

# “Am I Going to Die?” Considering the Preparation for Research on an Example of Hospice Patients

**Weronika Kamińska**   
Medical University of Gdańsk, Poland

DOI: <https://doi.org/10.18778/1733-8077.20.1.06>

## Keywords:

Hospice; Patient;  
Dying; Research;  
Ethical Issues

**Abstract:** This article concerns the situations experienced by the researcher in one of the sensitive research groups—hospice patients. The article is based on the author’s experiences in three studies in Poland—94 in-depth interviews and observations in inpatient and home care hospices. Through the seven presented categories the author faced during the interviews, she analyzes the dilemmas of conducting qualitative research from a practical perspective. During studies, we learn about our preferences, sometimes defining ourselves on one of the sides—becoming a quantitative or qualitative researcher, thus deciding further scientific paths. Conducting qualitative research requires specific activities, including knowledge of the literature, selection of the proper method, and analysis of the research group (Silverman 2012). These principles turn out to be only the beginning of the process in which we intuitively, through trial and error, pave the way to deal with demanding situations, previously inexperienced emotions, coordination, and technical and ethical problems. Some studies require special preparation, particularly considering the specificity of certain research groups, such as hospice patients, who will face the dying process soon.

**Weronika Kamińska**, Ph.D. in Sociology, an assistant in the Department of Sociology of Medicine and Social Pathology at the Medical University of Gdańsk. Fulbright scholarship holder (2021/2022) and a “PhDo” scholarship holder from the Polish-American Freedom Foundation (2019/2020). In both scholarships, she carried out projects on the psychosocial needs of hospice patients. From 2022, the co-coordina-

tor of the Polish part of public health projects for the Polish Society of Health Programs (PTPZ) and the European Public Health Alliance (EPHA). From July 2023, a team member in the NAWA intervention grant “Improving Migrants’ Access to Information on Vaccines in the TriCity.”

**email address:** [w.kaminska@gumed.edu.pl](mailto:w.kaminska@gumed.edu.pl)

## Throw into the Deep End or Just Research as Usual?

At the end of one of the interviews at the inpatient hospice about the social construct of femininity, a patient in her 50s (cancer with metastases) asked me if I could recommend what dress she could wear for her godson’s wedding, which was to take place in two months. She spoke a lot about that upcoming event with great excitement. She wanted to look beautiful to hide the physical effects of the cancer (especially the ostomy pouch, which occupied a large part of the patient’s abdominal surface). I advised her, and we talked about various details of the outfit and how much the patient waited for the family to see how beautiful she looked despite cancer. The patient died in a week.

Learning the methods of conducting qualitative research (without diminishing the knowledge contained in methodological manuals) is really just the tip of the iceberg of what a researcher who wants to interview vulnerable groups, including hospice patients, will face. Most of the knowledge on how to conduct research is obtained by the researcher through experience, observations, and conversations with the hospice’s interdisciplinary team, families, and relatives of patients. It is not without significance that the researcher experiences their feelings and reflects on what has happened and what this situation can give, and, unfortunately, we will not read this in methodological manuals or guides on how to conduct qualitative research.

The article describes research experiences in a group of hospice patients, but it is also an invitation to discuss research with other sensitive groups. Hospice patients seem to belong to one of the most sensitive research groups, as they will soon face death, and perhaps they can already feel it is breath-

ing behind their backs. This makes it a challenge in the context of research preparation (methodological and ethical) to talk with dying patients. It requires ethical preparation from the researcher, including taking into account the sometimes rapidly changing well-being of the patient due to pain or difficult memories appearing in the mind, the ability to listen carefully, and paying attention and caring for the researcher’s well-being and feelings. The article aims to show and analyze real situations that the researcher has met during almost ten years of interviews and meetings with hospice patients, as well as to answer the questions on how to help researchers prepare before the fieldwork and what the researcher should expect or avoid.

## Hospice Care—Its Impact on Patients’ Everyday Life and Conducting Research

The concept of hospice care arose in the 20th century in London, creating universal principles still respected and developed worldwide (Osterweis and Champagne 1979; Magno 1990). They may vary between countries in the forms or methods of providing medical and non-medical hospice services, but the core of the idea has remained unchanged. Differences in forms of care usually result from the culture and prevailing medical system in which the dying patients are found (Doorenbos and Myers Schim 2004; Fosler et al. 2015). Hospice care belongs to the broader concept of palliative care and is its last part (Billings 1998; Hui et al. 2013). It is started when not only the undertaken anti-cancer therapies are ineffective for the patient but also the patient’s condition (wasting of the organism or progressive effects of the disease) is defined as impending death, most likely within the next six months of the patient’s life (Buss and Lichodziejska-Niemierko 2008; Yenurajalingam and Bruera 2016). Hospice care is focused on providing patients with, above all, multi-level

comfort—holistic care (Rickerson et al. 2005; Torpy, Burke, and Golub 2012). The patient's support, according to the guidelines of the National Health Fund in Poland, includes the control of pain symptoms, support in hygienic and care activities, as well as help to meet non-medical needs of patients (religious, spiritual, emotional, social, and psychological aspects). The comprehensive help provided in this way is intended to support the patient in a new and difficult life situation.

In Poland, hospice care is provided in one of the two main forms of care—inpatient and home care (Ersek and Carpenter 2013). Inpatient care is the placement of the patient in a hospice facility. In that way, patients are under the care of staff at all times. Inpatient care is usually primarily dedicated to patients whose physical condition requires constant monitoring and help. As part of this type of care, the patient can call for help at any time by pressing a 'button,' and then a person will appear within a noticeably brief time. This often gives patients comfort and a sense of safety. On the other hand, it deprives patients of privacy—they are constantly with 'others,' which is also compounded by the fact that hospices in Poland have rooms for several people. Because of this, patients often compromise when they need to watch a different movie than their companions or want to turn off the lights when other patients would rather read a book. It is even difficult when other patients who stay in the same room are visited by relatives, as this can generate discomfort, sadness, or frustration if other patients are not visited often.

