

**mgr Maria Wysocka**

## **Analysis of selected needs and identification of challenges in palliative care in Poland from the perspective of patients, their caregivers, and physicians**

### **Abstract in English**

#### **Aim of the study**

The main aim of the study was to analyze needs and identify challenges in palliative care in Poland based on the point of view of patients, their carers and physicians.

Specific aims:

1. To compare the opinions of palliative care patients and physicians on the use of opioid medicines for pain relief.
2. To analyze the needs of patients and their families and potential differences in their hierarchy during the COVID-19 pandemic.
3. Identification of key factors influencing the success of palliative pain management based on a narrative literature review.

#### **Material and methods**

This series of publications presents the results of a quantitative and qualitative study and the conclusions of a narrative literature review, identifying the needs and challenges of palliative care in Poland from the perspective of patients, their carers and physicians. The study dedicated to assessing the opinions and attitudes towards opioid analgesic treatment of patients and physicians focused on comparing the results of the two groups. The study used original questionnaires developed by the research team. The questionnaire contained questions scored on a 5-point Likerts' scale and was conducted among patients of the Oncology Hospice in Warsaw and specialist physicians (in the form of an online survey). The scale responses were 1 - totally disagree, 2- disagree, 3- neither agree nor disagree, 4- agree, 5- totally agree. The question asked was: "to what extent do you agree with the statement?".

The survey was part of a research project to assess the availability and extent of opioid medicine use in Poland. Therefore, in addition to questions on opinions, the questionnaire directed at physicians also included questions on professional experience, drugs used and knowledge and experience in the area under study. The questionnaire for patients consisted of a section on opinions and experiences related to cancer pain management. The results collected in the questionnaires were statistically analyzed.

An exploratory study of the needs of patients and their families receiving palliative care in the era of the COVID-19 pandemic used questionnaires with open-ended questions. Patients completed them independently or with the help of the researchers. Questionnaires addressed to family members and carers were distributed by email or completed during a telephone interview with the researcher. Two groups took part in the study; inpatient hospice patients and their families and relatives. All patients on the ward during the study period, able to understand the questions and willing to answer, with a minimum stay of 7 days under hospice care were included. The questionnaires were a modified version, due to the ongoing SARS-CoV-2 epidemic at the time, of questionnaires used to assess the quality of care in the inpatient hospice unit where the study was conducted. A qualitative research method, a medical anthropology approach based on inductive thematic analysis, was chosen to provide an interpretive perspective on the results obtained.

The narrative review was based on the method of critical analysis and discussion of the current state of knowledge regarding the attitudes and opinions of patients, their families and physicians. It addressed aspects of palliative care, with a particular focus on opioid analgesic treatment.

## **Results**

Patients (n=104) and physicians (n=216) were recruited for the study of opinions and attitudes towards opioid analgesic treatment. Negative associations associated with the word 'morphine' were expressed in both study groups. The groups also shared the opinion that patients are afraid of using opioid medicine, while at the same time reaching for painkillers too readily. For both patients and doctors, survey responses were consistent with the phenomenon of 'opioidophobia'. The majority of cancer patients (87.5%) experienced pain during their illness (mean pain intensity:  $7.01 \pm 2.44$ ). In contrast, 53.3% of doctors shared the concern that patients misuse opioid medicine. For both patients and doctors, the survey responses were consistent with the definition of the phenomenon 'opioidophobia'.

The exploratory study of needs involved inpatient hospice patients (n=12) and family members and carers of patients (n=9). While a sense of safety was high on the hierarchy of needs in both groups, for patients it was mediated by the need for closeness and presence, and for families it was related to the need for care and control of care. Patients' sense of security was reinforced by the professionalism of the hospice staff, and families and relatives by good (empathetic and detailed) communication with the medical staff. An important need of patients revealed in the survey was the maintenance of social roles, both towards relatives and medical staff (maintaining relations threatened by anonymity - masks, overalls, visors etc. making it difficult to identify people around patients).

A narrative review of the literature from 1993 to 2020 (72 papers cited) identified specific barriers to effective opioid analgesic treatment lying on the side of patients and their caregivers: fears of distracting the physician's focus on cancer management, concerns about receiving the opinion of a difficult complaining patient, the belief that pain is important information about the course of the disease necessary for its treatment, or fatalistic attitudes about the possibility of pain relief. Lack of up-to-date knowledge, false beliefs, and negative attitudes about opioid analgesic treatment are identified in many studies as common to patients, carers and doctors. The paper distinguishes factors critical to treatment success such as the ability to build, correct and maintain a collaborative doctor-patient relationship over several or decades of treatment. The studies analyzed point to one important source of inadequate opioid use in the analgesic treatment of oncology patients. Inadequate low or high use of these drugs at particular stages of treatment may be the result of an inconsistent and inadequately supported education process in the knowledge and skills of both the medical community and patients and their caregivers.

## **Conclusions**

1. Most cancer patients in palliative care and physicians are apprehensive about opioid analgesic treatment. Low levels of patient knowledge of the mechanism of action, benefits and side effects of opioid drugs may be related to a lack of education and side-effects of opioid medicines may be related to a lack of education in this area during the course of treatment and may be one of the reasons for the failure of analgesic therapies.
3. A sense of safety is one of the values most highly valued by patients, realized through proximity (physical with the family or relational in the medical staff) and supported by the professionalism of the medical staff. For families, a sense of security is associated with the ability to control the care of their patients.
4. The main barriers to effective pain management identified in the literature that lie with patients and families are lack of up-to-date knowledge, false opinions and negative attitudes.

5. Collaborative preparation of patients and their relatives to participate in the treatment process and to be involved in therapeutic decision-making is supported by education and a therapeutic relationship centered on the patient and his/her relatives.

6. Patient retention in the long-term cancer treatment process is determined by the ability to build, correct and maintain a therapeutic relationship between doctor and patient, based on trust, a sense of security and ethics.