

Qualifications and social knowledge of medical staff in stationary hospices

Kwalifikacje i wiedza społeczna personelu medycznego w hospicjach stacjonarnych

Key words: qualifications, hospice, medical staff, patients, professional education, palliative medicine.

Abstract. Poor psychological and social qualifications of medical personnel affect the situation and condition of patients in stationary hospices. Patients often have no possibility of telling about their non-medical ailments, and it is a constant practice to limit the information provided to patients. Content related to accommodation and death are reduced only to the technical side of care, which can not only lead to information hype and confusion, but also to the deterioration of patients' well-being. It is important to emphasize the importance of balance between hope and honesty in providing information about the patient's actual condition, even among people under palliative care. Our research confirms that fears in the terminal phase of cancer appear as a result of a sense of powerlessness, worry, as well as an effect of information blocking. We can talk here about adaptive disorders, because the symptoms of anxiety do not weaken, and patients in hospices often do not have the resources or sufficient support to overcome them in disease conditions and new life circumstances. The need for action to reduce anxiety rather than strengthening it becomes one of the main skills of medical personnel in palliative care. Raising qualifications in the field of social and psychological impact allows for better organization of therapy in hospice conditions and comprehensive patient care.

Słowa kluczowe: kwalifikacje, hospicjum, personel medyczny, pacjent, edukacja zawodowa, medycyna paliatywna.

Streszczenie. Słabe kwalifikacje psychologiczne i społeczne personelu medycznego wpływają na sytuację i stan pacjentów w hospicjach stacjonarnych. Pacjenci często nie mają możliwości opowiedzenia o swoich pozamedycznych dolegliwościach, a stałą praktyką jest ograniczanie przekazywanych pacjentom informacji. Treści związane z miejscem pobytu i śmiercią sprowadzane są jedynie do technicznej strony opieki, co jednak może prowadzić nie tylko do szumu

informacyjnego i dezorientacji, ale pogorszenia samopoczucia pacjentów. Należy podkreślić znaczenie równowagi między nadzieją a uczciwością w informowaniu o rzeczywistym stanie pacjenta, nawet wśród osób objętych leczeniem paliatywnym. Nasze badania potwierdzają, że lęki w fazie terminalnej pojawiają się jako wynik poczucia bezsilności, zamartwiania się, a także jako efekt blokowania informacji. Możemy tu mówić o zaburzeniach adaptacyjnych, gdyż objawy lęków nie słabną, a pacjenci hospicjów często nie mają zasobów ani wystarczającego wsparcia na ich pokonanie w warunkach chorobowych i nowych okolicznościach życiowych. Konieczność działań w kierunku redukcji lęków, a nie ich wzmacniania staje się jedną z głównych umiejętności personelu medycznego w opiece paliatywnej. Podnoszenie kwalifikacji w zakresie oddziaływania społecznego i psychologicznego pozwala na lepsze organizowanie terapii w warunkach hospicyjnych i kompleksowej opieki pacjenta.

Introduction. Since the 70s of the last century, the tendency to medicalization, i.e. excessive concentration of attention on medical activities in relations with the patient and the increasingly clear treatment of patients as consumers, has been more and more noticeable in medical care.¹ Thus, psychosocial needs and emotional contact are diminished, and yet, especially in palliative medicine, the patient's mental and spiritual well-being is important.² Nowadays, the postulate is becoming valid to address non-medical needs, especially since the patients in the hospice are primarily people in the terminal phase of cancer.³ A patient who is undergoing palliative treatment leads the so-called "frugal functioning". Due to this, he has a lot of free time, which he spends sometimes alone. Patients often have no way of telling the interdisciplinary team about non-medical ailments: "no interest in the patient's problems, or lack of empathy?"⁴. Staff's reaction to non-medical topics are often so-called "Blocking behaviors" (e.g. generalizations, changing the topic of discussion), which can also be used to protect oneself by members of the medical team.⁵ In this situation, the patient is passively subjected to the actions of a doctor, thinking that the non-medical problems undertaken interfere with the work of the staff and worsen their relations with him. However, this increases the feeling of anxiety in patients, which is a typical emotional response of patients, and as the results of the study indicate, anxiety disorders often accompany chronic diseases.⁶ By choosing both the medical and nurse professions, you are required to meet the patient's different expectations. This is a big responsibility, hence training in psychosocial needs is just as important as new medical knowledge, and patient