The specificity of the place also affects interviews with patients. To be able to come to the facility, the researcher always called the hospice employee who previously agreed to cooperate in starting the

process. However, it often happened that when the researcher arrived on the spot, the patient's family was visiting. To not interfere in the meeting, the researcher started another interview with a different patient and returned later or conducted the interview at another suitable date. On one occasion, a patient was so excited about the upcoming interview at the agreed time that when the family unexpectedly visited the patient, the patient was angry at the family because, at that moment, she was focused on the interview, which put the researcher in an awkward situation. If there were more patients in the room at the time of the researcher's arrival, then, with the consent of the staff, the patient was offered a conversation in a gazebo, meeting room, or chapel (which was often a meeting place for the patient with a relative to have a private place to talk). Occasionally, there were patients in the infirmary who were unconscious or with a significant loss of awareness of place and time. At that time, the hospice team, including a psychologist, told the researcher that she could conduct an interview in the patient's room, and sometimes patients also liked staying in the room. During the interview, however, it happened several times that the other patient started talking to herself, calling out, and seeming to be talking to someone. The interviewed patient said that she got used to it, while the researcher had to make an effort to concentrate on the interview and not feel that the other patient needed help (the subject was also discussed with the interdisciplinary team).

In one hospice, the nurse took the researcher to the patient's room, who agreed to the interview. The researcher stayed with the patient in the room and started to talk about standard procedures related to data protection and archiving of research material. At one point, the patient looked at the researcher, exhaled, and froze. The researcher tried to ask the

patient a question, but seeing that he stopped moving and breathing, she ran to the nurse. It turned out that the patient just decided to play a trick, finding a good moment for it, and when the nurse came, he started talking and joking with both. The interview was successful—the patient told the researcher about how he was dealing with the impending death and about his relationship with his wife. This interview, however, was much more important, as a clever joke turned out to start the researcher’s reflections on what would happen if the patient died during the interview or if he died living alone in a home care during the interview. Although such a situation has not happened for so many years, it does not mean it could not have happened, which still raises big ethical dilemmas and fear.

Home care is dedicated to patients whose condition allows for independent functioning to a considerable extent or who can rely on family caregivers. At this point, the hospice staff visits the patients twice a week to prepare a proper dose of medications, take medical measurements (e.g., blood pressure or sugar level), as well as to make sure whether patients need any help, including non-medical support (Terrill et al. 2018). In Poland, in hospice home care, if necessary, the patient can also be visited by a psychologist cooperating with the hospice and a priest. The hospice provides medical support and helps with the rental of medical equipment if needed. However, patients’ free time during the day is determined by their sources (e.g., housing and financial conditions and support of relatives) (Abramson 2016; Carr 2016). However, if patients’ socio-economic status (SES) is low—with a limited budget that allows them to meet only basic needs—and they also live alone, the quality of life during home care may be unsatisfactory for the patients (Carr and Luth 2019; Clouston and Link 2021; French et al. 2021). The is-

sue of security is also important here. In the case of home care, the patients can call the hospice staff in an emergency, but they do not have the comfort that someone will appear at that very second (as in inpatient hospice). Thus, the risk of home accidents is much greater, especially if the patient lives alone (Oliver et al. 2013; Smucker et al. 2014). Another issue is the feeling of loneliness—if the patient’s relatives live far away or, due to their private situation, they cannot visit the patient often, this generates a sense of fear and loneliness, which may even intensify thoughts about death. Often, only visits by the hospice staff several times a week are not enough for the patient to reduce the feeling of loneliness.

Interviewing patients in home care looks slightly different. A crucial factor in conducting research is the safety aspect—for both the patient and the researcher. When patients invite a researcher to their home, they show great trust in both the staff and the researcher. Not knowing the researcher can cause discomfort, especially as some of the effects of the disease may make the patient appear weaker and more vulnerable in relation to the researcher. While conducting interviews in Poland, the researcher did not receive any preparation from the hospice about the risk of violence and the prevention of dangerous situations, which would result in protection for all groups (including personnel who agreed to the researcher’s contact with the patient). It relied solely on mutual trust between all groups, which initially caused uncertainty, especially when the patient lived in an unsafe neighborhood, or the meeting was held on the outskirts. It often happened that the patient’s family stayed in the other room. Sometimes patients in home care, to feel more comfortable, asked if the family could stay with them during the interview. At that time, the researcher assumed that the feeling of comfort in this situation was a prior-

ity, and if the presence of a loved one did not affect the patient's statements and the patient felt good to answer questions in front of a relative, then the researcher would respond to the patient's request. It was less safe when the patient lived alone. This triggered a first fear in the researcher that taking morphine would cause effects on the patient, who could behave differently or might potentially need medical help.

## Conducting Research and Its Ethical Dilemmas

These considerations are based on the researcher's experiences of conducting interviews in home care and inpatient hospices. For the analysis of the discussed phenomena, projects carried out in hospice care by the researcher were taken into account, which concerned conversations about patients' everyday lives, life experiences, identity constructs, or psychosocial needs of patients during hospice care. In this article, the author discusses collected experiences and events that significantly influenced the conducted research. It is therefore a collection of the researcher's reflections from the perspective of practical research among hospice patients. It should be noted that all interviews were conducted only by the researcher. So far, 94 interviews carried out in hospices in Poland in 2013 have been conducted with hospice patients of various ages (from 26 to 98 years) and with different SES. All interviews were conducted with the consent of the hospice management. The study involved patients whose disease state allowed them to talk freely and who agreed to the researcher's visit. During the interviews, patients could stop the conversation or pause at any time—about which they were informed before the interview, along with information on the purpose of the study and the form of data storage.

