independent before, but during the illness of colon cancer, she became deteriorated and was so weak. She felt not comfortable and always wanted to go home. She missed her daily activities when she could work, eat, and shower by herself. In the hospital, she could not do those activities. Everything needs assistance from the nurses. Mrs. Sb has the illness that influence and threaten her sense of dignity. She thought that she was a burden. She felt that her dignity was priceless just because she became not independent anymore.

But this morning, the mother seemed to feel why I was bothering the nurse, earlier, just this morning, I just wanted to go home, I am sorry for the nurse, from last night too, this is also what my children are bothering [the nurse], I think my mom feels why not her children [do helping]."

The Dignity Conserving Repertoire: Ms. Dn as the sister told that Mrs. Fr (36) somehow kept her dignity by telling her sister to continue running the food business. Every day she told her sister to do the job properly, like a business as usual, as if she did not want to lose her dignity. She made up the menu every single day and asked her sister to cook the menu as her plan. She did not give up easily with her cancer on ovary. Even though suffered from the injections, she did not really think about it.

"Tomorrow if I get well, please help me to check the food, at home before, I was selling ice anyway, so please you make the dumplings, and I make the cake."

In another case, Mrs. Su foretold that her mother-in-law, Mrs. Ls (90), were ready to take every treatment from the doctors. She felt no afraid. She said yes to every alternative treatment. If the doctor told her to be foot-amputated, she was not dare to do it. She just wanted to be healed. Her wish was organizing a prayer in her hometown. She wanted to pray together with all of her friends who has gone to Meccah together.

Based on the experiences of Mrs. Fr and Mrs. Ls, internal qualities of patients could be seen from their long standing personal characteristics. Mrs.

Fr was a strong and tough woman who used to cook and manage the business; Mrs. Ls was a religious and social person who used to engage in the prayer activities. Both of Mrs. Fr and Mrs. Ls used their own personal approaches or techniques to maintain the sense of dignity.

The Social Dignity Inventory: Mr. D told that his mom, Mrs. As (69) felt that everybody she knew, was visiting and watching her laying on the bed. She expressed her feelings that she was "such a performer." She did not feel strong enough and ready to welcome guests because of the sickness. She used to wear a proper clothes to meet the guests and also made up her face before. But in the hospital, she never did make up and could not wear clothes properly.

> *When somebody is visiting, don't you want to respect him, for Javanese, we come out and if we have not yet take a bath, ask the guest to wait for a minute, like this, it doesn't look well, in this case my mother, if she has a guest, she always maintains her appearance and good looks,… sometimes her hair falls down like that, that's my mom, don't like it, don't like it, so she allows just family near her, mom doesn't like it, oh no, I become a watching material, … we have lots of visits, but it's only for close family, there is an announcement there, not to accept everyone, with respect so, without reducing a respect, well, it has a writing on it, because of what, we want my mother's privacy is maintained, that's all."*

Mrs. As' experienced the social dynamics with the other people she knew and whom she related with affect her view of dignity. The social relation to others made her feel useless and not feel supported. The other became the threat for her. She was not comfortable when met the others.

Discussion: According to Chochinov *et al*, the terminally ill patients will experience the "fracture" moment, when they were not able to think competently or to do activities functionally. They felt nothing as a person [9]. Men and women has a cognitive ability and physical function as well. When they suffered from the terminal illness, the situation changes. They cannot think properly and do the functional activities with some limits. Because of the alternation of the normal to the unwanted situation, the patients feel frustrated, hopeless, and useless.

The "fracture" moment is similar with Kubler-Ross' five stages or attitudes toward death and dying, namely: denial and isolation, anger, bargaining, depression, and acceptance. The first four are related to the negative attitudes. The patients still reject and are against the facts. The alternation into the illness causes the negative feelings. The last one of Kubler-Ross' stages is more positive. The patients start to accept what their condition are and how weak they really are [10].