¹ P. Conrad, *The Shifting Engines of Medicalization*, „Journal of Health and Social Behavior”, vol. 46, 2005, ss. 3–14, J.E., *Davis Medicalization, social control, and the relief of suffering*. In: Cockerham W.C., [ed.] *The New Blackwell Companion to Medical Sociology*. Singapore: Wiley-Blackwell; 2010, pp. 211–41.

² Bartoszek A., *Moralne aspekty „jakości życia” w opiece paliatywnej*, Śląskie Studia Historyczno-Teologiczne, Katowice 2002.

³ Górecki M., *Hospicjum w służbie umierającym*, Wydawnictwo Akademickie „Żak”, Warszawa 2000, s. 109.

⁴ Ibidem.

⁵ Ibidem, s. 49.

⁶ M. Gilli, A. Comas, M. Garcia-Garcia, et al., *Comorbidity between common mental disorders and chronic somatic diseases in primary care*. „Gen Hosp Psychiatry” 2010; 32: 240–245.

relationships should not be based only on established practice, because this can do both good and harm – often not aware. Even medical other medical profession student is learning to treat ailments, not a human being as a participant in social life. Therefore, he perceives the patient through the prism of his illness and care needs. The patient himself, which we are trying to show through the research presented here, has a different view of the situation in which he finds himself as a result of the disease. He approaches his situation subjectively and expects support and empathy. Therefore, it becomes important for medical staff to deepen their knowledge about emotions experienced by a palliative patient, to understand the crisis underlying his fears, in addition to somatic problems.

The patient in the terminal phase experiences growing anxiety and strong fears that do not allow him to cope with the current situation. This causes further disorders in the body, but also problems in social relations. Patients experience significant changes resulting among others from reducing the number of contacts, or limiting the roles they have played so far⁷ – the indirect action of anxiety causes withdrawal from social contacts.⁸ Anxiety can also be associated with anger that is directed towards medical care (transferred anger). The patient may, for example, pay attention to trivial matters, which cause irritation in him, and then become convinced that medical personnel are not properly prepared for work or do not do what they should. Irritation is also caused by rejecting the patient's negative feelings and giving false hope. It should be noted that the level of patients' expectations of staff changes during hospitalization and becomes more demanding in certain phases of illness.⁹ Among hospice patients, the situation is usually perceived as unfair in both existential and social terms. Several respondents during the interviews spoke directly about their own merits for loved ones – in this case the disease is interpreted as an unjustified “payment” for life and sacrifice. This manifestation of anger can be defined as “an emotional reaction to an obstacle in achieving goals, to the appearance of injustice”.¹⁰ It should be emphasized that both anger and anxiety can have a positive effect in the form of mobilization to face the disease – greater activity or energy, on the other hand they can cause aggression directed towards the environment or towards itself (self-aggression).

The situation of the terminal phase of cancer significantly changes the perception of reality and the desire to meet a certain group of needs. Low-level (i.e. physiological) needs are again becoming the most important at this time. In this new and difficult situation for the patient, the most important thing is for the physical pain to be relieved, so that despite the body's physical reactions related to the effects of the disease (e.g. nausea, vomiting) he would not have difficulty satisfying hunger (eating a meal or drinking coffee) or sleep. However, self-esteem is also important for the patient. First of all, the feeling that the patient is treated subjectively as a person, not like a disease

⁷ *Pedagogika rewalidacyjna*, pod red. A. Hulek, PWN, Warszawa 1998.

⁸ A. Kępiński, *Lęk*, Państwowy Zakład Wydawnictw Lekarskich, Warszawa 1977, s. 159.

⁹ A.M. Zienuk, *Oczekiwania pacjenta onkologicznego wobec personelu medycznego*, „Psychoonkologia” 2009, vol. 1–2, s. 17–27.