Despite the differences in age or the place of conducting the study, many situations during the researcher's contact with patients were similar and may be grouped into seven categories: *Building trust; Gestures and hugs during the interview; The appearance of the patient; The physical effects of the disease; Fainting, asking for help; Coordination of research with a sensitive group; Seeking reassurance and truth about the situation; Re-contact with the patient, commitment, and showing feelings.*

### Building Trust

What information the researcher obtains during the interviews is often determined by the extent to which they will gain the patient's trust (Jemielniak 2012). Building trust with the interviewer as a guideline may seem at first glance to be disingenuous in building a relationship (as it is necessary to achieve the intended goal). However, it is an important guideline if the researcher takes it seriously, as it determines what can be learned during the interview (Barbour and Schostak 2005; Dempsey et al. 2016). Building trust must, however, take place through the sincere intentions of the researcher because the patients can 'sense' the researcher's intentions and whether they care about getting to know the reflections and situation of the patient or if it is related only to the study conducted. It happens that during the interviews, the patients tell the researcher that they have never told anyone about certain emotions, and the researcher is the first person to hear about it. The researcher's assurance of the anonymity of the interview and the removal of information details that could cause someone to recognize the patients make them more open to sharing even the most sensitive and private life situations. Sometimes, a patient, feeling the researcher's sincere intentions, asks the researcher to use a specific quote from the



patient’s statement in a future article, which gives the patient a feeling that what they say is important and will be noted and remembered. It is sometimes salient for the patient and can bring relief in a situation of imminent death—*Because this is a story worth telling everyone.*

A principal issue in building trust during the interview was the encouragement that the patient may also raise topics that, in their opinion, are important and which the researcher may not include in the questions. It gave the feeling that the patient could also feel involved in the interview and not only answer the researcher’s questions. After the opportunity to tell the researcher everything important to the patient, they can also feel that what was said was gripping and important for the researcher. It sometimes happened that the patients, even after the interview, asked for a moment of conversation with the researcher to say something else, or during the next visit, they gave the researcher notes about life in the hospice, thus feeling that they were fulfilling a ‘quest’ for the researcher to get to know even more pieces of the reality of life in a hospice: *This is homework for you. These are the notes that I took daily when communicating with staff and other patients.*

Such gestures show how much trust building is salient not only for the researcher but also helps patients—they begin to feel that they can be guided in the context of reality, through which the patients had the impression that it deprived them of self-determination. It also manifests the important role of feeling to be heard.

### **Gestures and Hugs During the Interview**

Hospices are places where, apart from medical support, emotional, psychological, and spiritual help

is also important. As a result, in hospices, there are often different relationships between staff and patients, much closer than in hospitals or other medical facilities. Patients can always count on words of support or hug people with whom they have contact. Both in the US and Poland, it has been seen that touching the shoulder or hugging are essential elements in contact with a hospice patient. It very often happened that during the interview, the patient needed to touch the researcher’s arm or hug her at the end of the interview. On the one hand, the patients were used to this expression of emotions, and, on the other hand, these situations proved that during the interview, the patient felt that the researcher was an important person at that moment. This feeling was also intensified by the fact that the patient often shared with the researcher important personal thoughts, and the hug was a ‘thank you’ for the meeting, emphasizing the importance of the interview for both of them. However, it was seen that the expression of emotions was much greater for female patients. Female patients were more likely to hug the researcher, whereas male patients were much more reserved about expressing their feelings, reducing them to gestures such as grabbing the arm. Not sharing this kind of gesture by the researcher could cause a feeling of incomprehension by the patient or even a feeling of rejection, thus affecting the patient’s well-being. Perhaps the female gender identity played an important role in referring to the researcher in this way—if the researcher had been a man, maybe the patients were not so willing to hug, and the relationship between the researcher and the patient would have been different. This is undoubtedly a topic that needs to be explored further in further research.

Knowledge of the rules of the culture of the place can significantly affect the creation of trust and rela-

tionship with the patient and can also help avoid potential misunderstandings or unpleasant situations. When entering the research field, it is worth asking people who introduce us (e.g., nurses or psychologists about their contact with patients and what the researcher can expect), which will help in preparing for interviews.

### **The Appearance of the Patient, the Physical Effects of the Disease**

Hospice patients sometimes have visible physical effects that their disease has left on them. Before starting research on a specific research group, the researchers must ask themselves whether they are afraid of views related to body deformities, lack of a limb, or visible wounds. Lack of reflection on this situation before starting the study can cause unpleasantness for both the researcher and the patient. One of the patients told the researcher that once, during bath time, a volunteer helped with these activities. Looking at the patient's wound, the volunteer vomited. From that moment on, the patient was afraid of further contact with volunteers, even during other situations (apart from hygiene procedures), such as spending time together in the garden or watching a movie. The patient said that this situation made her wonder if it also disgusted other people, and for some time, she began to isolate herself from people in the hospice.

Patients who are aware of changes in their appearance tend to be sensitive to how they are perceived by the environment. One of the patients had an extensive tumor covering a large part of the face, which meant that during the day, the patient had to hide defects in the skin (no cheek and lack of parts of the nose and mouth) under a dressing. The patient said he knew perfectly well when someone was dis-

gusted with his appearance, dodged to sit next to him, or did not want to look at him. The observation of the patient that the researcher was unconcerned about his physical defects was a relief for the patient and made him freely express his emotions or talk about how he coped with the physical effects of cancer and impending death. Interestingly, seeing that their condition did not make a negative impression on the researcher, the patients often directly communicated to the researcher their surprise, telling about the unpleasantness they experienced from other people in the context of their physical appearance. Concerning the patient's sense of social isolation, it was especially important for the patient to find someone who treated him as if he looked like before the disease as if his visual appearance did not matter.