Brown *et al* suggest that the health professionals should pay attention to the dignity-related tasks. The dignity-related service is useful for a palliative care. The patients will experience the dying with dignity when they are well dignity-related served [7]. (Brown *et al* make and suggest the form of care actions which can be applied to the terminally ill patients and their family. Related with symptom distress, the health professionals should have an early communication to patient and their family; should provide equipment to the needs of patients and families necessary. Related with dignity conserving perspectives, the health professionals should give the patients and families a chance to be sad; help patients to articulate what is important; and able to accommodate particular visit requests. Related with social dignity inventory, the health professionals should be sensitive to the patient's need for privacy; be respectful when providing care; and be helpful assistance.

Conclusions: There are various stages and shifting happening during the illness. The first reactions usually are contradictory to the sickness. The negative feelings arise. Not all of the patients could pass the feelings. But not few of them can maintain their dignity by conserving themselves. Some patients felt that the illness weaken their physical body and social relations. Some others tried to conserve their mental

condition after the illness. All of the experiences describe the call for special understanding to the personal needs of the patients. The different perspectives on viewing the sickness made the patients unique. Their dignity as the terminally ill patients could be affected by the sickness. Because of the dignity shifting, the health professionals should be aware, paid attention and be trained. The care needs to be adapted and given considerably according to the patients.

References

1. Unesco,. Human dignity and human rights Organization 2011.DOI: http://doi.org/10.1024/1012-5302/a000334
2. Bader, J.-M.UNESCO and bioethics. *Lancet* 2003; 342: 798. DOI: https://doi.org/10.1016/0140-6736(93)91554-y
3. Kirby, M. Human rights and bioethics: the universal declaration of human rights and UNESCO universal declaration of bioethics and human rights. *J Contemp Heal. Law Policy* 2009;25: 309–331.
4. Gumedze, S.The Nepad and Human Rights , South African Journal on Human Rights. 2006. DOI: https://doi.org/1080/19962126.2006.11864886
5. Shamima, P.L. Challenges of Palliative Care. Bangladesh Journal of Bioethics 2013; 4(3):19- DOI: http://doi.org/10.3329/bioethics.v4i3.17374
6. Tronto, J. Moral Boundaries. Routledge, New York; 1993.
7. Brown, H., Johnston, B., Östlund, U. Identifying care actions to conserve dignity in end-of-life care. *Br. J. Community Nurs.* 2011; 16: 238–245. DOI:. https://doi.org/10.12968/bjcn.2011.16.5.238
8. Chochinov, H.M., Hassard, T., McClement, S., Hack, T., Kristjanson, L.J., Harlos, M., Sinclair, S., Murray, A.,. The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care. *J. Pain Symptom Manage.* 2008;36: 559–571. DOI: https://doi.org/10.1016/j.jpainsymman.2007.12.018
9. Chochinov, H.M., Hack, T., Hassard, T., Kristjanson, L.J., McClement, S., Harlos, M.,. Dignity in the terminally ill: A cross-sectional, cohort study. *Lancet* 2002;360: 2026–2030. DOI: https://doi.org/10.1016/S0140-6736(02)12022-8
10. Östlund, U., Blomberg, K., Söderman, A., Werkander Harstäde, C. How to conserve dignity in palliative care: Suggestions from older patients, significant others, and healthcare professionals in Swedish municipal care. *BMC Palliat. Care*., 2019; 18: 1–12. DOI: https://doi.org/10.1186/s12904-019-0393-x
11. Kubler-Ross Ross, Elisabeth Kubler. (1969). On Death and Dying. New York: The Macmillan Company.

Author Declaration: 1st Author conceived the idea, wrote the manuscript, and checked the manuscript meticulously. 2nd author was the co-researcher and helped the development of ideas and 3rd author advised the writing of ideas.

Conflict of interests. The authors declare that there is no conflict of interest in this study.

Funding: None