

**PERAN KELUARGA DALAM Mendukung PASIEN DENGAN  
PENYAKIT TERMINAL: PELAJARAN DARI BANYUMAS – JAWA  
TENGAH**

**FAMILY’S ROLES ON SUPPORTING PATIENTS WITH TERMINAL  
ILLNESS: LESSON LEARNED FROM BANYUMAS REGION –  
CENTRAL JAVA**

**Diyah Woro Dwi Lestari<sup>1\*</sup>, Miko Ferine<sup>1</sup>, Bagas Wicaksono<sup>1</sup>, Arfi Nurul Hidayah<sup>1</sup>,  
Amalia Muhaimin<sup>1</sup>**

*<sup>1</sup>Departemen Bioetik dan Humaniora, Fakultas Kedokteran, Universitas Jenderal Soedirman  
Jl Gumbreg No 1 Purwokerto 53112  
Email : diyah.woro.dwi.lestari@unsoed.ac.id*

**ABSTRAK**

Menyampaikan berita buruk dianggap sebagai salah satu bagian tersulit dari komunikasi antara dokter dan pasien. Dengan demikian pasien dan keluarga berhak memahami kondisi kesehatannya yang sebenarnya. Menyampaikan berita buruk dapat menyebabkan situasi yang tidak nyaman ketika pasien dan keluarga mereka menunjukkan reaksi negatif terhadap percakapan tersebut. Selain itu, situasi seperti itu dapat menyebabkan pengalaman negatif dan dapat berkembang menjadi pengalaman emosional yang buruk antara dokter dan pasien. Masalah komunikasi diidentifikasi sebagai faktor utama dalam menyampaikan berita buruk. Di sisi lain, budaya, faktor utama yang menentukan hasil komunikasi, akan memainkan peran penting dalam situasi ini. Tulisan ini bertujuan untuk menggali peran keluarga dalam proses penyampaian kabar buruk dari dokter kepada pasiennya. Metode kualitatif dilakukan dalam makalah ini dengan menggunakan wawancara mendalam dengan 7 anggota keluarga pasien dalam kondisi terminal. Hasil penelitian menunjukkan beberapa tema, yaitu peran keluarga dalam menjaga kondisi emosi dan psikologis pasien, peran keluarga sebagai orang penting untuk diandalkan (dalam hal pengobatan), keluarga sebagai pengambil keputusan yang menentukan terapi bagi pasien dan juga berperan dalam komunikasi antara dokter dan pasien.

**Kata kunci:** Peran Keluarga, Penyampaian Kabar Buruk, Komunikasi

**ABSTRACT**

*Delivering bad news is considered one of the hardest parts of communication between doctor and patient. Thus patients and families have the right to understand their actual health condition. Delivering bad news could lead to an uncomfortable situation when the patients and their families showed negative reactions to the conversation. Moreover, such a situation could lead to a negative experience and could develop into a bad emotional experience between doctor and patient.*

*Communication problems are identified as the main factor in delivering bad news. On the other side, culture, the main factor that determines the result of communication, would play an important role in this situation. This paper aimed to explore the family's role in the process of delivering bad news from physicians to their patients. Qualitative methods were conducted in this paper using in-depth interviews with 7 family members of patients in a terminal condition. The result showed several themes, which are the role of the family in maintaining patients' emotional and psychological condition, the role of the family as an important person to rely on (in terms of medication), family as decision-maker who determines the therapy for patients and also play a role in communication between doctor and patients.*

**Keywords :** *Family's Role, Delivering Bad News, Communication*

---

**Penulis korespondensi:**

Diyah Woro Dwi Lestari

Departemen Bioetik dan Humaniora Fakultas Kedokteran Universitas Jenderal Soedirman

Alamat institusi. Jl Gumbreg No 1 Purwokerto

Email: diyah.woro.dwi.lestari@unsoed.ac.id

## **BACKGROUND**

Conveying bad news is one of the most important duties of doctors. A doctor does not spend on delivering uncomfortable news to get patients, but also needs to manage patients and themselves. Patients may become emotional while responding to information provided by doctors who were convinced that they could not help the patients any further. The process may bring negative memory for doctors, patients, and family members (Monden et al. 2016).