¹⁰ *Ibidem*.

unit.¹¹ De Walden-Gałaszko is of the opinion that the terminal phase of the disease triggers the patient's egocentric attitude, which is manifested, among others, in the need for acceptance, sympathy or love.¹²

The very awareness of the incurability of the disease – according to Stelert research – usually occurs sporadically. More often, patients think that the accompanying symptoms, which have intensified significantly, will disappear in a few days. They are not aware that these symptoms are the final phase of the disease leading to death. Patients are afraid of the word cancer. Most often they describe their illness as a fight with a dangerous opponent. They do not identify with the disease and believe that it is something beyond them, something they can “cut off” from. Talking about the prognosis and lack of chances of survival is particularly difficult for both the doctor and the patient and their relatives. According to Janiszewska, talking about prognosis is even more difficult when the staff is dealing with a young person or an optimistic approach to the result of treatment.¹³ To minimize the discomfort associated with such a conversation, restrictions on the information provided are practiced, and death-related content is reduced only to the clinical and technical perspective of care, which can lead to confusion and a sense of inconsistency among patients. It can be said that they do not reduce level of anxiety, creating a permanent area of ambiguity and understatement in the relationship with the patient. According to Wagner's research, palliative patients are almost three times less likely to be informed about the goal of treatment (33%) than patients with radical treatment (89%).¹⁴

In a different situation there are people who are informed about the end of therapy. During this time they undergo “mental disorganization” with intertwined feelings of fear, anger or despair. This is followed by adaptation to the new situation. Oncological patients, because of the therapy used, hope for recovery – sometimes, in the absence of effectiveness of one therapy, patients have the opportunity to switch to another, until the cure or inhibition of tumor growth and surgery. This perspective, even if they don't have enough information, usually increases their confidence. On the other hand, palliative patients do not undergo any therapies to cure them, because the condition of the disease does not allow it. Palliative care consists only of relieving symptoms. Despite this, while under the care of the hospice, patients are sometimes unaware that the therapy that was intended to fight the cancer was over. In some cases, the family also does not inform the patient about the cessation of treatment, which on the one hand would intentionally protect the patient from knowing his real state, while on the other hand, he can generate guesses about the state in which he is and, as a consequence, lead to anxiety.

¹¹ P. Salomon, *Psychologia w medycynie wspomaga pracę z pacjentem i proces leczenia*. Gdańskie Towarzystwo Psychologiczne, Gdańsk 2005.

¹² K. De Walden-Gałaszko, op.cit., s. 32.

¹³ Ibidem, s. 50.

¹⁴ J.Y. Wagner, A. Wuensch, H. Friess, P.O. Berberat, *Surgeon-patient communication in oncology*. „Eur J Cancer Care”, 2014: 23(5).

Anxiety has social dimensions and not all patients directly confess to anxiety. According to research, this is due to a lack of self-analysis, but also a shame before showing lack of courage. Talking about fear can indicate a lack of character, a lack of spirit to fight the opponent. The characteristic features identified with anxiety are: “using symbols, alleged carelessness, nonchalance” but also “accelerated pulse and breathing, nightmarish dreams or difficulty falling asleep”.¹⁵ Patients in conversation sometimes begin to confide in emotions with which they have never shared with anyone before. Usually they choose one person from their loved ones as a trustee. Some patients have a need to share their experiences with someone outside the family. Such a person can be a direct carer, or someone else (e.g. a researcher) who came to them, with whom they think they can talk about their needs, ailments and their own reflections. Appropriate communication with the patient is important to reduce the feeling of anxiety. Not only is it important when it comes to medical history, but above all as contact and creating a communication platform. Communication diagnoses patients' problems and needs, but also at least a bit of mental adjustment of patients. According to Janiszewska, “almost always communication is a central part of therapy.”¹⁶ The author also shows how to properly communicate with patients, from conditions for conversation to ways to summarize conversations.¹⁷