It also often happens that patients treat the researcher as a specialist and a person with whom they would like to share literally everything in the context of the disease. There were many times when the patient showed the researcher a stoma pouch, an unhealed wound after an amputated limb, or fresh cavities after surgery on the patient's head. Patients showed their wounds to express more clearly what they must face and how much physical ailments determine their quality of life. There were also situations in which the patient checked the current content of the catheter bag in front of the researcher or the level of the exudate from his wound on the abdomen. It also happened that the patient spat out various secretions into the bag or container. These situations happened without prior information from the patient, so the researcher could not be prepared. The researcher was often treated by patients as part of the hospice team—who, with the patient's consent, referred the researcher to a meeting at the patient's home or in an inpatient hospice. Therefore,

accustomed to the fact that their situation did not require any embarrassment in contact with the hospice staff, they did the same with the researcher, treating her as part of the hospice team. Moreover, perhaps they even felt obliged to show the researcher the whole situation of their illness and ailments as an essential part of their everyday lives (they assumed it was an important part of the study).

In this context, the information from the staff about the patient's specific physical condition was helpful for the researcher to prepare her so she could 'get used to' what she might expect before the visit. During long-term cooperation with the hospice staff, it sometimes happened that the staff asked the researcher whether she would like to talk to a specific patient if the nurse or psychologist thought that the patient's condition could somehow adversely affect the researcher.

### **Fainting, Asking for Help**

During the study, the researcher should constantly be aware of the nature of the research group and the consequences that the patient's condition may have. Patients in hospice care are often in a condition that can change rapidly or involve sudden alarming situations. Even when the staff stated that the patient's condition was adequate for communication with the researcher and the patient has agreed to meet the researcher, there are situations when the patient may faint during the interview. Then, the question arises as to how the researcher should react. Without medical education or voluntary training, it is difficult to have the reflex to help a patient when it unexpectedly happens. The researcher usually does not know how to help, what the help should look like, and what help the researcher can provide (or whether they should help). It is also important where the sit-

uation takes place. In a facility, the researcher has the comfort that, in case of an unexpected situation, she can count on the staff's help—she can call someone at any time, who will be able to react quickly. During the interview, the patient lost balance several times while walking or standing up. Each time, the patient was grasped, or the patient leaned on the researcher's arm, which prevented a fall. If there was a situation where the patient fell, it could be difficult for both of them and cause remorse in the researcher and fear that something could have been done differently. There were also times when the patient dropped a cannula, part of the drip mechanism, or other medical equipment during the interview. At such moments, the researcher was asked by the patient if she could put the mechanism back in. Fortunately, due to the researcher's parents' profession, she knew that she had no right to help the patient in such situations because the wrong application of the equipment could cause the patient's death. However, it is unimaginable if the researcher did not have basic knowledge about helping the patient and wanted to interfere with medical equipment even with a sincere willingness to help. Another quite specific ethical situation during interviews in inpatient care was that in the case of bedridden patients, with whom it was impossible to have an interview in the living room, patio, or chapel, there were other patients in the same room. Although they were at such a distance that allowed them to talk freely with the researcher (sometimes patients were additionally separated by a screen), in the case of the confused and problematic patients, they made communication with the researcher difficult. For example, there have been occasions when another patient lying on the bed started screaming frightfully. It was often an inconvenient situation. Initially, the researcher asked the patient whom she interviewed what action was usually taken. When the patient said that



this was normal behavior of the patient and the nurses asked him not to call in such a situation, the interview was continued. However, it happened that the situation was sudden, and the confused patient showed pain or anxiety in a way that required the researcher to call a nurse to administer proper medications to the patient. Such situations cause fear and confusion—what was normal for the staff and did not require any intervention from the researcher often was a patient's cry for help, and the information about ignoring the patient's screams and continuing the interview was awkward and gave the researcher a feeling that she must do something or help this person. On the other hand, it also required concentration to continue the interview with the patient during the screams of another patient and to focus on the interviewed patient then so that they did not feel that what they were saying was ignored. Often, to ease the event, but also to not leave the situation without discussion, the researcher asked the patient about their comfort in the room, relations with other patients, or what every day in the room looks like. At that time, patients often talked about their relationship with other patients, sometimes saying that they took the role of a mediator or caregiver for the patient in their contact with the staff, or they said that sometimes the patient begins to communicate with them. Directing the conversation in this way blurs the first awkwardness in the researcher and patient about the other patient and causes further focus on the interview.

### **Coordination of Research with a Sensitive Group**

Conducting research with a vulnerable group must include undertaking a specific research concept—including a material collection plan. Usually, when the researcher determines the next research steps, they have to define a timeframe for conducting the re-

search. The researcher also wants to have an impact on figuring out the coordination of the interviews, as it also affects the reconciliation of project activities with other scientific or personal life of the researcher. The specificity of research with hospice patients can cause the researcher to not predict when the interviews will be finished, which requires setting up a time reserve for this purpose. What is more, the researcher cannot predict whether, by arranging several interviews on a given day, she will conduct any. The ethical aspect is significantly bound to issues concerning finding contact with the patient. For example, the researcher was going for interviews at an inpatient hospice several dozen kilometers away from her place of residence. She was informed that three patients had initially agreed to contact and that it would be best to come to the facility within a few hours. In the facility, however, it turned out that one of the patients experienced intense pain, the other fell asleep, and the third felt bad at that moment. It should be remembered that during the research with patients in a hospice, respect for the patient and their situation (illness or imminent death) is the most important. Apart from asking about the possibility of conducting the interview, the researcher has never encouraged the patient to the interview, ensuring that the interview would be nice or short, as it would violate the ethics of conducting interviews. Such situations occur most often in inpatient care. Getting used to the fact that the joy of the information about the interviews can turn into disorientation and sadness when, after arrival, there was no way to do any, helped to understand the differences in hospice care. Inpatient hospice is usually for patients who, for several reasons, cannot stay at home. In this context, they often have deteriorating health conditions requiring 24/7 monitoring by staff. Thus, by definition, the facility includes patients with more severe, rapidly changing health conditions. Realiz-

ing this resulted in a lack of focus on conducting a certain number of interviews during the stay in the hospice. However, there were also situations where, after the researcher arrived at the hospice, another patient, hearing that it was possible to talk to the researcher, reacted with interest, asking for details and consented to the interview.

