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UNMET NEEDS IN THE PROCESS OF CHEMOTHERAPY PROVISION IN PANCREATIC CANCER PATIENTS FROM THE HEALTHCARE PROVIDER PERSPECTIVE: A PHENOMENOLOGICAL STUDY IN GREECE

NEIZPOLNJENE POTREBE V PROCESU ZAGOTAVLJANJA KEMOTERAPIJE PRI BOLNIKIH Z RAKOM TREBUŠNE SLINAVKE Z VIDIKA IZVAJALCEV ZDRAVSTVENEGA VARSTVA: FENOMENOLOŠKA ŠTUDIJA V GRČIJI

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ABSTRACT

Keywords: Pancreatic cancer End-of-life care Unmet needs Holistic care

Introduction: Pancreatic cancer is the fourth leading cause of cancer death overall, with 1.5 years life expectancy and minimal therapeutic progress in the last decades. Despite the burden it causes, there is little research on the needs of this specific population. This study aimed to explore healthcare professionals' views on providing care and patients' unsatisfied needs.

Methods: This qualitative descriptive study was carried out at a cancer hospital in Northern Greece. A total of 12 participants (6 physicians and 6 nurses), treating patients with pancreatic cancer undergoing chemotherapy, were recruited through purposive sampling and underwent face-to-face semi-structured interviews. Data were analyzed through the thematic analysis method in NVivo12 software.

Results: The analysis highlighted two themes: "needs of patients with pancreatic cancer" consisted of 6 subthemes ("daily activities", "symptoms management", "psychological support", "information needs", "multidisciplinary care" and "end-of-life care") and "needs of healthcare professionals" had 3 subthemes ("psychological support", "education" and "organizational support"). Several symptoms are identified and affect the daily activities of these patients, and psychological support is important for the majority of them, even at the time of diagnosis. The participants express dissatisfaction with the absence of palliative care structures and services and stated that an interdisciplinary approach would improve the quality of care.

Conclusions: Healthcare professionals report a wide range of unsatisfied needs of patients with pancreatic cancer, with the majority expressing their concerns about the complete lack of patient support in the last stages of their lives.

IZVLEČEK

Ključne besede:
rak trebušne slinavke
oskrba ob koncu
življenja
neizpolnjene potrebe
celostna oskrba

Uvod: Rak trebušne slinavke je četrti najpogostejši vzrok smrti zaradi raka. Pričakovana življenjska doba bolnikov z rakom trebušne slinavke je 1,5 leta, terapevtski napredek v zadnjih desetletjih pa je skromen. Kljub bremenu, ki ga povzroča, je zelo malo raziskav o potrebah te specifične populacije. Cilj te študije je proučiti mnenja zdravstvenih delavcev o zagotavljanju oskrbe in neizpolnjenih potrebah bolnikov.

Metode: Ta kvalitativna deskriptivna študija je bila izvedena v bolnišnici za zdravljenje raka v severni Grčiji. V njej je sodelovalo 12 zdravstvenih delavcev (6 zdravnikov in 6 medicinskih sester), ki so s kemoterapijo zdravili bolnike z rakom trebušne slinavke. Sodelujoči so bili izbrani z namenskim vzorčenjem, z njimi pa so bili opravljeni osebni polstrukturirani intervjuji. Podatki so bili analizirani z metodo tematske analize v programski opremi NVivo12.

Rezultati: Pri analizi sta bili izpostavljeni dve temi: tema »potrebe bolnikov z rakom trebušne slinavke« s 6 podtemami (»vsakodnevne dejavnosti«, »simptomatsko zdravljenje«, »psihološka podpora«, »potrebe po informacijah«, »multidisciplinarna oskrba« in »oskrba ob koncu življenja«) in tema »potrebe zdravstvenih delavcev« s 3 podtemami (»psihološka podpora«, »izobraževanje« in »organizacijska podpora«). Ugotovljenih je bilo več simptomov, ki vplivajo na vsakodnevne dejavnosti teh bolnikov, za večino teh simptomov pa je pomembna psihološka podpora, celo v času diagnoze. Udeleženci so izrazili nezadovoljstvo zaradi pomanjkanja struktur in storitev paliativne oskrbe ter navedli, da bi interdisciplinarni pristop izboljšal kakovost oskrbe.

