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ORIGINAL PAPER

The fulfilment and importance of the needs of patients with cancer and advanced chronic disease in palliative care

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Abstract

Aim: The aim is to determine how fully the needs of patients with cancer and those of patients with advanced chronic disease are met in palliative care and how needs differ in importance between the two groups. *Design:* A cross-sectional study. *Methods:* The study population consisted of patients with advanced chronic disease and cancer patients admitted either to cancer wards or a hospice. The study period was from January 2023 to May 2023. A valid and reliable tool, the Patients' Needs Assessment in Palliative Care, was used to assess the needs of patients. The total number of respondents was 126. *Results:* Physical needs are most important to patients with advanced chronic illness. Autonomy needs are most important to cancer patients. For patients with advanced chronic illness, the highest level of needs fulfilment was in the area of social needs. The highest rate of fulfilment for cancer patients was in the area of social needs. *Conclusion:* Needs assessment of patients in palliative care is essential since it allows healthcare professionals to better understand the individual needs of patients in their final phase of life.

Keywords: fulfilment, importance, needs, palliative care, Patients' Needs Assessment in Palliative Care (PNAP).

Introduction

Palliative care is defined as *"...active and comprehensive care provided to people of all ages who suffer serious disability as a result of serious illness, especially those at the end of life. It aims to improve the quality of life of patients, their families and carers"* (International Association for Hospice and Palliative Care, 2018). Palliative care focuses on improving the quality of life of patients with advanced illness, and it is vital to identify and understand their needs. In addition to meeting basic needs, which are usually addressed by medical staff in palliative care, patients also attach great importance to their psychological, social, and spiritual needs (Hajnová Fukasová et al., 2015). A patient is classified as having unmet needs if they do not have access to the quality care they require (Carr & Wolfe, 1976). In nursing, a need is unmet if there is a problem for which an adequate solution has not been offered (Sandman & Hofmann, 2019). Inadequate need satisfaction has a significant negative impact on the patient's quality of life in the final phase of life. Therefore, assessment of patients' needs fulfilment in palliative care provides an important indicator of the quality of care given (Bužgová et al., 2013). There is extensive research evidence highlighting the benefits of early implementation of palliative care for cancer patients and it is increasingly recognized as an integral aspect of cancer treatment. However, these advances have not been developed to the same extent in the approach to non-cancer chronic diseases. In this context, patients with advanced chronic disease are rarely offered this form of care, although when they are admitted to a specialist palliative care unit, they are often at a more advanced stage of their disease and show a lower level of functional status compared to cancer patients. It is important to draw attention to this situation since the vast majority of adults who require palliative care die from non-cancer diseases, namely cardiovascular diseases, chronic respiratory diseases, and diabetes (Doñate-Martínez et al., 2019). There are differences between needs assessments for the two patient groups. For cancer patients, physical needs are the area of importance most frequently reported (Finucane et al., 2021). The most frequently reported physical

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symptoms in cancer patients are shortness of breath, pain and ascites (Verhoef et al., 2020), and insomnia and other sleep problems (Mithrason & Parasuraman, 2017). Psychological needs are also considered important, with 20 to 24.3% of patients reporting moderate to high levels of need within the ‘psychological’ domain (Rachakonda et al., 2015). The role of a loved one has been found to be important in the area of psychosocial needs (Novotná & Kala, 2016). The results of a survey of cancer patients showed that their most common spiritual need was to be regarded as human until the end of their lives. They also had a strong desire to know the truth about their illness and felt a need for reconciliation with and forgiveness of others (Vilalta et al., 2014). In studies conducted with patients with advanced chronic illness, the psychological domain has often emerged as very important. Patients’ physical symptoms are more often emphasized and these needs are only partially satisfied (Jang et al., 2022). A significant proportion of participants in Chan et al.’s (2021) research reported feeling anxious (79.2%), finding it difficult to find a sense of calm (79.1%), not being able to obtain the information they required (79.1%) or share their feelings with family / friends (72.9%), and they were troubled by unresolved practical matters (77.1%). The evaluation showed that these emotional symptoms and communication problems were even more prevalent than physical symptoms. In terms of physical symptoms, the three most common were weakness / lack of energy (70.8%), limited mobility (64.6%) and pain (52.1%). Patients without cancer also show higher levels of need in psychosocial domains such as anxiety, depression and worry, and, in the physical domain, are generally more likely to report shortness of breath than those with cancer (Jang et al., 2022). To date, no research has been conducted in the Czech Republic that compares needs assessment between these two patient groups in palliative care.