The understanding of patients and doctors about related situations will determine the process of delivering bad news. Nevertheless, there are great variations of the forms of communication and the role of doctors, patients, and families. The difficulty of the disease does not seem to be the only factor that influences the attitudes of doctors in delivering bad news to patients and their families. Culture can also influence the process of delivering bad news since it determines how someone understands something and behaves. The cultural background will affect someone in understanding illness, suffering, and death (Vehling and Kissane 2018).

A factor of one's religion and spirituality also influences the perspective while encountering negative situations. According to a study, a doctor is considered unaware of someone's life story and only God knows everything. God has the power to determine one's life and death. This belief will support a patient to remain passionate about life (Kagawa-Singer 2011). The principles, values, culture, and spirituality held by the patient will determine their life choices. The patient's choice will certainly influence the choice of doctors in delivering bad news. Doctors in the United States are more likely to convey bad news directly to patients. Patient autonomy is the focus of health services in Europe and America – which is also known as a patient-centered view. The patient has the right to know everything about his illness, including therapy and prognosis. In these circumstances, determining therapy is the full right of the patient (Kagawa-Singer 2011).

Different phenomena can be found in several Eastern European countries, South America, Asia, and Africa. Doctors in Asian countries tend to keep bad conditions in front of patients. Most Asian doctors prefer to deliver bad news to the patient's family first. Family involvement of patients in the process of delivering bad news to patients is very important. Doing good (beneficence) is still the main focus of health services. Doctors practice in this region prioritize ways to protect patients from dangerous situations, including bad news delivery. This situation might be considered cruel and

---

family's roles on supporting patients with terminal illness:

lesson learned from banyumas region – central java, **dyah woro dwi lestari**

endanger patient safety. Keeping secrets of poor patient conditions is considered more humanistic and ethical in this area (Sobczak et al. 2018)

Culture with patrilineal characteristics and close family ties certainly has a distinctive pattern related to the delivery of bad news and decision making. Families play an important role in this kind of culture. Everything that will be done to the patient is determined by the patient by involving his family. In some situations, the decision-maker will be the older member of the patient's family. Doctors would provide information to family members without regard to patient privacy and confidentiality (Hanlon et al. 2021)

Banyumas is one region with distinctive community characteristics. Developing culture is not entirely the same as Javanese culture and not the same as Sundanese culture. The pattern of health communication including the delivery of bad news in Banyumas has not been widely explored. This phenomenon needs attention since understanding the patient's choice and the role of the family in receiving bad news is crucial for doctors. Doctors should understand how to deliver bad news and to what extent doctors can involve family members in the process of delivering bad news. This situation will be determined by the patient's culture and spirituality. Therefore, it is necessary to explore the role of the family in the process of delivering bad news by doctors to patients with a Banyumas cultural background.

## **METHODS**

This was a qualitative study that emphasized the exploration of the meaning of a phenomenon that focuses on the overall experience of the research subjects (Moustakas, 1994., Iskandar, 2008). The research subjects in this study were considered experts who knew exactly their own experiences and were considered to be able to provide understanding to researchers regarding the phenomenon they experienced (Smith 2011). This study will use a phenomenological approach, to delve deeper into an individual's experience of certain diseases. Hegel, in (Moustakas 1994) explains that phenomenology is aimed at experiences that arise in human consciousness, so phenomenology is a science that describes the human experience, which is accepted, felt, and known in his consciousness. Specifically, the phenomenological tradition that will be used is classical phenomenology or transcendental phenomenology. Transcendental phenomenology emphasizes the subjectivity and disclosure of the core of experience in a systematic way or method. This approach only uses data that the informant discloses consciously. It is called transcendental because it refers to an experience that can be expressed through subjective reflection, which connects it to events that are objectively realized (Moustakas 1994). Thus, researchers will uncover and understand and articulate experiences that are realized by the research subjects.