Zaključki: Zdravstveni delavci navajajo številne neizpolnjene potrebe bolnikov z rakom trebušne slinavke, večina pa je zaskrbljenih zaradi tega, ker bolniki ob koncu življenja ne prejmejo nobene podpore.

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1 INTRODUCTION

Pancreatic cancer (PC) is a significant global and Greek public health challenge. It is the 9th cause of death in Greece (1) and the 7th most fatal cancer worldwide, with approximately 466,003 deaths in 2020 (2) and only a 3% five-year relative survival rate for patients with metastasis (3). There are usually no symptoms in the early stages of the disease and when they appear the disease has spread to other parts of the body with a poor prognosis and limited treatment options (4).

The main signs and symptoms are jaundice, abdominal or back pain, unexplained weight loss, light-colored stools, dark urine, and loss of appetite (5). Cachexia and sarcopenia are the two most common problems, which limit the ability to perform daily activities, are associated with poor overall survival and reduce patients' quality of life (QOL) (6). Disease progression is rapid and the burden is enormous, suggesting that early palliative support is needed to improve QOL and symptom management (7), especially for patients under chemotherapy.

Cancer is a multidimensional disease, with millions of incidences globally and increasing challenges to health systems. Various issues related to deficiencies in cancer care have been repeatedly discussed in the literature, with the most frequently being the unmet needs of psychosocial support, multidisciplinary cooperation, patient-doctor communication and palliative care systems (8-10).

Greece provides free health services to all citizens in public structures (11), however, due to shortages and delays, especially in primary healthcare, patients have many unmet needs and as a consequence, many of them turn to the private sector for care (11). Across the country, there are specialized public and also private cancer hospitals and oncology clinics, but Greece belongs to the countries characterized by a very small number of hospices and palliative care services, which are usually provided by non-governmental organizations in outpatient facilities and at-home and are limited compared to the country's population (12). In this context, cancer patients are not adequately supported.

Despite the plethora of research into cancer treatments, there is little research on the specific needs of patients with PC and fewer on the views of healthcare professionals (HCPs) on this issue. To improve the quality of health services, HCPs and patients must openly discuss their wishes, needs and care options (9). Their experience is important and can shed light on unseen aspects of care deficits (10). Earlier studies have investigated HCPs' views on the supportive care needs of patients with advanced cancers such as colorectal or prostate, and others on the prevalence, barriers and psychosocial issues in cancer care (13). To the best of our knowledge, there is no study about the supportive care needs of PC from HCPs' perspective in Greece.

Aimed at preparing the basis for improvement of the chemotherapy process in patients with PC, the objective of the present study was to explore the perception of unmet needs of patients as well as of those of healthcare providers during the provision of chemotherapy from the perspective of HCPs.

2 METHODS

2.1 Study design, time frame and setting

The study we present is designed as a phenomenological study that is part of broader research that explores the needs of PC patients in the light of HCPs, patients and their informal caregivers. The first study concerns the perspective of HCPs - oncologists and oncology nurses. The study was carried out in the only cancer hospital in Northern Greece in May and June of 2019.

2.2 Participants and Sampling

The study included participants who have dealt with a variety of patients with PC and have gained significant experience in this field - participants from a specialized hospital who treat a considerable number of PC patients yearly.

The inclusion criteria for HCPs were a) working in a department treating PC patients undergoing chemotherapy, b) having at least one year of experience in the department, and c) being a physician or nurse. A purposive sample strategy of maximum variation (variables: gender, age, and work experience) was used to capture the widest range of possible perspectives.