The researcher can intuitively get the impression that in inpatient care, due to a large number of patients in one place, this part of the interviews can be conducted much faster than interviews in home care. Still, it was influenced by so many factors (a large number of patients in very poor condition, time of the day of the interviews [evening interviews usually did not take place, but only those conducted in the morning], season, or the upcoming holidays) that this was not the rule. There were places where the researcher conducted five or six interviews at one visit, but usually these were smaller numbers. It should also be noted that the topics and experiences of patients may be significantly burdensome for the researcher, which, with many interviews, could be even more aggravated. This could affect both the quality of the interviews and the well-being of the researcher after leaving the hospice. Contrary to inpatient patients, in-home care pre-arranged interviews were not conducted in only a few cases—they were usually postponed to another day at the patient’s request. As mentioned before, home care patients often did not need round-the-clock care and were also in a condition that allowed them to continue their daily activities or duties from the time before the disease. Due to this, when scheduling an interview in home care, they were usually carried out the first time without interruption. Perhaps it was also influenced by the fact that by inviting the researcher, the patients had a sense of responsibility or obligation for the meeting to take place.

The researcher’s mobility and allowing herself to appear as soon as possible were of immense importance in planning interviews with patients under the care of the hospice. As mentioned previously, it was seen that at certain times of the day or seasons of the year, the interviews were almost non-existent because the patients were more occupied with visiting their family and daily duties, or they felt tired. Regardless of the researcher’s will, if she had not been able to show up quickly, the interview would not have happened. Two issues arise in this context. If the researchers want to conduct interviews in hospices, they must be in constant contact with the designated staff member. Refusing to visit a patient several times who initially agreed to meet with the researcher would undermine the trust of the staff member and the researcher could expose the patient to sadness, who, after being informed about the possibility of an interview, could impatiently await the researcher’s presence. There is an opportunity to set up availability, but the researcher would not have a guarantee that someone would agree to the interview at that time. The help from the hospice staff is a huge favor and should not be abused.

Healthcare research was significantly influenced by the COVID-19 pandemic. At that time, hospices changed their rules about visiting patients by their relatives or contacting volunteers, which has always been an immense value of hospice care. Relatives were only able to bring things to patients, which were then quarantined. Relatives contacted patients only by phone or video calls. Sometimes it happened that relatives could see the patient through the window glass in the patient’s room. Even in the situation of the patient’s active dying, the family could not be with them in these last moments. The pandemic also inhibited the possibility of conducting scientific research in direct contact with the patient or visiting

medical facilities. This resulted in the inhibition of new scientific research, as well as the interruption of existing ones. Initially, the researcher offered the hospices the possibility of conducting interviews in the same way as family meetings—via a video chat, but, due to the inconvenient situation, stress, constant fear, and added duties of the staff, cooperation was refused until the number of COVID-19 infections was reduced and restrictions lifted. Even when the statistics of new cases decreased and the isolation ended, the return to research was slow, and maximum precautions were needed each time when contacting patients—protective masks, temperature check, keeping distance, or conducting an interview outside the facility, in the open air. Some hospices, even for a long time, despite the possibility of visiting relatives and restarting volunteering, were not favorable to scientific research due to the safety of patients.

### **Seeking Reassurance and Truth about the Situation**

During the research, some patients were not fully aware of how serious their health condition was. Sometimes, they consciously dismissed the disturbing signs about the possible bad ending of the neoplastic disease. Even though the patients knew what the study was about and what the researcher was going to be asking, they sometimes seemed to be deliberately ignoring the fact that their death was imminent or that it could happen at any time. Some of them, as mentioned in the introduction to this article, talked about their plans for the next months, giving them importance and waiting for these events. During the interviews, the following principle was followed—not to cause strong (especially negative) emotions in the patients and not to reveal information to the patients that may adversely affect

their condition and well-being. Therefore, if the patients were convinced that they would return home soon and were occupied with what they would do then, the researcher did not move them out of this state. Initially, the researcher struggled with the sense of meaning in the research and doubts whether to research a group of hospice patients. However, the understanding that in this way patients try to take part in the present reality, or they begin to define the world in their own way, the researcher realized that this is their way of dealing with reality, regardless of how patients understand it and how do they want to understand it (what thoughts and information they admit to each other). The most morally painful for the researcher, however, was when the patients tried to involve the researcher in conversation about their plans—when they asked the researcher for advice on clothes, decorations, or opinions about the painting they wanted to buy and hang after coming back to their home from hospice. The awareness that the patient's plans would not come true, which the researcher had to hide, was very painful. Especially when, during later visits to the facility, it turned out that the room where the researcher talked to the patient a few days ago had another resident (the previous patient died). An example of this is a woman in her thirties who told the researcher that she wanted to gain strength in the hospice to help her parents organize the Holy Communion of her 9-year-old daughter in May. The sight of another patient in the room where the patient was lying before will always be painful.

Sometimes, even though the patients are aware of the impending death and talk freely about it with the researcher, the feeling of empathy for the information they hear can cause many emotions in the researcher. One of the patients told the researcher that before the interview, he had been in a shop

to buy his youngest grandson a bicycle and teach him how to ride a bike. The patient was aware that he had little time left, but expressed the hope that, at least, he could give his grandson this bicycle as a gift. Then he said that he was not afraid of death but of how his son and daughter-in-law would be able to explain to the patient's grandson that his grandfather was dead.