In short, this research took place in 4 stages, namely the orientation stage, the exploration phase, checking the findings, and preparing the report. At the orientation stage, researchers talked with research informants, in this study, families of patients who get bad news from doctors about their illness. In the exploration stage, researchers asked in more depth about the role of the family in the delivery of bad news by doctors to patients. The last step is to check the findings again and the last is to compile a research report.

### **Data collection technique**

Respondent was selected with the recommendation from a hemato-oncologist at the Department of Internal Medicine, RSUD Prof. Dr. Margono Soekarjo, who was related to potential research subjects. The data collection strategy in this study uses in-depth interview and observation techniques. The purpose of this interview is to provide an understanding to the researcher about the meaning of the things to be examined from an individual's point of view (Poerwandari 2007). In this

study, the research topic was the role of the family in the process of delivering bad news by doctors to patients with Banyumas cultural backgrounds. This interview will be conducted with semi-structured interviews. The selection of this type of interview is related to the approach used. In this phenomenological approach, the data that is suitable for use are data obtained from individual interviews in a semi-structured format (Madill 2011). In semi-structured interviews, researchers will ask informants about the research topic with an interview guide with an open question format.

### **Process of Data Analysis and Interpretation**

The first step in processing, analyzing, and interpreting data is to make interview transcripts. This transcript will be completed with page numbers and lines as markers. Interviews that are reported are not only in the form of conversation narratives but also small details such as the use of words (such as mistakes in words) as well as expressions when interviewed. All of that is recorded in the interview transcript. In general, there are four stages of phenomenological data analysis, which are epoche, phenomenology reduction, imaginative variation, and synthesis (Moustakas 1994). Epoche is focusing on what is received or fully aware of the symptoms captured by not assuming, not judging, and interpreting it. Furthermore, the reduction of phenomenology is to describe the phenomenon as a whole, which includes the characteristics of experience such as thoughts and feelings that arise and lead to the phenomena that are intended to be explained. Through the reduction of phenomenology, the main elements of experience can be identified so that researchers can realize the experience as it is or what is experienced (textural description). Imaginative variations, namely efforts to achieve structural components of phenomena, namely how the experience is built (structural description). The most important thing in imaginative variation is identifying conditions that relate to phenomena that include space, time, and social relations. After that, the textural description (what happens) and structural descriptions are integrated so that an understanding of the essence of the phenomenon (synthesis) is obtained (Neubauer et al. 2019). state that phenomenological qualitative research analyzes have similar steps.

### **Research Ethics**

This research was exempted from ethical review by the Health Research Ethics Committee of the Faculty of Medicine, Universitas Jenderal Soedirman.

## **RESULT AND DISCUSSION**

The results of the discussion were then continued by starting interviews with the subjects of the research subjects that were selected by the criteria previously set. Until this report, interviews were made with 7 people. In this study, respondents interviewed were families of patients with terminal diseases, such as liver cancer, breast cancer, uterine cancer, and colon cancer. Patient patients came from the Banyumas and Cilacap regions. A total of 3 patients had died at the time of the interview to family members, while other respondents were still in therapy.

Based on the results of the interview there are some themes found as follows:

1. The family has an important role in providing support for patients, especially psychological support and utility support.

Psychological support is carried out in the form of giving enthusiasm and motivation for treatment for the patient. Some respondents gave motivation by saying that they should routinely undergo chemotherapy to recover quickly. Another form of support is by providing entertainment and recreation to patients who are undergoing treatment. This form of entertainment and recreation is

---

family's roles on supporting patients with terminal illness:

lesson learned from banyumas region – central java, **dyah woro dwi lestari**

realized by providing what the patient wants. The main concern for the family member was the decline of the patient's emotional and psychological condition after hearing the diagnosis. Thus, the family member tried to communicate very carefully with additional Islamic suggestions, as pictured in this quotation.

