

# Lived experiences of patients with advanced pancreatic cancer on patient reported outcomes (PROs) management: a qualitative phenomenological study in Southwest China



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## Introduction

Pancreatic cancer is a highly aggressive tumor of the digestive system. Patients often experience debilitating symptoms such as pain, fatigue and gastrointestinal issues, alongside psychological distress, including anxiety and depression. The management of these symptoms and enhancement of life quality form a crucial component of the care and support for patients with pancreatic cancer.

PROs can offer an essential perspective on the impact of cancer and its treatment from the patient's viewpoint to enable a more comprehensive approach to care beyond traditional clinical parameters. However, to our best knowledge, research to investigate the effects of PROs management among patients with pancreatic cancer, especially in their advanced stages, remains lacking. This gap is significant because patients with advanced pancreatic cancer face unique challenges and burdens. The complexity and severity of their symptoms, coupled with the emotional and psychological toll of a terminal diagnosis, necessitate a tailored approach to PROs management.

To bridge this gap, we devised the current study by employing a qualitative phenomenological approach to explore the lived experiences of patients with advanced pancreatic cancer in the context of PRO management.

## Methods

This is a qualitative phenomenological study designed to explore the lived experiences of patients with advanced pancreatic cancer. The work was conducted at Chengdu Seventh People's Hospital, a palliative care center for oncology patients in southwest China, renowned for our expertise in the treatment of various types of cancer and systematic palliative care for advanced patients.

Patient diagnosed with advanced pancreatic cancer and with the age between 18 and 70 years were included in this study from 1 August 2023 to 30 November 2023. Informed consent was obtained from all participants prior to enrollment. We employed semi-structured, in-depth face-to-face interviews, which took place in a designated meeting room specially set up with a private and undisturbed environment. No family members or other individuals were allowed to be present during the interview. The sampling process was continued until data saturation reached. Colaizzi's methodology was used for thematic analysis, ensuring a systematic and rigorous process for identifying key themes that reflect the essence of the patients' experiences.

## Results

### Demographic and clinical characteristics

A total of 15 participants were included in this study between 1 August 2023 and 30 November 2023 before reaching data saturation. The participants were aged 58.7 years on average (range, 43–70 years), including 7 women (46.7%). Most participants had an education level of senior high school or below, were undergoing palliative chemotherapy and having an ECOG PS score  $\leq 1$  (all of them are  $n=14$ , 93.3%). The demographic and clinical information of the participants is presented in table 1.

### Themes

Each interview lasted approximately 17min on average (range, 14–23min). The interviews yielded abundant information, from which five overarching themes were generated, which were shown as follows.

#### Theme 1: PROs management improves communication with healthcare providers

The structured process on PROs management program of reporting symptoms, side effects and overall well-being led to more meaningful and efficient interactions of patients with their medical teams. The effects seemed to be bilateral, manifested on both sides of the healthcare providers and patients.

#### Theme 2: PROs management improves perceived sense of care

The participants seemed to experience a heightened sense of being cared for after they were started on PROs management, who expressed that the act of regularly documenting and sharing their symptoms and experiences gave them a feeling of being more closely monitored.

#### Theme 3: PROs management is helpful for treatment decision-making

The structured reporting process of PROs management seemed to enable the participants to describe their experiences and symptoms in greater detail and in a better organized fashion, which was helpful for informing their own decision-making relating to their treatments. Also, by regularly documenting symptoms, side effects and overall well-being, they felt that their healthcare providers could make more informed, timely and tailored treatment decisions.

#### Theme 4: PROs management is instrumental for communicating with family

Participants also indicated that sharing their PROs with family members helped in conveying the reality of their condition and daily struggles more effectively. This transparency fostered a better understanding among family members about the patient's needs, symptoms and the impact of the disease on their life, which also served as a tool for patients to involve their families in their care journey, allowing for more supportive and empathetic family interactions.

#### Theme 5: Possible but uncertain quality of life benefits

Interestingly, the participants' perceptions on the impact of PROs management on quality of life were inconsistently. While some participants expressed a belief that PROs contributed positively to their quality of living, others were less certain or did not perceive a significant change.

Characteristic	Categories	Frequency (n)	Percentage (%)
Age, yr	< 50	1	6.7%
	50-60	9	60.0%
	> 60	5	33.3%
Gender	Female	7	46.7%
	Male	8	53.3%
Palliative care	Palliative chemotherapy	14	93.3%
	Symptomatic management	1	6.7%
Education level	Senior high or below	14	93.3%
	College or over	1	6.7%
PS ECOG	$\leq 1$	14	93.3%
	>1	1	6.7%

TABLE 1. Demographic and clinical information of participants ( $n = 15$ )

Themes	Content
Theme 1	PROs management improves communication with healthcare providers
Theme 2	PROs management improves perceived sense of care
Theme 3	PROs management is helpful for treatment decision-making
Theme 4	PROs management is instrumental for communicating with family
Theme 5	Possible but uncertain quality of life benefits

TABLE 2. Five themes obtained from the interviews

## Discussion

Our interviews uncovered five significant overarching themes, which seem to reveal multiple aspects of the impact of PROs on these patients' care and treatment experience.

Theme 1 focused on the improvement in communication between healthcare providers and patients through PROs management, which is a pivotal aspect of our findings and use of PROs management in clinical practice. The participants' experiences suggest a notable enhancement in the clarity and effectiveness of their interactions with medical professionals. This enhancement is largely attributed to the structured nature of PROs, which allows for a more comprehensive and detailed account of the patient's symptoms, side effects and overall well-being.

Theme 2 reflected a profound shift in the participants' perception of the care that they receive, which is central to patient-centered healthcare models. Another important aspect is the patients' act of participating in PROs management.

Theme 3 reveals a crucial role of PROs management in enhancing patients' involvement in treatment decision-making with their perceptions of improved communication and empowerment in their care, which also resonates with themes 1 and 2. Quick and specific reporting via PROs creates a direct and efficient channel of communication, which enables healthcare professionals to gain a better understanding of the patient's condition in real-time and tailor treatment plans promptly. Also, being able to regularly report their conditions and treatment experiences could allow them to feel more confident in their care, as repeatedly mentioned in theme 2. As a result, the use of PROs could significantly enhance the trust and improve rapport between patients and healthcare providers, leading to a more comfortable, open dialogue as well as better clinical decision-making.

Theme 4 reveals a significant yet often overlooked aspect, the role of PROs management in enhancing communication between patients and their families. The family members sometimes helped the patients document and report their conditions, which allowed the family members to learn about the patient's outcomes comprehensively. Healthcare professionals may draw on this finding by tailoring and implementing strategies to enhance patient care and support.

Theme 5 suggested the effect of PROs management in improving quality of life was complex. Quality of life in palliative care is influenced by a myriad of factors, including physical symptoms, psychological well-being, social relationships and existential concerns, improvements in one aspect may not necessarily lead to a holistic enhancement of quality of life. As a result, further quantitative investigations of the effects of PROs management on quality of life using mature assessment instruments should be conducted to establish the objective effects.

## References

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