During the research, there was a group of patients who had not been informed by their relatives that they were in a hospice and that they had already completed cancer treatment. It often happened that the researcher was informed about this fact before the meeting with the patient. The patient's family would then notify the researcher in the corridor of the facility or at home, asking the researcher to not use the word "hospice." Putting the researcher in such a situation caused an ethical dilemma about the rightness of starting the interview—abandoning the patient who waited for an interview could constitute a greater ethical issue. Reflecting on such situations, however, it was noticed that these patients are also an important part of hospice care, regardless of whether they were informed that they were under the care of a hospice or would receive such information somehow from their family. Even though the researcher was allowed to ask the prepared questions, she felt stressed each time to not accidentally reveal to the patients that they were under the care of a hospice. During one of the visits to an inpatient hospice, the researcher was introduced to the patient by a hospice psychologist. At the beginning of the interview, the patient asked the psychologist directly: *Am I going to die? Because here you must wait for death, right?* As it turned out during the interview, the patient recently discovered that she was under the care of a hospice, and perhaps through that question, she wanted to be assured about her sus-

picious about the truth of her condition. The patient received real comfort from the psychologist and, at the same time, information that her condition may bring death, but it may be a closer or very distant event. Another patient, ninety years old, talked about her life, mentioning her grandchildren and great-grandchildren during a conversation with the researcher, then looked at the researcher and said with tears in her eyes that she did not want to die, thus shedding a few tears. In such situations, the researcher tried not to continue the topic but to leave the patient a decision at what point they wanted to stop talking about unpleasant emotions, so they did not feel ignored when opening up to the researcher. It was a solution tested by the researcher several times, and she received many thanks from patients who were surprised that, for the first time, someone wanted to hear them. At that time, patients often called the interview a kind of catharsis—cleansing of all thoughts and fears, which, due to their condition, they had in themselves and which, for assorted reasons, they did not want to expose during conversations with their relatives or hospice staff.

### **Re-Contact with the Patient, Commitment, and Showing Feelings**

A big dilemma was the risk of engaging in contact with the patient through the patient's life history. A psychologist from one of the hospices was also consulted on this matter. She did not see any contraindications for contact with the patient after the interview if the patient expressed such a willingness, although, as the psychologist noted, it should be considered whether such contact would be burdensome for the researcher. It was, therefore, concluded that it would be best for both sides to re-contact at the facility only with a warm welcome. As a result, neither the patients would feel uncomfortable know-

ing that they were talking to the researcher about private stories and reflections, nor the researcher, considering her role (professional approach to being a researcher) but also her protection against the patient's death. Engaging in relationships with patients during interviews to receive information about their death would be a difficult experience for the researcher. In this context, it was also avoided when talking to the staff to not accidentally find out that the patient was dead. It was different in the case of interviews at the patient's home, where the researcher visited the patient only once, which made it possible to avoid uncomfortable or sad situations.

Another doubt during the interviews was the issue of showing/not showing emotions by the researcher. This raises questions of: 1) patient protection; 2) research professionalism; and 3) the researcher's expression as an individual feeling emotions back. Not showing emotions (or not overexposing emotions), the researcher would protect the patients so they would feel comfortable during the interview. This protection is also intended to prevent patients from generating many emotions that could cause them distress and incite the risk of leaving the patient alone with these reflections after the interview. Expressing the researcher's emotions or shedding a tear could cause the patients to be confused. On the other hand, it could cause a sense of guilt in the patients that they exposed the researcher to negative emotions, or the patients might realize that what they were telling was even more sad than they might think, which would escalate their malaise about health condition and imminent death.

Not showing emotions can be perceived as professionalism and preparation by the researcher. Self-control may allow the researcher to fully concentrate on the situation of the interview and the

patient, whose reflections are very important to the researcher. On the other hand, the conscious blocking of emotions can pose a threat—suppressed emotions can cause frustration, but also a sense of guilt. They can affect the well-being of the researcher. In this context, in conducting qualitative research with a sensitive group, it becomes necessary to prepare the researcher to work on emotions, especially those with which the researcher deals during the interview with the patient and which they feel (or may feel). In conducting research with hospice patients, many different emotions can appear during one interview—from joy to crying and fear. These emotions often also have a feedback effect on the researcher who, experiencing them with a certain intensity, without being in the patient's situation, has to deal with them.

## Summary and Invitation to the Discussion

As shown above, when researching with a group of patients under the care of a hospice, the researcher must not only have workshop skills allowing for independent work on the research. The established principles of research methods turn out to be highly insufficient. When working with a sensitive group, it comes to light that the researcher's soft skills, knowledge of the environment, and preparation for the specific situations of the selected research group are equally important. Moreover, these skills can sometimes be deciding factors in whether the study will continue. The examples presented above show that the response to certain situations must be learned, and sometimes it is also necessary to 'get used to' the environment the researcher enters. If the researcher had prior knowledge of what to expect, they would know how to influence the comfort of both the patients and their own during the



interview. Then, many worries or stresses that arise during and after contact with the patient could be avoided. The discussed experiences appeared over the years of research work in the group of hospice patients. When the researcher was convinced that nothing more could surprise her during this type of project, something appeared that forced the researcher to stop and wonder why it happened, why the researcher felt such emotions at that moment, and what could help in such a situation. It should be emphasized that this is not a complete list of experienced situations—there were more. However, it is a description of the most common or difficult events that the researcher had to deal with. The selected examples aimed to show what situations, in the researcher’s opinion, can help students and researchers who intend to start this type of research.

Hospice staff often see the researcher as a professional. A person who can handle any information they receive during her stay at the hospice. By this, staff can ‘sense’ if the researcher is ‘their’ person, if they can speak the language of the industry, and if the researcher understands the ‘codes’ used by the staff. The interdisciplinary team usually assumes that since a researcher deals with the research about hospice patients, they have basic knowledge not only in their discipline but also of patient care. Communicating with the jargon characteristic of hospice staff can help not only to better understand the reality of their work and place but also ease setting up relationships.