Aim

The aim is to determine how fully the needs of patients with cancer and those of patients with advanced chronic disease are met in palliative care and how needs differ in importance between the two groups.

Methods

Design

A cross-sectional study. STROBE guidelines were followed in the conduct of the study.

Sample

A purposive sample of respondents was used. The primary research population consisted of patients with advanced chronic disease and cancer patients admitted to oncology wards and a hospice. These patients were subsequently divided into two groups. The first group included patients with advanced chronic disease (the predominant chronic diseases that were identified included chronic heart failure – 32.6%, end-stage liver failure – 19.6%, and end-stage renal failure – 10.9%) aged 18 years or older, able to communicate, whose disease was end-stage, and who were receiving palliative treatment, as recorded in their medical records. The second group consisted of cancer patients aged 18 years or older whose cancer treatment was discontinued due to uncontrollable disease progression, and who were able to communicate. Their disease was in an advanced stage, and they were receiving palliative treatment, as recorded in the medical records. The selection of the two research groups was deliberate. The minimum number of respondents needed for the research survey was calculated at 103, based on the methods of Hendl (2004).

Data collection

The study period was from January 2023 to May 2023. A standardized tool, the Patients’ Needs Assessment in Palliative Care (PNAP) by Assoc. Prof. R. Bužgová, PhD (who gave her approval for its use), was used. The tool contains a total of 40 items, which are classified into five categories: physical symptoms (biological needs), social domain (social needs), respect and support from healthcare professionals (psychological needs), sharing of emotions and religious needs (spiritual needs), and autonomy (Bužgová, 2014). The tool contains two scales, with the first assessing the importance and the second the fulfilment of patients’ needs in palliative care. Importance is rated on a Likert scale with five levels: 1 (not at all important), 2 (fairly unimportant), 3 (don’t know), 4 (fairly important) and 5 (very important). The second scale assesses need fulfilment and is only completed if the need is important to the respondents (responses 4 and 5). The Cronbach’s α of the full PNAP questionnaire was 0.89 for the importance scale and 0.80 for the fulfilment scale. Retest reliability exceeded 0.7 in all domains for both scales. Construct validity was verified by Spearman’s correlation coefficient and achieved a value of low dependence (r = 0.1–0.3) for both the importance and fulfilment scales (Bužgová, 2014). Given the sample, data collection was conducted in the form of a face-to-face meeting, which allowed the researcher or nurse to estimate any potential burdens and, if necessary, immediately terminate the assessment. A recording sheet containing demographic data such as age, gender, and specific disease was attached to the questionnaire.

Data collection took place at the following facilities, which we will name only by clinical focus to preserve anonymity:

- oncology department,
- inpatient hospice.

After the approval of the management of each facility, the necessary data collection was carried out. A total of 150 respondents were approached by the researchers or general nurses who were trained in the use of the tool. Of this total, four respondents declined to participate due to fatigue. A further 20 questionnaires were not completed due to insufficient numbers of patients meeting the criteria. A final total of 126 correctly completed PNAP questionnaires were returned, representing a return rate of 84%. After signing the informed consent and receiving instruction on how to fill in the questionnaire, respondents were asked to complete it, which took approximately 25 to 30 minutes. Once completed, the tool was returned to the researcher or general nurses and placed in an envelope. In other cases, the questionnaire was completed jointly by the researcher and patient during a face-to-face meeting (face-to-face method). Once completed, the questionnaire was placed in an envelope and handed over to the researcher.

Data analysis

Absolute and relative frequencies and descriptive statistics (mean, standard deviation, median, minimum and maximum values) were calculated for quantitative variables. Statistical hypothesis testing was performed using Tibco Statistica and IBM SPSS Statistics for Windows. Friedman's (ANOVA) and Kendall's coefficient of concordance tests were used for inferential statistics. Comparison of the importance / fullness of each domain was performed using Student's t-test. All tests were completed at the statistical significance level of $\alpha = 0.05$.