2.3 Data collection

Semi-structured, face-to-face, in-depth interviews were conducted, recorded and saved in mp3 format. Each participant was interviewed one time, in a quiet room of the hospital, without the presence of other people, at a preselected time that the participant had chosen. We preferred this method to focus groups because it is easier to recruit participants to commit to an interview rather than a focus group and they may feel safer expressing themselves when they are alone. The recruiter and interviewer were the first author, a PhD candidate trained in qualitative research, and a female oncology nurse with 13 years of experience. The interviewer worked in the same hospital as the participants but in a different ward and did not have personal relationships with them. The interview guide was pilot-tested on two HCPs to ensure clarity, and all the necessary adjustments were made.

Table 1. Interview topic guide.

Topic heading	Issues discussed
Opening	Study purpose
Exploration of topics	Confidentiality Data management General thoughts about pancreatic cancer Symptoms Daily activities Psychology Support Healthcare professional-patient communication Quality of care Coordination and organization of care
Ending	Summarisation (from the interviewer) Feedback on completeness Further comments

2.4 Data analysis

Interviews were transcribed verbatim from mp3 format to MS WORD. The qualitative inductive thematic analysis proposed by Braun and Clarke (14) was the initial method and was performed with the software NVIVO12, by two researchers (first and second author) separately to gain a common understanding of the HCPs' perspectives and to enhance the validity of the results. For better results, we analyzed all the collected data and searched for negative or deviant cases that could improve the overall results. Disagreements on the categorization of subjects were resolved after discussion among them. Recruitment stopped when theoretical saturation was accomplished and interviews did not offer new concepts or contribute to what already exists. The authors' team decided on theoretical saturation after discussion.

2.4 Ethics

All the participants were informed in advance about the study aim, content and procedure with a leaflet and signed consent for their participation. There was a clear statement that there would be no reward for their participation and that they could withdraw at any time. Sixteen HCPs were initially interested in participating, one nurse was excluded and finally, 12 were interviewed until saturation was reached. Participants received an identification code so that their personal data could remain protected throughout the study.

2.5 Rigour

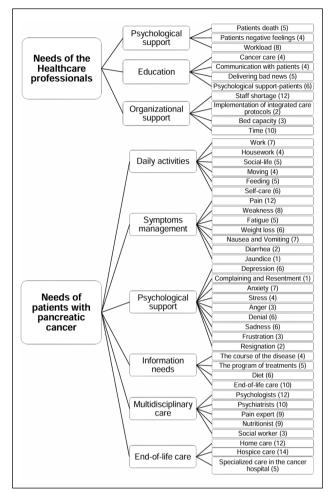
Consolidated Criteria for Reporting Qualitative Research Guidelines were used in this study to improve rigour, and participants and the context in which data was collected was fully described to enhance transferability. Credibility was enhanced by the first author who was familiar with the field, as an oncology nurse and doctoral student with training in qualitative research. The use of the same recording method and questions in all the interviews was for dependability. The second author and analyst was also an experienced researcher in qualitative research, a female psychologist, but has no relationship with the issue of cancer care or the setting of the cancer hospital. Lastly, at the end of the interview, the interviewer summarised the collected data, and requested the HCPs to give feedback about the accuracy of the information gathered and add anything considered important that had not been mentioned.

3 RESULTS

Twelve HCPs participated, with an average duration of interviews being 26:10 minutes for the physicians and 32:50 for the nurses. The descriptive characteristics of participants are presented in Table 2. The results of the thematic analysis presented in Figure 1 highlighted two themes, "needs of patients with pancreatic cancer" and "needs of healthcare professionals". The first theme consisted of six subthemes: "daily activities", "symptoms management", "psychological support", "information needs", " multidisciplinary care" and "end-of-life care". The theme "needs of healthcare professionals" consisted of three subthemes, "psychological support", "education" and "organizational support" which did not belong to the design of the study, but emerged from the inductive analysis of the interviews. Participants particularly emphasized the specific topic and therefore it was included in the presentation of the results.

Table 2. Descriptive characteristics of participants.

•			
Number of Participants/Range	6 Physicians 6 Nurses		
Gender			
Men	3	0	
Women	3	6	
Age (Range: years)	30-45	45-53	
Education			
Bachelor (Medical School Vs Nursing School)	5	6	
Master	0	0	
Doctoral	1	0	
Work experience (mean: years)	9	15	
Number of treated patients with pancreatic cancer			
<100	2	2	
100-200	4	3	
>200	0	1	
-			



Note: Within each code cell the number of quotes analyzed is written in parentheses

Figure 1. Thematic map.

