



## Original Article

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**Abstract:** Objective: Death with dignity in Indonesia generally means a death that happens naturally, and timely way. Indonesians believe that matters related to death is God's alone to decide. In Indonesia, there is no options for terminal patients to stop their suffering by ending their lives. The objective in this research is to explore the understanding of death with dignity in Java, Indonesia. Methods: This research uses qualitative methods with a phenomenology approach. Study was carried out on 29 participants as a part of bigger study in Catholic hospital in Java, Indonesia. In-depth interviews were conducted for data collection. Data is analyzed using inductive content analysis. The participants were the primary caregivers to terminally ill patients. Results: The findings revealed that participants believe that their family members received death with dignity because they have lived a good life throughout their lives. Such good life involves not borrowing money in order to leave the family with debts to be paid after he/she died, conducted all the affairs in the good manner, well intentioned and dignified way. Always caring for the families and others member of society, and being faithful to his/her belief. When a person died, people can say that he/she had death with dignity. Conclusions: In Indonesia, euthanasia is illegal, thus not an option and not the right choice. The family member of the terminally ill patients needs a holistic approach in assisting their loved ones at the end-of-life. Therefore, a good palliative care becomes increasingly significant to have and must be available whether it is at home service or as part of the hospital.

**Keywords:** dignity, death with dignity, terminally ill, palliative care, phenomenology

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**Introduction:** Everyone has ever known without a doubt one day he will die. Death is a natural process of human life. There are many definitions and understandings of the term death<sup>1</sup>. The differences of understanding are based on differences in religions, cultures, social and economic aspects<sup>2,3,4,5</sup>. One of the controversial issues like personal autonomy of the patients can be used as an example of the difference. Western societies embrace individualism that promotes the personal autonomy of the dying in choosing the timing and the way to end one's life<sup>6</sup>, while Eastern societies embrace terminal conditions and long-suffering sickness as "chosen path" decided by God<sup>3,7</sup>. A death which will be the end of that path, naturally only will be deemed as a good death when it happens in God's timing alone.

Established in 1970, Institute of Medicine (IOM) is an independent and a nonprofit organization that works outside of government in United States of America (USA), to provide unbiased and authoritative advice to decision makers and the public. Safety, effectiveness, equity, timeliness, patient-centeredness, and efficiency are the "six aims for improvement" of IOM to identify the fundamental domains to improve the health care services delivered<sup>8</sup>. In 2007, IOM defined a good death as free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards. Therefore, it is then commonly said that the terminally ill patients in their care should die with dignity without any suffering by the withdrawal or withholding of life-preserving treatment, or by the direct administration of some life-ending treatment. The idea seems to be that certain conditions are such that palliative treatment is insufficient to ensure a death with dignity and that therefore euthanasia should be used<sup>8</sup>.

This research aims to explore the experience of primary care givers (families) of terminally ill patients in caring and accompanying their loved ones in their end-of-life journey. They were questioned about death and what is 'a good death' and death with dignity and its meaning to them (the family and the patients themselves). By knowing the families and

patients' perception of good death and dying with dignity, health care providers and communities can work together to assist, support and ensure that terminally ill patients have 'death with dignity' in their perspective or dignified death, at the end of their life journey.

**Methodology:** This is qualitative research with phenomenology approach. This research is part of a research study conducted in a private hospital in Java, Indonesia. The research was conducted in a type B private hospital equipped with 380 beds, in Special Region of Yogyakarta. The research period was from May 2019 until May 2020.

Sample is purposive, the subjects were the families of terminally ill patients as well as the patients themselves if physically capable and willing to be interviewed who had been in the hospital for more than three days or died in less than six months. 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.

A total 29 participants were included in this study. The main participants in this study were 15 family members (primary care givers) of terminally ill patients and 1 terminal patient, 4 doctors, 3 nurses, 2 pastoral care staffs, 2 religious leaders and 2 management staffs of the hospital. They were interviewed as triangulation sources. Triangulation method is used to develop a comprehensive understanding of a good death as phenomena for terminally ill patient and their family (Patton, 1999). This is viewed as a strategy to test validity through the convergence of information from different subjects.

The participants' data were collected from in-depth-interviews, observation and studying documents. All data were analyzed using inductive content analysis. Each interview then transcribed and then coded, and the coding was categorized in sub-theme. After that, the existing sub themes were synthesized into the themes. The researcher organized data in matrix table form and added the field notes then wrote into the result of the research. Data is

presented using a descriptive (narrative) phenomenological method.