Results

Characteristics of the sample

Table 1 presents the characteristics of the sample. The total number of respondents was 126. The average age of the respondents was 69.8 years. The largest age group of respondents was 60–69 years (32.54%), while the smallest was 40–49 years (3.97%). A minimum age of 40 years and a maximum age of 89 years were observed among the respondents. Slightly over half of the respondents were female (50.8%). The majority of the respondents (63.49%) had cancer, while 36.51% had chronic advanced disease. The predominant chronic diseases identified in the patients' responses included chronic heart failure, end stage renal failure, and end stage liver failure.

Table 1 Characteristics of the sample

Variable	N (%)	Variable	N (%)
Gender		**Disease**	
male	62 (49.2%)	cancer	80 (63.49%)
female	64 (50.8%)	advanced chronic disease	46 (36.51%)
Age		**Distribution of advanced chronic diseases**	
40–49	5 (3.97%)	chronic heart failure	15 (32.6%)
50–59	17 (13.49%)	end-stage liver failure	9 (19.6%)
60–69	41 (32.54%)	end-stage renal failure	5 (10.9%)
70–79	37 (29.37%)	chronic obstructive pulmonary disease	4 (8.7%)
80+	26 (20.63%)	other	13 (28.3%)

Importance of needs in patients with advanced chronic / oncological disease

The results indicated a significant difference between the mean values of each domain and a statistically significant difference in importance ratings within these domains ($p < 0.001$). Table 2 shows that physical needs were the most important needs for patients with advanced chronic illness (mean = 4.66). Other important needs related to the domains of autonomy (mean = 4.41) and social needs (mean = 4.37). Ranked slightly lower in importance were psychological needs (mean = 3.83). The least important area was spiritual needs (mean = 3.8). The most important needs for cancer patients were in the autonomy domain (mean = 4.7), with physical needs ranking second (mean = 4.46), followed by social (mean = 4.33), psychological (mean = 3.85) and, finally, spiritual needs (mean = 3.74).

Table 2 Importance of individual domains in patients with advanced chronic / oncological disease

Domain	Mean	Min	Max	Median	SD	p
Patients with advanced chronic disease in palliative care						
physical needs	4.66	2.57	5	4.79	0.62	< 0.001
psychological needs	3.83	2	5	3.91	1.27	
social needs	4.37	2.57	5	4.43	0.92	
autonomy	4.41	1.67	5	4.51	0.9	
spiritual needs	3.8	2.43	5	3.88	1.5	
Cancer patients in palliative care						
physical needs	4.46	1.78	5	4.52	0.97	< 0.001
psychological needs	3.85	1.44	5	3.92	1.26	
social needs	4.33	1.29	5	4.45	0.98	
autonomy	4.7	1.67	5	4.83	0.69	
spiritual needs	3.74	1.91	4.86	3.79	1.5	

SD – standard deviation; p – statistical significance

Fulfilling the needs of patients with advanced chronic / oncological disease

The results indicated a significant difference between the mean values of each domain and a statistically significant difference in the ratings of fulfilment within these domains ($p < 0.001$). Analysis of the data in Table 3 indicated that the highest level of fulfilment for patients with advanced chronic illness was in the social domain, with a mean of 4.47. The second highest fulfilled domain was autonomy (mean = 4.29). This was followed by spiritual needs (mean = 4.13), psychological needs (mean = 3.61) and physical needs (mean = 3.14). For cancer patients, the highest level of fulfilment was achieved in the area of social needs (mean = 4.43). This was followed by autonomy (mean = 4.39), spiritual needs (mean = 4.2) and psychological needs (mean = 3.83). The area least fulfilled for cancer patients was physical needs, with a mean of 3.6.

Table 3 Fulfillment of individual domains in patients with advanced chronic / oncological disease

Domain	Mean	Min	Max	Median	SD	p
Patients with advanced chronic disease in palliative care						
physical needs	3.14	1	4.86	3.38	1.32	< 0.001
psychological needs	3.61	2.1	5	3.82	1.38	
social needs	4.47	3.43	5	4.59	0.62	
autonomy	4.29	2	5	4.38	0.77	
spiritual needs	4.13	1.86	4.57	4.29	1.04	
Cancer patients in palliative care						
physical needs	3.6	1.07	5	3.76	1.25	< 0.001
psychological needs	3.83	2	5	3.98	1.12	
social needs	4.43	2.57	5	4.55	0.75	
autonomy	4.39	2	5	4.48	0.75	
spiritual needs	4.2	1.72	5	4.34	0.89	

SD – standard deviation; p – statistical significance

Comparison of the importance / fulfillment of each domain in patients with cancer / advanced chronic disease

Significant differences in the importance of needs between the two patient groups were found only in the Autonomy domain ($p = 0.045$). For the other domains, no differences in importance were found between the groups (Table 4). With regard to need fulfillment, a difference very close to the significance level (0.05) was found only in the domain of Physical Needs ($p = 0.054$); nevertheless, it was not statistically significant. The other domains (psychological, social, autonomy, and spiritual needs) had p-values higher than 0.05, indicating that the differences between chronic and cancer patients in these domains were not statistically significant (Table 5).