3.1 Needs of patients with pancreatic cancer

HCPs understand the complexity of PC and the burden it causes on patients. The first thought common to all was that this type of cancer is associated with a short and painful path, which in the vast majority ends in death. Figure 2 captures illustrative quotes for every subtheme.

3.1.1 Daily activities

At the time of diagnosis, patients most often present with advanced disease that has already affected their daily activities. They usually interrupt their work and operate more conservatively during the day. In most cases, their clinical condition improves for a couple of months after the start of chemotherapy, but quickly recedes and follows a rapidly declining course. During the period of improvement, their functionality increases, which allows them to perform efficiently in their daily life. The improvement lasts a very short time and after that patients can neither work nor be self-sufficient. They

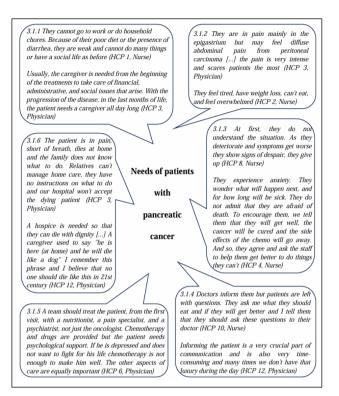


Figure 2. Illustrative quotes of "Needs of patients with pancreatic cancer".

need help with all day-to-day activities and this makes them feel sad, isolated and disadvantaged.

The support they receive from informal caregivers in various areas of their daily life is emphasized. This assistance concerns issues of transportation, communication with HCPs, housework, personal care, etc. The assistance of family members is considered especially important in the final stage of the disease where the patients lose much of their functionality and cannot even perform daily self-care activities such as walking, hygiene and eating.

3.1.2 Symptoms management

Pain, fatigue and weight loss are the predominant symptoms experienced by these patients at all stages of the disease and the main concern for relief by HCPs. In fact, for the particular symptom of pain, there is frequent collaboration with a specialist within the hospital. In addition, these patients often have symptoms of weakness, feeding difficulties, nausea and vomiting, diarrhea and jaundice.

3.1.3 Psychological support

HCPs recognize several psychological symptoms that are related to and affect the daily activities and consequently the QOL of these patients. Depression, anxiety, stress, complaining, resentment, anger, denial, sadness,

frustration and resignation are present in the majority of patients and sometimes even from the time of diagnosis. These symptoms are recognized by HCPs but are often not perceived by patients and their family members and therefore they do not ask for psychological support.

3.1.4 Information needs

All participants agree that patients should be well informed but the information they receive is not enough. Specifically, it was mentioned that patients seek more information about the course of the disease, the programme of treatments, nutritional advice, and end-of-life care. Lack of time, doctors' difficulty in communicating unpleasant information, and also the wishes of their family, especially if the patient is elderly and the family takes all the responsibility for the care, are the main reasons why patients are not fully informed.

3.1.5 Multidisciplinary care

Except for physicians and nurses, several other HCP specialties should be included in the context of holistic care. Earlier in this paper there was a reported need for psychologists, psychiatrists, and physicians experts in pain management. Also, they experience symptoms of malnutrition and cachexia for which the presence of a nutritionist is considered important to guide and follow up with the patient from the moment of diagnosis until the end. Finally, many patients need support from social workers to resolve financial and insurance issues arising from the disease.

3.1.6 End-of-life care

HCPs expressed their dissatisfaction with the lack of palliative care structures throughout the country, especially in the final stage of the disease, where the unmet needs of patients are maximized. They report that the terminally ill patient needs home care or specialized structures such as hospice. The priority of the cancer hospital and tertiary hospitals is to support patients with the prospect of a cure because hospital beds are limited. In the final stage, there are specific needs that cannot be served there. On the other hand, public health workers cannot urge and direct patients to private providers of home care and palliative care services because they find it unethical or because patients have financial hardship. All the respondents state that there is no support for these patients in or out of the hospital, and that is very frustrating.