The very feeling of hope among patients when dealing with the disease situation seems very important, nevertheless, the importance of balance between hope and honesty in informing about the patient's actual condition should be emphasized, even among people under palliative care. Real information provided in this context is also an opportunity to plan the time left to those people as best as possible – to plan specific activities at the time when they will be able to perform them. There are also patients who need to maintain some ambiguity in information, if it can be concluded from the conversation that they need it. One of the patients during the interview admitted that he was aware that he was intentionally not informed by his family about certain situations so that they did not adversely affect the condition of the disease: *they do not tell me how something bad will happen there. Only after time. They know that I get angry and the pressure jumps and the nurses have a problem because it can't be calmed down. W35.*

Methodology. Qualitative studies, the results of which are discussed here, were conducted with patients under the care of stationary hospices or in home care. The total sample was 42 people – 25 patients in the facility and 17 people under home care. Patients were between 24 and 97 years old. Interviews were conducted from November 2018 to February 2019 in the Pomeranian Voivodeship – in 3 stationary hospices and in 2 home hospices. It should be mentioned that in one of the hospices there were interviews with stationary and home care patients. In the research IDI technique (in-depth interviews)

¹⁵ Ibidem, s. 35.

¹⁶ M. Janiszewska, *Umiejętności komunikowania się z chorym i rodziną*, [w:] *Medycyna paliatywna*, pod red. K. De Walden-Gałuszko, A. Ciałkowska-Rysz, Warszawa 2017, s. 46.

¹⁷ Ibidem, s. 47–48.

was used. Interview time, due to the specific research group, was not standardized and was between 7 and 58 minutes. This was due to the condition of patients who feel tired relatively quickly, have problems with the effects of treatment (connected apparatus that required constant monitoring), or have to take medication / have dressings changed. Prior to the interview, patients were asked to consent to the interview. At the beginning the interviewer informed about the recording of the interview in the form of audio, the purpose of the interview and where the transcript of the conversation would be used. Before each interview, the researcher had previously consulted with the interdisciplinary team the patient's condition and well-being, so that health conditions allow for free communication. In all discussed cases the patient's condition was defined as at least good/stable.

Fear of information: the words: “hospice”, “hospital”, “here”. Among hospice patients, the word hospice is not used, and the name was not used during interviews, because sometimes patients were not informed by relatives that they were in such institution. Prior to the interview, the staff asked not to use the term “hospice” or to use the name “hospital/facility” interchangeably. It seems that replacing “hospice” with another word may, in the intention of loved ones, protect the patient from probable shock related to information about the incurability of his illness. Hospice still has negative associations in society, evokes the attitude of being in a place from which there is no return.

The wife of one of the patients died in the hospice where the patient currently stays, which could have resulted in greater awareness of the patient's places: *And here we took her; here. She was here, she ended her life. In the hospice.* W9. One patient identifies the hospice with a type of substitute hospital. One where people require more intensive care. The patient is aware of the medical conditions with which people go to the hospice, also from the phenomena observed around them, but says: *Yesterday. at 8:00 o'clock he died. [...] They don't make it, they bring them here [...]. They just have to let them know that he'll be out of the hospital, because when they call the hospice so that it can be seen that he is going to the hospital, no? I bathroom and he is here, 8:00 o'clock and the end.* W9.

Among the patients are patients who deny the fact that they are in the hospice: *I think my daughter will also go to the hospital with her husband, she will stop coming. [...] Because she knows this scope of regulations a little and knows what to do. And he always sets me in favor of the hospital.* W10. They treat their stay as temporary or even temporary. In their actions and aspirations they settle in a home location. The patient says about her location and plans from the perspective of her permanent place of residence, and not her current place of stay: *yes, only that I have such neighbors, [...] they come to me, I look after all the time, I don't worry about shopping. Without a break, if not one is with me, the other is a neighbor; we have traffic all the time. So really ... it's the niece comes, one is the other, there is always someone hanging around at home. I don't have something that I'm afraid of, that someone won't come, that I'm*

alone. I am not alone. W1. There is a pressure on the temporary nature of the stay in the facility, it can also be seen in the plans for further actions and events that will take place: *"next year, maybe I will go [to my granddaughter's wedding].* W1; In the statements there is often a thread of rest, which one should, when a person is sick, and staying in a medical facility is a detachment from current activity: *In June we closed our activities and immediately found myself in this hospital, so that I didn't use much ...* W12; The patient points out that "here" is forced to rest, because: *"when it comes to here in the hospital, I do not have such great opportunities.* W14.