*"...before telling her the nasopharyngeal carcinoma diagnosis, I talked to her about life and destiny for quite some time. I told her that everything comes from Allah. We, as humans should surrender to Allah and must think positively toward Allah's arrangement toward us. And at the end, when I told her, she looked sad but she then said that everything was meant to be and all she had to do was doing her best to follow the medication"* (F, 48)

Another concern was raised by a family member was about the potential deterioration of the patient's emotional condition, so they informed these concerns to the physician. The family members imagined the emotional storm of the patient as follows.

*"...my aunt said that no matter the diagnosis, she will hide it from her husband. I also agree since I know how hard that would be for him. Just a week ago, he mentioned to me his wish to be discharged from the hospital since he missed his granddaughter and he wanted to pick her granddaughter from school... He would be devastated if knowing that he was in the end stage of his life"* (C,40)

Family members also face hardship towards the course of the illness. They were not only needed to understand the patient's feelings but also tended to keep the patient's emotional condition in stable condition.

*"We were not crying in front of her. We didn't want to make her sad, so I told my sister – we must not cry in front of her. But after she fell asleep, we shed our tears and said "Astagfirullah Hal adzim (May God forgives us)... it was so hard but we (I and my sister) keep our promise to not cry in front of her"* (A,35)

2. The family is an active part in determining what treatments can / cannot be followed by patients. Another important role that is carried out by the family is to be the determinant of care that will be carried out by the patient. Conventionally – in Western point of view - the decision-maker for the care is the patient himself or the patient together with the doctor. However, it was found that the patient's family also had an important role in decision-making, such as in a uterine cancer patient who eventually did not continue treatment because her family members felt that medical treatment had no results, so they switched to traditional medicine. They actively sought medical and non-medical information for the patient. Another family member of a breast cancer patient even showed his curiosity about the diagnosis of the patient by asking for more explanation from the pathologist.

*"Mama expresses her objection toward conventional medical therapy. She wanted to have herbal medicine. Then I tried to find information about it, not only related to herbal medicine but also other, like massage therapy in another city, Banjarnegara. I also saw the therapy with my own eyes, I wanted to know how the healer did it"* (A,35)

*"I went and ask the pathologist about my mother's diagnosis ("unspecified adenocarcinoma"). She brought the tissue's slide and showed the image under the microscope to me and I then convinced"* (D,25)

Another role given by the family member was giving an elaborate explanation of the medical therapy for the patient

*"...I was the one who break the bad news, not the physician. I said to her "I have the result from Pathologist" and then my mother said "The result is bad right?". I then explained to her that she had breast cancer..."* (D, 25)

*“My husband understand the diagnosis clearly and passed the information to my aunt. She was shocked but managed to control herself in front of her husband, but later outside the ward, she cried endlessly onto my husband’s shoulder...” (C,40)*

3. The family strives and expects information about the patient's illness to detail so that the family can provide support, especially psychologically and financially, also make decisions about patient care. In this study, we found that the family expects the doctor to provide detailed and comprehensive information about the patient’s condition. All respondents stated that the diagnosis of the disease was conveyed to the family. Related to this, the family asked the doctor to give medical information in detail, up to the prognosis. The family also gave a strong influence on the choice of therapy.

*“When I had information from the pathologist that the result was not very good, I decided to proceed to medical therapy. I had many experiences with my own family. Cancer is not something to avoid, you have to do something. I keep persuading my husband to comply with medical therapy. He is now in nuclear therapy” (G,35)*

*“I had my mother cancel the massage therapy since I thought I was nonsense, but I could accept the Breast Holder therapy from Jakarta” (A,35)*

Patients also tend to comply with family member suggestions after some time, although some patients had different wishes at the beginning.

*“At first, she just want to be treated in Jakarta, but due to financial problems, I decided to go home and told her that she would be treated in Purwokerto. She was okay with that, she thought that she might become a burden if she was treated in Jakarta” (E, 35)*

*“I was surprised when my husband came to the hospital to have his referral letter to be treated to another city. I guess he finally knows my good intention toward him” (G,35)*

4. The family functions as an intermediary between patients and doctors.

Family members have an important role in the care of terminal illnesses. When getting bad news about a severe illness, the family acts as the recipient of the doctor's initial notification. After the family gets information about the bad news, the family will determine whether it will be delivered to the patient or not. One respondent stated that he directly requested that information about the patient's illness was not informed to the patient, considering the psychological condition of the patient. Until the death, the patient did not know anything about the disease clearly, both from his family and his doctor. Another thing found regarding this theme is that the family also functions as an intermediary or a messenger of the patient to his doctor. The family will ask the patient about the wishes of the patient and family who will convey what the patient wants to the doctor.