3.2 Needs of the healthcare professionals

The majority of HCPs state that they are not satisfied with the health system in which they work, and consider that it does not meet the needs of these patients. The only positive element of the system is the free service provision and the loyalty of the workers, but they find no other positive elements, emphasizing the issues discussed below. Figure 3 captures illustrative quotes for every subtheme.

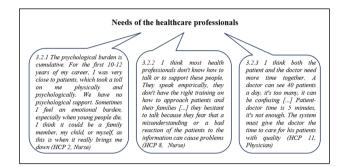


Figure 3. Illustrative quotes of "Needs of the healthcare professionals".

3.2.1 Psychological support

Participants report that they need psychological support for several reasons that affect negatively their psychology and performance. Firstly, they are adversely affected by the increased mortality of these patients, especially when young patients die. Secondly, they face their patients' anger, frustration, anxiety and denial and lastly, they feel pressured to provide optimal care to their patients in understaffed conditions.

3.2.2 Education

Half of the participants found it important to report that they are not trained and feel insecure about informing or supporting patients. This insecurity concerns issues of cancer care, the announcement of the diagnosis or the progression of the disease, but also psychological support from the moment of diagnosis until the end.

3.2.3 Organizational support

Staff shortages are known to be a problem that negatively affects the provision of quality patient care. Specialized HCPs such as psychologists and psychiatrists are almost absent, and the majority of responders mentioned the need for more physicians and nurses. Implementing integrated care protocols and increasing bed capacity will increase the quality of providing services and decrease patients' discomfort. HCPs believe that they need more time to treat and inform their patients sufficiently because everything is done in a hurry and in the wrong way and this dissatisfies them.

4 DISCUSSION

In the findings of the present study, HCPs support the fact that patients with PC experience unmet needs in the areas of daily living, psychological support, end-of-life care, symptoms management, information and care by a multidisciplinary team. Also, HCPs need psychological and organizational support, as well as training to cope with the tasks of caring for their patients. These findings are interconnected and indicate that patients and HCPs experience needs that negatively affect the QOL of patients and the quality of care respectively. Although a growing literature addresses these research questions for various types of cancer or advanced cancer stages, there is a lack of research data supporting similar beliefs of HCPs related solely to PC.

In previous quantitative studies of PC, patients experience daily needs of at least 50%, which are maximized in the final stage of the disease, when patients lose their functionality (15). They are particularly vulnerable and have many unique needs during treatments, as they reported the worst physical well-being scores compared to survivors of other malignancies and people without cancer (16).

Pain, fatigue and severe weight loss/cachexia are the predominant symptoms in our study, but other symptoms of indigestion, dry mouth and altered bowel activity are described in the relevant literature (17). Very few studies examined the influence of PC on spiritual and sexual QOL (18), while no reference has been made to our study. Sociability problems have been investigated but have not been concluded if they are more pronounced than other types of cancer, although they are higher than in the general population (17).

Physical needs in PC patients with pain, fatigue, pancreatic enzyme deficiency and nutritional problems require early detection and a multidisciplinary approach (19). Generally, a multidisciplinary approach to symptom management and psychosocial support improves patients' QOL and avoids errors in decision-making (20), while in cancer care shows positive effects on patient satisfaction, cost of care and symptom relief (21). HCPs in our study agreed that a multidisciplinary approach is interconnected with holistic care, improving the quality of care for patients with poor physical and psychological well-being scores.

Psychological support is crucial for cancer patients, especially in gastrointestinal cancers, where psychopathology rates are higher (22), subclinical symptoms of depression and anxiety range from 12% to 78%, and patients show unsatisfied needs in this sector (23). Poor oncologist accuracy on subclinical symptoms (24) contradicts the importance of psychological support, as all participants in our study recognize it as being just as crucial as the other aspects of treatment.