The presented situations raise questions about the validity of researching a sensitive group of hospice patients. Some authors analyzed from the methodological or ethical perspective the rightness of investigating hospice patients. Among the doubts, respect for the situation of approaching death was

analyzed (Raudonis 1992). Clarification of moral issues was also important, including the use of patients to obtain research material and who is to decide whether a patient can participate in an interview (Addington-Hall 2022). As Sandra Pereira and Pablo Hernández-Marrero (2019) note, “excluding vulnerable patients from participating in relevant research could suggest that society is failing in its obligation to improve high-quality, evidence-based healthcare due to misguided paternalism.” However, it should be remembered that in studies with palliative and hospice patients, time and changing disease status play an important role (Wilkie 1997). Being guided by the patient’s welfare or simply ‘using’ the patient’s situation may be questioned. Ashley Wohleber, Daniel McKittrick, and Shawn Davis (2012) noted that it is also questionable that research on hospice patients may take up their time, which they do not have much left. On the other hand, the omission of hospice patients for moral reasons and whether it is appropriate to meet the patient for an interview during impending death leads to the omission of an important voice of people who also struggle with other experiences such as difficulties in obtaining support and quality care, a sense of social exclusion, and misunderstanding caused by not raising topics related to death and dying in the social arena. Therefore, the solution to the dilemmas considered, including the issue of researching a group of patients in hospices, may come down to the need to start a conscious discussion among researchers on how to prepare for this type of research to be able to resolve as many dilemmas and ethical doubts as possible and to question the sense of conducting such research in general. Examining the effects of conducting research with palliative patients, Marjolene Gysels, Cathy Shipman, and Irene Higginson (2008) noted that respondents stated the interviews were therapeutic for them and their fam-

ily members. The possibility of telling a life story also plays an important role (Sivell et al. 2019). However, this position of patients may change due to the well-being and medical condition of the patient (Sivell et al. 2019).

The second thing is that when research is carried out with a sensitive group, their ethics are primarily related to the interviewee. However, there is no ethical care for the researcher. In studies involving sensitive research groups, care should be taken not only for the comfort of the subject but also for the researcher. The latter is often forgotten as it is the researcher who wants to conduct interviews as part of the project. The researcher is expected to adjust. This approach affects the quality of the study, resulting in discouragement, fear, and trauma. The researcher is someone who will probably meet the patient only one time. From an ethical perspective, it is better, and also because of the probable imminent death of the patient. However, each patient's situation is different. Sometimes the researcher learns things that the patient has only told them, not the family or the hospice team. Several aspects are important here: (1) the individual predisposition of the researcher to conduct this type of research. If the researcher is a young person, inexperienced in conducting research, or not having previously dealt with hospice patients, such research may prove problematic for the researcher or even cause trauma. Then, the researcher should consult someone about whether they are ready to start research now and what situations they may face. (2) It would be worthwhile for the researcher to be offered the support of someone, for example, at the university, who specializes in research on a sensitive group and who could provide the researcher with (ethical or personal) support and mentoring during the research. There are many situations during research that we

are unable to predict. It may happen that, despite preparation, the story of one of the patients speaks to the researcher so much that they will not be able to distance themselves again. It can happen regardless of the research experience and at any stage of the research or the scientific path. It is important to have someone who can help process the situation, define it, and find its meaning, which could help the researcher move on. In working through these emotions, regular supervision conducted by professionals may be a crucial help, which would guide the researcher in understanding these experiences. (3) Research with a sensitive group may, to some extent, affect the personal life of the researcher. The more difficult the study, the more it can absorb our thoughts at work and in our free time. This constant commitment can cause a scientific burnout.

These situations may cause researchers to hesitate or not research on a sensitive group, or study it largely intuitively, based on their trial and error method. Researchers are also often ashamed to talk about dilemmas, deep reflections, or stories that they collect and believe it is not proper and that they will be unprofessional in front of their colleagues. They are afraid of being criticized and exposed to their feelings and thoughts. It would be important to implement in institutes thematic meetings related to ethics in research on specific examples of research with vulnerable groups. Communicating to students and researchers what problems the project leader is dealing with could become an invitation to discussion and an opportunity to analyze the solution to the problem. In addition, it could also become the beginning of openness in admitting that such problems exist, which, at first glance, is often taboo in the academic world. Private doubts and embarrassing events occurring during the study are not discussed, and mention-

ing them is made only in secret as the researcher can share such information only with a few trusted people. It gives the constant feeling that the researcher should always behave like a professional and that it is not proper to talk about problems other than logistic or substantive. The researcher's experiences that affect them directly as a human seem to be out of place here, escalating the feeling that these experiences happen only to them, and they must deal with them. It would be recommend-

ed to create materials or a textbook based on real experiences, which could help both the researcher and the research group—to counteract uncomfortable situations and negative emotions. There is no preparation, ready-made training, manuals, or checklists that could help researchers to implement and work through potential problems that may be met during the study, and that will help in some sense considering what the researchers will see and what they will experience.