Table 4 Comparison of the importance of each domain in patients with cancer / advanced chronic disease

Patients with advanced chronic disease in palliative care			**Cancer patients in palliative care**			**Comparison of importance**
Domain	**Mean**	**SD**	**Domain**	**Mean**	**SD**	**p**
physical needs	4.66	0.62	physical needs	4.46	0.97	0.211
psychological needs	3.83	1.27	psychological needs	3.85	1.26	0.932
social needs	4.37	0.92	social needs	4.33	0.98	0.822
autonomy	4.41	0.9	autonomy	4.7	0.69	0.045
spiritual needs	3.8	1.5	spiritual needs	3.74	1.5	0.829

SD – standard deviation; p – statistical significance

Table 5 Comparison of the fulfillment of each domain in patients with cancer / advanced chronic disease

Patients with advanced chronic disease in palliative care			**Cancer patients in palliative care**			**Fulfillment comparison**
Domain	**Mean**	**SD**	**Domain**	**Mean**	**SD**	**p**
physical needs	3.14	1.32	physical needs	3.6	1.25	0.054
psychological needs	3.61	1.38	psychological needs	3.83	1.12	0.332
social needs	4.47	0.62	social needs	4.43	0.75	0.759
autonomy	4.29	0.77	autonomy	4.39	0.75	0.477
spiritual needs	4.13	1.04	spiritual needs	4.2	0.89	0.69

SD – standard deviation; p – statistical significance

Discussion

The aim was to determine how the needs of patients with cancer are met and how important they are compared to those of patients with advanced chronic disease in palliative care. With increasing life expectancy and medical advances, the number of people living with terminal illnesses is increasing (World Health Organization, 2020). Those affected by these diseases often face complex bio-psycho-social issues that can result from the disease itself and its treatment (Rimmer et al., 2022). In the field of cancer and palliative care, general nurses are challenged to recognize the specific diversity of problems faced by patients and incorporate possible solutions and interventions into their treatment planning (Radionova et al., 2020). Assessment of patients' needs over time with appropriate tools are key to monitoring changes in health status and assessing the effectiveness and quality of care provided. However, the use of these tools alone may not prompt health professionals to respond to the needs identified, since they may lack the skills and knowledge to interpret the results. Thus, their use does not necessarily contribute directly to decision-making on the appropriate course of treatment. On the other hand, needs assessment instruments can serve as a tool for clinical decision-making, facilitating the assessment of patient needs, the allocation of interventions to address them, and the understanding of care options and outcomes. These assessments can then be used to respond to identified needs in order to improve patient quality of life (Remawi et al., 2021). The PNAP tool was used to assess needs in this study. It was chosen due to its linguistic and cultural adaptations to the Czech clinical setting. In addition, this instrument fulfils the necessary validity and reliability values (Bužgová, 2014). It assesses individual patient needs both in terms of importance and fulfilment.

In cancer patients, results indicated that the need for autonomy was most important, followed by physical, social, psychological, and spiritual needs. These results are consistent with research conducted by Bužgová et al. (2013), as well as a study by Novotná & Kala (2016). In our study, physical needs ranked second for cancer patients. For patients with advanced chronic disease, physical needs were the most important, followed by autonomy, social, psychological, and spiritual needs. Thus, for both groups, the two most important areas were the same. Why these two areas were most important to patients may be down to a number of reasons. Autonomy is key to maintaining psychological well-being and self-esteem. Patients who have control over their lives and treatment often experience less anxiety and depression (Wan et al., 2021). A sense of autonomy can also improve overall quality of life, which is particularly important for long-term conditions such as cancer and chronic illnesses. Patients who feel that they are actively involved in decisions about their treatment are more motivated to adhere to their treatment regimen and are more open to cooperation (Martinez et al., 2015). Meanwhile, physical symptoms such as pain, fatigue and nausea are very common in palliative care patients (Finucane et al., 2021). Effective control of these symptoms is essential to maintain patient comfort and dignity. Preserving physical function and independence allows patients to perform activities of daily living and maintain a degree of autonomy (Tralongo et al., 2017).