The emphasis on the place of stay – the hospital – is due to the fact that, unlike the hospice, it is associated with a place where you can regenerate and regain health: *it must be, I have to be here in the hospital, I have to heal if I want to live, it has be and already.* W1; Hospital is also associated with life. Another patient during the conversation assures that she knows that people who "get here" have good conditions: *In general, what to say here. The hospital is clean, I know people live here for a long time.* W8. The woman talks about her plans, which she intends to fulfill, when she leaves "from the hospital" because she will regain strength: *[...] I baked, I cook like that, all the time by the pots, the kitchen is just like the plans to go home from the hospital, then I'll make it, I do bigos.* W8.

Some do not use the word hospice or hospital. They just use the phrase "here/here" to specify their location. They use the phrase 'here' when talking about the city they live in, the apartment where they lived, and their current location. They do not want to distinguish these places, they rather unify them: *I used to watch more, and now it takes too much time for me, and man here, we women always have our work, washing, cleaning.* W16; *And then I worked here as a press press in a car [...] only one [talks about my son] lives here [...].* When asked about what the patient does every day during her stay in the facility she answers: *Such a normal life, nothing interesting is happening here.* W2, or yes, *I am prepared for everything, it's good here.* W15. The phrase "here" is also used in the context of failing to get to the hospice, with regret that the loved ones could not look after the patient at home: *because this was all the beginning, even my son put me in here, he had nothing to do, because I work, I am myself, my husband is not there.* W20.

There are also patients who use the word hospice, but this is rather done in the context of a palliative condition. They then juxtapose the concept of a hospice with oncology, as if assuring themselves of the development of a healing process, e.g. that they are going to go for a consultation to determine further treatment – in the hospice they maintain the thoughts that they have a chance to recover: *[...] because the kidneys stop working, something with the kidneys already, that's why I have a problem now with the kidneys and now I do not get chemistry for today, and I have my next follow-up visit in a week, I have to go to oncology and then the doctor will decide what to do next.* W4; *A neighbor helped, this lady helped, she helped with food and now that she wouldn't be because I was so weak, I was already so weak that I went to bed and slept, several times and this last time this lady Iwonka flew and my neighbor and I called my son to take care of the hospice.* W17.

One of the intentions of bypassing the word hospice in contact with the patient or placing it in a substitute sense seems to be concern for the patient's condition, his psychological and emotional comfort, which in effect causes the patient's information not to be informed about his condition. Patients sometimes do not realize but also seem to run away from the information that they are in a palliative care facility. As a result, it blocks potential reflections on the current situation of the patient, who thus remains in the area of ignorance and lack of opportunities to get used to reality, to reconcile with it. There is another effect of this state of affairs, withholding information may generate in the patient's suspicions or suspicions about the state of the disease, which, as a consequence, usually leads to an escalation of the state of anxiety and disorders in his body.

Loneliness. All examined patients, regardless of their condition or type of care, expressed the need to visit relatives. The differences appeared only in the assessment of the frequency of visits of relatives, which is appropriate for individual patients. Each of the patients spoke about the joy associated with the interactions that took place during the stay of relatives. It is about listening to joyful stories and sharing information about current events in their lives: *friends who come, say that they liked me, they lack my person [...] Now the grandchildren come to this and they like to be very much in company, and listen as parents talk and recall, and it's really fun. W2; Here, on Sunday, they came together, on this sofa, photos from all sides, I have on the phone. So that nothing decreases. W3.*

On the other hand, one can observe regret at the lack of visits or contacts of a specific nature. A young patient (24 years old, metastatic glioma), emphasizes how often she invited friends, but despite promises they never came to her. The patient feels lonely, and due to the lack of contact with peers (the disease appeared when she was in elementary school), she has so far lacked experiences that are characteristic of people in a given age group. It effectively reduces self-esteem and the patient cannot think about her strengths.¹⁸ There is also information about friends or family who had not previously dealt with patients in the terminal phase of cancer, that sometimes they do not know how to conduct a conversation, what topics to deal with, which may be the reason for avoiding contact.