## References

- Abramson, Corey M. 2016. “Unequal Aging: Lessons from Inequality's End Game.” *Public Policy & Aging Report* 2016:1-5.
- Addington-Hall, Julia. 2022. “Research Sensitivities to Palliative Care Patients.” *Cancer Care* 11(3):220-224.
- Barbour, Rosaline S. and John Schostak. 2005. “Interviewing and Focus Groups.” Pp. 41-48 in *Research Methods in the Social Sciences*, edited by B. Somekh and C. Lewin. London, Thousand Oaks, New Delhi: Sage Publications.
- Billings, J. Andrew. 1998. “What Is Palliative Care?” *Journal of Palliative Medicine* 1(1):73-81.
- Buss, Tomasz and Monika Lichodziejska-Niemierko. 2008. “Opieka Paliatywna W Polsce – Od idei do praktyki (również lekarza rodzinnego) [Palliative Care in Poland—From Idea to Practice (Also Family Doctor)].” *Forum Medycyny Rodzinnej* 2(4):277-285.
- Carr, Deborah. 2016. “Is Death ‘The Great Equalizer?’ The Social Stratification of Death Quality in the United States.” *The Annals of the American Academy of Political and Social Science* 663(1):331-354.
- Carr, Deborah and Elizabeth A. Luth. 2019. “Well-Being at the End of Life.” *Annual Review of Sociology* 45:515-534.
- Clouston, Sean A. P. and Bruce G. Link. 2021. “A Retrospective on Fundamental Cause Theory: State of the Literature and Goals for the Future.” *Annual Review of Sociology* 47:131-156.
- Dempsey, Laura et al. 2016. “Sensitive Interviewing in Qualitative Research.” *Research in Nursing & Health* 39(6):480-490.
- Doorenbos, Ardith Z. and Stephanie Myers Schim. 2004. “Cultural Competence in Hospice.” *American Journal of Hospice and Palliative Medicine* 21(1):28-32.
- Ersek, Mary and Joan G. Carpenter. 2013. “Geriatric Palliative Care in Long-Term Care Settings with a Focus on Nursing Homes.” *Journal of Palliative Medicine* 16(10):1180-1187.
- Fosler, Laura et al. 2015. “Cultural Differences in Discussion of Do-Not-Resuscitate Status and Hospice.” *Journal of Hospice & Palliative Nursing* 17(2):128-132.
- French, Maddy et al. 2021. “Exploring Socioeconomic Inequities in Access to Palliative and End-of-Life Care in the UK: A Narrative Synthesis.” *BMC Palliative Care* 20(1):1-20.
- Hui, David et al. 2013. “Concepts and Definitions for ‘Supportive Care,’ ‘Best Supportive Care,’ ‘Palliative Care,’ and ‘Hospice Care’ in the Published Literature, Dictionaries, and Textbooks.” *Supportive Care in Cancer* 21(3):659-685.
- Gysels, Marjolein, Cathy Shipman, and Irene J. Higginson. 2008. “Is the Qualitative Research Interview an Acceptable Medium for Research with Palliative Care Patients and Carers?” *BMC Medical Ethics* 9:1-6. Retrieved November 24, 2023 (<https://bmcmethics.biomedcentral.com/articles/10.1186/1472-6939-9-7>).

Jemielniak, Dariusz. 2012. *Badania jakościowe [Qualitative Research]*, vol. 1. Warsaw: Wydawnictwo Naukowe PWN.

Magno, Josefina B. 1990. "The Hospice Concept of Care: Facing the 1990s." *Death Studies* 14(2):109-119.

Oliver, Debra et al. 2013. "Patient Safety Incidents in Hospice Care: Observations from Interdisciplinary Case Conferences." *Journal of Palliative Medicine* 16(12):1561-1567.

Osterweis, Marian and Daphne S. Champagne. 1979. "The U.S. Hospice Movement: Issues in Development." *American Journal of Public Health* 69(5):492-496.

Pereira, Sandra and Pablo Hernández-Marrero. 2019. "Research Ethics in Palliative Care: A Hallmark in Palliative Medicine." *Palliative Medicine*. Retrieved November 24, 2023 (<https://journals.sagepub.com/doi/10.1177/0269216319827178>).

Raudonis, Barbara. 1992. "Ethical Considerations in Qualitative Research with Hospice Patients." *Qualitative Health Research* 2(2):238-249.

Rickerson, Elizabeth et al. 2005. "Timing of Hospice Referral and Families' Perceptions of Services: Are Earlier Hospice Referrals Better?" *Journal of the American Geriatrics Society* 53(5):819-823.

Silverman, David. (2010). *Doing Qualitative Research*, 3rd ed. Los Angeles, London, New Delhi, Singapore, Washington: Sage.

Sivell, Stephanie et al. 2019. "Considerations and Recommendations for Conducting Qualitative Research Interviews with Palliative and End-of-Life Care Patients in the Home Setting: A Consensus Paper." *BMJ Supportive & Palliative Care* 9(1):e14.

Smucker, Douglas R. et al. 2014. "Patient Safety Incidents in Home Hospice Care: The Experiences of Hospice Interdisciplinary Team Members." *Journal of Palliative Medicine* 17(5):540-544.

Terrill, Alexandra L. et al. 2018. "Positive Emotion Communication: Fostering Well-Being at the End of Life." *Patient Education and Counseling* 101(4):631-638.

Torpy, Janet M., Alison Burke, and Robert M. Golub. 2012. "Hospice Care." *JAMA* 308(2):200-220.

Yenurajalingam, Sriram and Eduardo Bruera. 2016. *Oxford American Handbook of Hospice and Palliative Medicine and Supportive Care*, 2nd ed. New York: Oxford University Press.

Wilkie, Patricia. 1997. "Ethical Issues in Qualitative Research in Palliative Care." *Palliative Medicine* 11:321-324.

Wohleber, Ashley, Daniel McKittrick, and Shawn Davis. 2012. "Designing Research with Hospice and Palliative Care Populations." *American Journal of Hospice and Palliative Medicine* 29(5):335-345.

## Citation

Kamińska, Weronika. 2024. "'Am I Going to Die?' Considering the Preparation for Research on an Example of Hospice Patients." *Qualitative Sociology Review* 20(1):82-98. Retrieved Month, Year ([http://www.qualitativesociologyreview.org/ENG/archive\\_eng.php](http://www.qualitativesociologyreview.org/ENG/archive_eng.php)). DOI: <https://doi.org/10.18778/1733-8077.20.1.06>