*“My wife could not say anything. She always mention the chance of being 100% cured and I was the one who mentioned to the doctor what she want to know” (F,48)*

*“The doctor was very supportive toward patient and family. After my aunt mentioned to the doctor that he (the patient) should not be informed about the actual diagnosis, the doctor said he understand and only informing the result from the surgery” (C,40)*

## CONCLUSION

In conclusion, a family member of patients who received bad news from a physician regarding the patients’ health plays important role in supporting the patient. In Indonesia, the role of a family of the patient is not only beneficial for the patient, but in some cases, they also play a role as a “connecting bridge” between doctor and patient. They filled the emotional and cognitive gap between doctors and patients, and also play a role as the ones who deliver bad news to the patient. Although the result of this research is limited to certain parts of Indonesia, the lesson learned was physicians should consider the value and culture of the patient. In a culture where the bond between family members - not only nuclear family but also extended family - was strong, physicians should consider involving the family in the communication and treatment of patients with bad conditions.

---

family’s roles on supporting patients with terminal illness:

lesson learned from banyumas region – central java, **dyah woro dwi lestari**

**DAFTAR PUSTAKA**

- Hanlon, H. R., Prihodova, L., Russell, T., Donegan, D., O'Shaughnessy, A. and Hoey, H., 2021. Doctors' engagement with a formal system of continuing professional development in Ireland: a qualitative study in perceived benefits, barriers and potential improvements. *BMJ open*, 11 (11), e049204.
- Kagawa-Singer, M., 2011. Impact of Culture on Health Outcomes. *Journal of Pediatric Hematology/Oncology* [online], 33. Available from: [https://journals.lww.com/jpho-online/Fulltext/2011/10001/Impact\\_of\\_Culture\\_on\\_Health\\_Outcomes.4.aspx](https://journals.lww.com/jpho-online/Fulltext/2011/10001/Impact_of_Culture_on_Health_Outcomes.4.aspx).
- Madill, A., 2011. Interaction in the Semi-Structured Interview: A Comparative Analysis of the Use of and Response to Indirect Complaints. *Qualitative Research in Psychology* [online], 8 (4), 333–353. Available from: <https://doi.org/10.1080/14780880903521633>.
- Monden, K. R., Gentry, L. and Cox, T. R., 2016. Delivering bad news to patients. *Proceedings (Baylor University. Medical Center)*, 29 (1), 101–102.
- Moustakas, C. E., 1994. *Phenomenological research methods*. Phenomenological research methods. Thousand Oaks, CA, US: Sage Publications, Inc.
- Neubauer, B. E., Witkop, C. T. and Varpio, L., 2019. How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education* [online], 8 (2), 90–97. Available from: <https://doi.org/10.1007/s40037-019-0509-2>.
- Poerwandari, E. K., 2007. *Pendekatan kualitatif untuk penelitian perilaku manusia*. Jakarta: LPSP3 Fakultas Psikologi Universitas Indonesia.
- Smith, J. A., 2011. Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review* [online], 5 (1), 9–27. Available from: <https://doi.org/10.1080/17437199.2010.510659>.
- Sobczak, K., Leoniuk, K. and Janaszczyk, A., 2018. Delivering bad news: patient's perspective and opinions. *Patient preference and adherence*, 12, 2397–2404.
- Vehling, S. and Kissane, D. W., 2018. Existential distress in cancer: Alleviating suffering from fundamental loss and change. *Psycho-Oncology* [online], 27 (11), 2525–2530. Available from: <https://doi.org/10.1002/pon.4872>.