However, the types of visits are uncomfortable when several patients come to the patients at the same time, and although no patient told the visitors about it so as not to hurt them, they feel very tired, confused, overwhelmed because the guests at the same time require concentration and ask a lot of questions. Patients, due to the excess of visitors sometimes experience physical ailments, have shortness of breath, feel more advanced disease or even clear weakness. Too frequent visits are also a lack of time to rest, regenerate: *I am glad that they remember me and think about me, but on the other hand I approach it in such a way that if there were less guests, a man would rest more. W19; [The number of visits] is enough, I would not want to anymore. Sometimes*

¹⁸ Lacey R.E., Kumaria M., Bartley M., *Social isolation in childhood and adult inflammation: Evidence from the National Child Development Study*, „Psychoneuroendocrinology” 2014, Vol. 50, ss. 85–94.

I also want to have some peace, I have my horrors on TV or “Wheel of Fortune”. W1; It doesn't bother me if they come in 2 months or in a month or twice a month. In fact, it doesn't really matter to me that I miss it or feel lonely there. W13.

However, some patients signal the need for frequent contact with loved ones. When they are not there or visits are rare, patients experience loneliness, longing, regret: *I tried so, nobody is interested in such Włodek to visit, talk. W10; Of course the worst is that a man works, I miss him more. I feel better when he comes [patient's son], he comes every day. W20.*

One of the patients describes his loneliness not because of the lack of visits, which he has many, but from the perspective of the lack of understanding of the emotional state in which he finds himself: *It is such a state, as if between two worlds. Nobody can experience this than the sick. And then you feel lonely, despite the fact that someone will visit, talk, joke. W29.* In his opinion, his relatives, despite showing interest in his condition, do not have the opportunity to empathize and understand what he feels. The patient is aware of this and misunderstanding increases his loneliness. After such visits, he is usually irritable, and thoughts about why he is under hospice care come back. A home care patient said directly how she feels every day since she was subjected to chemotherapy and then came under the care of a home hospice: *My friends do not understand this; Kaśka, what is difficult in dressing and going out? But I really don't even have the strength to shower and wash your hair. It may be weird, but it really is. I would like to go out with my younger daughter and buy her shoes, I would love to, but I will take a few steps and I feel exhausted. W34.* The patient at her own request is under the constant care of a psychologist, because, as she admitted during the interview, she feels the need to participate in family life and meet with loved ones, but because of her condition she feels an internal blockade that she cannot overcome.

Death. Patients in the home hospice do not have a disturbed sense of security from a perspective of the place and do not relate to the area – the space in which they reside. Usually these people stay in their apartment and / or with their loved ones. In this group, the security category was primarily associated with financial security – the option of paying bills, access to medicines, and ensuring current needs. In addition to the financial sphere, security is understood as maintaining a relatively stable life situation (without deterioration, deterioration of well-being). *This grandson 2 years and 5 months and grandpa come and grandpa come to this Ilawa. Today I went to the city to buy him a bike, a very talented kid. [...] Even I am afraid of how they will later explain to this kid how grandfather will run out. But they will have to come up with something. W3.* Patients also refer to the uncertainty of the disease state – the coming death: *I do not feel safe, I have fear, I am undergoing such anxiety, this strange feeling is, such a nervous anxiety, sometimes such scrapies take me without anything, something in connection with this disease, with these operations, so many operations I had, it all accumulates. W5.*

Some of the respondents, due to relatives who died of cancer, have somehow become accustomed to the situation of cancer and what is associated with failure in

treatment: *The youngest sister, 5 years younger than me, is now 8 years old, also cancer lungs died. And my brother also had cancer, but not lung cancer, he only found this cancer when he had liver metastases. And my mother also died of cancer, so it's genetic in our country.* W2. Others are fully aware of the disease situation. In their conversation, they showed peace telling about predictions for the future: *Now, the grandchildren come to this, and they like to be around each other very much, and listen to parents and tell and recall, and it really is fun. It is so festive, family-friendly and I think this will be the most for me ... but I believe that I will be there [after my death] with my loved ones.* W2; *And now these metastases have started so seriously, so to speak, and that's how it is.* W3.