In the area of fulfilment of needs, the highest level of fulfilment for cancer patients was achieved in the area of social needs (rated only third in terms of importance). This was followed by autonomy, spiritual needs, psychological needs, and physical needs. Explanations as to why social needs are the most fulfilled may be as follows: patients often receive intensive support from family and friends, many patients join support groups that provide emotional support and allow them to share experiences with people going through similar situations, and healthcare professionals also pay attention to patients' emotional and social needs, besides physical needs, as part of their care (Graboyes et al., 2024). The highest level of fulfilment for patients with advanced chronic illness was also achieved in the area of social needs, followed by the autonomy domain, the spiritual needs domain, and the psychological and physical needs domain. The areas with the lowest level of fulfilment were psychological and physical needs. According to the results of a study conducted by Gřiva et al. (2015), it seems that the gradual deterioration of the patient's general health status is a significant factor contributing to a reduction in quality of life, due to psychological burden. According to the aforementioned authors, the occurrence of depressive states is common in patients with chronic heart failure, with a prevalence exceeding 20%, and this rate increases with advancement in NYHA classification.

Comparison of the needs of patients with cancer and advanced chronic diseases revealed significant differences only in the area of autonomy ($p = 0.045$), suggesting that patients with cancer perceive this need to be more important than patients with advanced chronic diseases. There may be several reasons for this: a cancer diagnosis often triggers intense emotional reactions such as fear and anxiety, which may increase patients' need for control over their decisions and life. Cancer patients face greater uncertainty about the future and, therefore, autonomy is crucial to their psychological well-being (Martinez et al., 2015). Cancer patients often have more treatment options, which means they need to be more involved in decision-making processes regarding their care. This enhances their perception of autonomy since they become active participants in their health plan (van Kleffens et al., 2004). Autonomy can have a positive impact on psychological and emotional health, which is crucial for cancer patients. Perceived control over one's own treatment can reduce anxiety and depression (Teo et al., 2019).

Based on the results of our research, several recommendations can be proposed. It is increasingly important that the focus of the nursing team is not only on cancer patients but also on patients with advanced chronic disease, involving non-cancer diagnoses. These patients often face similar bio-psycho-social challenges and have similar unmet needs. Focusing on palliative care for non-cancer patients means recognizing and providing support to these patients. This includes a thorough assessment of their needs and comprehensive management of symptoms that affect their physical and psychological health. It is also important to attend to their social and spiritual needs and ensure that they have access to information and support in all aspects of their care. Another important aspect is the continuous improvement of the nursing team's skills in interpreting the results of patients' needs assessments. Sufficient training and education of nursing staff should be provided to ensure that they are able to interpret the results correctly and make informed decisions about appropriate nursing management. It is, therefore, essential that nursing practice, education, and nursing research focused on palliative care begin to actively include non-cancer patients with advanced chronic disease.

Limitation of study

There are several limitations to this study. First, the study focused only on hospital-based palliative care and did not adequately address home care or community-based palliative services. Second, the study focused predominantly on the healthcare domain and should be expanded to include social aspects of care that have a significant impact on the quality of life of palliative patients. Third, the participant pool was limited to a specific area or population, which limited extrapolation of the results to the general population. Future research should include a larger and more diverse sample of patients.

Conclusion

Autonomy was the most important domain for cancer patients, whereas patients with advanced chronic disease prioritized physical needs. Social needs were those most often met in both patient groups. Assessing the needs of patients in palliative care is essential because it allows healthcare professionals to better understand the individual needs of patients in their final phase of life. This creates the opportunity to provide them with more precise and targeted care, thus contributing to improvements in their quality of life and the maintenance of their dignity and comfort during their illness.

Ethical aspects and conflict of interest

The authors have no conflict of interests to declare. The Faculty of Health Sciences of Palacký University in Olomouc Ethics Committee approved the research.

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Author contributions

Conception and design (LS, KD), data analysis and interpretation (LS, KD), manuscript draft (LS), critical revision of the manuscript (LS, KD), final approval of the manuscript (LS, KD).

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