Proper communication is also crucial for cancer patients to ensure compliance with recommended treatments (9). Clinicians face challenges in disclosing complex information, especially in advanced cancer patients related to unrealistic patient expectations, and trying to explain in simple terms the treatment options and side effects (25). A systematic review suggests that patients and caregivers need honesty, compassion and patience throughout the communication process (26) with cultural differences affecting successful communication, as families of Chinese, Arab and Greek patients intervene and guide doctors on the information they give to patients (27). This is supported in societies with strong family bonds, which oblige the family to undertake disease management for the patient, and is also in agreement with the findings of the present study.

Literature suggests that the severity of symptoms affects the prognosis and survival of these patients (28), but high-quality palliative care is often unavailable. End-of-life care is crucial for PC patients, and hospice services can help manage symptoms and improve QOL (7). However, evidence shows that aggressive care (chemotherapy, hospitalizations and intensive care unit admissions) in the last days of life has increased in recent years (29), and many patients do not receive hospice care, resulting in missed benefits and support (7).

The work environment lacks adequate structural conditions, human resources, time, space, and control, which leads to dissatisfaction among HCPs. Oncology staff, especially oncologists and nurses, need psychological support because they often experience stress and burnout due to the complex work environment with cancer patients, in which they have to deal with the concept of death and patient/family pain and receive complex moral decisions (30). Clinicians also need training to communicate and inform patients properly, and to support this, guidelines and recommendations have been published and workshops have been established to develop communication skills (31). However, nurses need more money and time to attend training programmes to improve their performance (32). All of the above improvements are important because insufficient or incorrect knowledge of disease management can lead to a deterioration of care (10, 25, 31).

Greece has not made significant progress in palliative care, but plans to develop it are underway (12). Two new pieces of legislation on palliative care (Law 5007/2022) and home care (Ministerial Decision 3396/B/2023) have recently been published by the state but have not yet been implemented. The fact that HCPs in our study did not refer to the contribution of primary health care to the QOL of cancer patients indicates the lack of coordination between health structures in Greece. The assessment of patients' healthcare needs is essential for effective treatment,

but it requires multidisciplinary and interdisciplinary collaboration, with the active participation of patients (33). A limitation of the present study is that HCPs from one cancer hospital are not representative of all hospitals in Greece, but it was chosen because it is the only hospital with extensive experience in PC in northern Greece. Thus, the purposive maximum variation of the sample was used to gain transferability. Another limitation is the absence of inter-rater reliability, that the transcripts did not return to the participants to provide feedback, but at the end of the interview, the interviewer summarized the collected data and requested the HCPs to state their opinion about the accuracy of the gathered information. The researcher's presence during the interviews could affect the subjects' responses and for that reason, the interviewer did not have personal relationships with the interviewees. Finally, triangulation will emerge when the study is completed with the findings from patients, informal caregivers and HCPs, but cannot be supported by the preliminary results of this part of the study.

A pilot study on the needs of patients and caregivers requiring palliative care and the capabilities of primary healthcare professionals in Slovenia was recently published (34). Such research would be useful to be carried out in Greece to help create the most suitable infrastructures for the care of these patients and in this context, the knowledge of the perceptions of HPCs which emerged from the present study, can be seen as important revealing information that is apparent only from their side.

5 CONCLUSION

The findings of the views of HCPs in PC indicate many unmet patient needs, highlighting the absence of palliative care and multidisciplinary collaboration from the beginning of treatment, which has an immeasurable cost on patients' QOL and is consistent with previous studies (12, 15, 35). Even if new, more effective treatments improve QOL in terms of pain relief or increase patients' survival time, the invaluable and irreplaceable value of human care, both between patients and HCPs and between professionals, should not be underestimated. The obvious impact on a professional, financial and existential level makes it an immediate priority to strengthen palliative care and multidisciplinary teams that assess all stages of treatment.

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CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist

FUNDING

The authors declare that they received no funding

ETHICAL APPROVAL

The study was performed in accordance with the Helsinki Declaration and approved by the Aristotle University of Thessaloniki Ethics Committee (Ref. 3.132/2-5-2018) and the 4th Regional Unit of Greece (Ref. 17.746/14-11-2017).

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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