During the interview, the patient talked about his ways of dealing with death fears: *I am aware of what can be done, I know. There is no great hope there, when. And because I don't know when, I don't get there a bit, unnecessarily. This is how it looks. I'll turn on the television. When I wake up at night and can't sleep, I play such pleasant situations from TV or something in my head. Until I sleep. And this is how it looks.* W3.

Patients are usually aware that they need holistic round-the-clock care: *in general, I already know that I already have ... I have already passed my life, I am already years old, 87 will be in May, as I say, I have already gone through a bit and I can't count on anything, I can count on it, you know, which [the patient points his finger at the ground]. And when this disease has pressed itself, I don't count on getting out of here anymore.* W9.

(No) permission to stay in a stationary facility. In most cases, patients in a stationary hospice were referred to the institution, because at home they did not receive or could not receive proper care related to the terminal stage of cancer (they lived alone or the family was unable to care for them). In this context, patients can be divided into two groups:

- Patients who agreed or opted for staying in a stationary hospice, on their own initiative,
- Patients who for some reason (e.g. unconsciousness) did not know that they would be in the hospice.

The first group that was aware of the referral to the hospice is satisfied with the care they have regarding the facility as a place to stay, including medical care, meals and other services (e.g. washing, changing bed linen). They claim that at home they would not be able to provide such assistance. In the hospice, they are constantly monitored by the staff, if necessary they can call for help (e.g. at the time of a dyspnoea) or ask for a specific service. Thanks to this, they have a stable sense of security.

The second group, although they usually do not contest the fact of getting to the hospice institution, because they are satisfied with the care, they are not very good at thinking about the reasons for their relocation to their hospice. They cannot accept the situation that the family rather mechanically – unknowingly directed them to the institution. In the conversation, they looked for motives for such action, while at the same time they were convinced that they had the right conditions to stay at home, and even that they should return there. They talk about the lack of participation in home events, the longing for loved ones who currently only visit them – they do not come

with them. They are sometimes confused, they feel regret: *So to speak, it is not for me what I am doing here. That I am lying, I am lying here too young, it is not agreed with me, and that they did it, it is difficult, because they were obviously right, they had to, because there was no other way.* W2; *And the fate that I came here because there is no one to look after me, so that I am here. I feel very well here, I have protection, I have everything. [...] And I am here, it is difficult. I have to accept this. Because I have a flat, but I have no care.* W7.

Conclusions. Patients in the hospice often feel alienated, and their statements and actions lack greater commitment to the reality in which they now find themselves. Our research reveals existential fears, which despite the involvement of the hospice staff are not fully reduced. It should be noted that anxiety is not a symptom that always recognizes itself correctly, because it is not the most important component of the set of symptoms that the patient has. On the other hand, fears always accompany a human being and are a normal, necessary element of our lives, something of a universal, fundamental and natural state related to human condition.¹⁹ However, they are a defense mechanism and usually accompany unwanted changes, thus creating individual adaptive barriers. One can say that fear is an evolutionarily developed emotional signal, a reaction to events perceived as threats.²⁰ Anxiety usually arises out of a sense of powerlessness in relation to the situation, including worrying, as well as a sense of rejection. One of the main possible causes of anxiety are unexpected changes in human life, such as: death of a loved one, or developing a serious (especially chronic) disease. These changes cause a need for sudden reorientation and adaptation to new conditions. In the case of disease states, anxiety is caused by the very experience of the disease and the side effects of drugs that are usually necessary (primarily painkillers) during palliative therapy. These events are accompanied by strong emotions, which, however, may subside and lead to a stabilized mood and increased acceptance of living conditions. It is related to the natural desire of man to seek balance and a sense of continuity of his own human life.²¹