**Meaning of death with dignity:** The origin of word “dignity” is derived from the Latin, ‘*dignitas*’, meaning worthiness and nobility<sup>9</sup>. According to the medical dictionary, death with dignity means: a death that is allowed to occur in accordance with the wishes of a patient<sup>10</sup>. Death with dignity in Western societies is an option chosen by a competent individual (or one having power of attorney when he/she is incompetent to make an informed choice) about actions to be taken when that individual is dying:<sup>7,11, 12</sup>

**Indonesian Position of death with dignity:** In Indonesian, the word dignity means ‘*martabat*’, also carried the meaning *tingkat, harkat or derajat*, which means ‘level’. ‘*Tingkat, harkat or derajat*’ can be explain as ‘the level or value of someone’<sup>13</sup>. While in Indonesia ‘death with dignity’ generally means a death that happens naturally and timely. Allmark, P (2002) citing Kass, L. writing in his book ‘Averting one’s eyes or facing the music? - on dignity in death’. Kass suggests that the discussion of death with dignity conceals four senses of the term “death”<sup>6</sup>:

1. Non-being—the rather mysterious state of being dead.
2. Transition—the point at which one moves from being to non-being.
3. Process—the period leading to death. This is not entirely straightforward as we are in this process from the moment of conception. In practice it usually means a period in which there is an awareness of what will end a particular person’s life and, roughly, when.
4. The fact of mortality—death as a universal truth that attaches to us all.

**Results:** This research is ongoing. So we cannot provide the result as a whole. We are providing here the perception of good and dignifying death from people of Indonesia.

Death is predetermined by God or describe as “*Takdir*” in Indonesian. God alone can take life because he is the creator of man. When one died, only the body remains on earth to be

buried but the spirit and soul move to next life, to reunite with God in a much better place. Death does not end with the last breath in Javanese belief. When one died, the spirit of the dying lives on and only able to move on to the next life after all the rituals and prayer completed (3<sup>rd</sup> day, 7<sup>th</sup> day, 40<sup>th</sup> day, a year and 1000 days after the death prayers). Prior death there are sign such as the feeling that someone, something from another world comes to collect the dying spirit. If the dying found “difficulty” to die, then the wise man be called to ‘clear and release’ magic power from the soul and body of the dying one.

In Indonesian, common people do not discuss the matter of dignity (*martabat*). They reserve such topics for politicians or upper class societies. For the commoner, ‘*martabat*’ means good conduct, do good thing according to norm and social measurement. Someone who has been a good person during his/her whole lifetime, categorized as dignity on their death. This is because of the common social perception and belief that someone who has been kind, caring, good and upstanding person, shall deserve a death that is good, regardless that the death came as the result of illness or an accident.

Euthanasia and physician assisted suicide (PAS) are illegal in Indonesia as well as withholding treatments to terminally ill patients. Indonesians believe that matters related to death is God’s alone to decide. Therefore, when the time of death comes, how it happens, and its timing determine if it can be seen as a dignified death. Then, can illness or unfortunate events that because death takes away one’s self-worth or dignity?

**Perception of “a good death”** Perception of a good death varied and influenced by religions, beliefs and faiths, social and cultural aspect as well social-economic situation of the speaker. However, there are few perceptions shared among the participants regardless those differences above.

A good death is when a death happened to the person who was somehow prepared for it, mentally and spiritually. Being prepared mentally mean the person who was dying has reached awareness and had accepted the fact

that the end of time is near. Being prepared spiritually means that the dying person have admitted all sins and have asked forgiveness from God and family members or friends.

When the last moment comes, a good death will happen in a peaceful manner, without much physical suffering (easy death). Surrounded by family member and loved ones when she or he dies. A death that would not leave burden or cause a problem for the family.

The family member of the terminally ill patients needs a holistic approach in assisting their loved ones at the end-of-life. Therefore, a good palliative care which involve spiritual aspect as major part becomes increasingly significant to have and must be available whether the patients are care for in the hospital setting or at home.

Currently, the concept of palliative care which can start long before the patients died is not commonly known and accepted. Although hospital provides what they called palliative care, administering pain killer and assisting patients by calling religious leader, those are in fact just a component or part of palliative care. The whole concept of 'Palliative Care' need to be understood by health care provider and family and patients specifically and society in general, need to be educate on that prior caring for the terminally ill patients.

**Conclusions:** In Indonesia, euthanasia is illegal, thus not an option and not the right choice. The family member of the terminally ill patients needs a holistic approach in assisting their loved ones at the end-of-life. Therefore, a good palliative care becomes increasingly significant to have and must be available whether it is at home service or as part of the hospital.

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**Conflict of interests.** The authors declares that there is no conflict of interests in this study.

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