We talk about adaptive disorders when the symptoms of anxiety still persist, even though some time has passed since the change in the situation of the individual.²² It is worth emphasizing that hospice patients often do not have the resources or sufficient support to overcome their fears and strengthen their sense of adaptation in new life conditions and circumstances. Their stay in hospice institutions is usually associated with emotional disorders that can turn into states of destabilization and depression, because anxiety may eventually make the individual unable to make contact with another person.²³ As

¹⁹ Whitehead T., *Pokonać lęk*, Warszawa Wydawnictwo AB, 1995, s. 5–21.

²⁰ Krynicki W., *Na początku był lęk. Teoria psychiki i zaburzeń psychicznych*, Wydawnictwo Adam Marszałek. Toruń 2007.

²¹ Erickson E. H., *Identity and the Life Cycle*, New York – London: W.W Norton Company, 1980.

²² Nitt D., Ballender J., *Anxiety disorders: Panic disorder and social anxiety disorder*. Published by Blackwell Publishing, Lundbeck Institute, 2005.

²³ Nowak A.J., *Identyfikacja postaw*. Redakcja Wydawnictw Katolickiego Uniwersytetu Lubelskiego, Lublin 2000, s. 208–211.

a result of fears patient may lose not only control over his inner life, but also against the world in which she lives. Antoni Kępiński has already pointed out the occurrence of the phenomena of waiting for final states, which are simultaneously devastating – having a direct impact on the health and life of the patient, indicating that degrading attitudes in terminal patients are becoming anxious.²⁴ In addition to medical supplies and care, it becomes necessary to focus on building good relationships in which the patient is still himself and feels that his identity is being respected. It is also worth realizing that the principles of shaping interpersonal interactions are increasingly recognizable by social sciences and can help build good relationships as well as emotional relationships in various life and institutional contexts giving participants a sense of satisfaction.

Medical staff-patient relationships must therefore change as these branch of science develop. It is necessary that doctors and nurses, in addition to medical knowledge, supplement and deepen their psychological and sociological knowledge. Medical staff usually know what they can offer the patient in the medical dimension, because somatic suffering is clear and painful, hence easier to define. It is much harder to understand and meet psychosocial needs that are extensive and evolving. Interaction with the patient during palliative therapy is not without tension and uncertainty, and patients and family directly signal doubts and negative feelings. In addition, the role of staff changes at particular stages of the disease – from support and assistance in accepting and understanding the situation, through profession education and supportive roles, working with attitudes and beliefs, and working with a family in mourning. Understanding the patient's fears and stress and making the right style of communication are one of the basic skills that will determine the effectiveness of professional behavior of doctors and nurses. This requires raising qualifications in therapeutic communication, developing the ability to recognize the patient's attitude towards his illness, and further developing an approach to this state of affairs with the patient. Each patient is, after all, a separate social unit, hence during hospice care we must leave his autonomy as long as possible and create an atmosphere of trust. It should be emphasized that although changes in human life occur from birth to death, despite these changes the individual has a sense of continuity: “the individual perceives himself as a changing whole, but can distinguish what is permanent and characteristic of him”.²⁵ Even in difficult health conditions do not cease to be yourself, a family member, specific community or professional group, which can be lost in the conditions of terminal illness. Cut off from information and released from all duties – efforts to organize his own life, the patient ceases to act as a responsible and independent subject and participant in collective life, which increases the feeling of anxiety and experiencing apprehension is transformed into constant anxiety tension.

²⁴ Kępiński A., *Melancholia*, Państwowy Zakład Wydawnictw Lekarskich, Warszawa 1979, s. 185.

²⁵ Stelter Ż., *Kształtowanie poczucia tożsamości przez dorastających niepełnosprawnych*, [w:] Polskie Forum Psychologiczne, tom 13, nr 1, Wydawnictwo Uniwersytetu Kazimierza Wielkiego, Bydgoszcz 2008, s. 24.

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