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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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ABSTRACT

Objectives To explore the lived experiences of patients with advanced pancreatic cancer enrolled in a patient-reported outcomes (PROs) management programme and to preliminarily understand how PROs management influences various aspects of patient care and overall quality of life.

Design A qualitative phenomenological study.

Setting A national cancer care centre in Southwest China specialised in cancer care, with a comprehensive PROs management programme.

Participants 15 participants diagnosed with advanced pancreatic cancer.

Results Five key themes emerged from our interviews, including enhanced communication with healthcare providers, attributed to the structured nature of PROs; increased perceived sense of care, with patients feeling more valued and heard; PROs management facilitated better treatment decision-making, with patients feeling more involved and empowered; improved communication with family members, aiding in better understanding and support; and varied perceptions of the impact on quality of life, with some noting improvements in specific aspects like symptom management, while others were uncertain about the overall benefit.

Conclusions PROs management plays a significant role in improving communication between patients with advanced pancreatic cancer and their healthcare providers, enhancing patients' involvement in treatment decisions, and potentially improving family dynamics. However, the impact of PROs management on the overall quality of life of patients remains complex and individualised. The findings suggest that further research with a more diverse patient population is needed to fully understand the implications of PROs management in advanced cancer care.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study employed in-depth qualitative interviews to explore patient-reported outcomes (PROs) management, providing detailed insights into the experiences of patients with advanced pancreatic cancer.
- ⇒ We built basis for future quantitative investigations of PROs management applications in clinical settings.
- ⇒ The study included participants with relatively better physical health, whose Eastern Cooperative Oncology Group Performance Status (ECOG PS) scoring was 0–2, limiting the applicability of the findings to patients in more advanced stages of pancreatic cancer.

BACKGROUND

Pancreatic cancer is a highly aggressive tumour of the digestive system. According to the 2020 GLOBOCAN data, there were approximately 496 000 new cases of pancreatic cancer worldwide, with about 466 000 new deaths.[1] In China, the mortality and disease burden of pancreatic cancer is showing an increasing trend year by year.[2–4]

The high mortality rate of pancreatic cancer is mainly due to the lack of specific early symptoms, the absence of sensitive diagnostic methods, and effective treatments.[5 6] While chemotherapy remains the primary treatment recommended by clinical guidelines,[7 8] other treatment options such as immunotherapy may be available for select patients, particularly those with certain genetic markers.[9] Patients who fail second-line or higher chemotherapy have no effective treatment options, and there is a lack of effective drugs in clinical practice.[10]

Despite a slight improvement from previous years, the 5-year survival rate remains below 10%, one of the lowest among all cancers.[11 12] The quality of life for these patients is significantly impacted, who often experience debilitating symptoms such as pain, fatigue and gastrointestinal issues, alongside psychological distress, including anxiety and depression.[13–15] The management of these symptoms and enhancement of life quality form a crucial component of the care and support for patients with pancreatic cancer.

Patient-reported outcomes (PROs) are direct reports from patients about their health condition and treatment, without interpretation by healthcare professionals or others. They include a wide range of health data, such as symptoms, functional status and quality of life.[16] In oncology, the importance of PROs has been increasingly recognised for offering 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.[17–19]

Existing studies have demonstrated that routine collection of PROs can lead to improved patient-clinician communication, better symptom management and even enhanced survival outcomes. For example, Caminiti *et al* found that routine patient-reported outcomes screening may positively influence overall survival in cancer patients, with the largest benefits seen in individuals with advanced lung cancer.[18] According to Hinds' findings, PROs help determine the total impact of cancer therapies and provide individualised supportive care, but traditional approaches need a methodological shift to better understand patient-reported outcomes.[20] Other research has focused on the development and validation of PRO measurement tools, ensuring they are reliable, valid and sensitive to changes in a patient's condition.[21 22] Furthermore, literature has explored the challenges in implementing PROs in clinical practice, including issues related to technology, data management and integration into healthcare systems.[23 24] 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.

In the context of advanced pancreatic cancer, PROs can play a pivotal role in patient-centred care. By effectively capturing the patient's voice, PROs provide insights into the day-to-day challenges faced by these patients. This information may enable healthcare providers to understand the full impact of the disease and treatment on patients' quality of life. This is especially true in palliative care settings, where the focus shifts from curative treatment to symptom management and quality of life. With a well-structured and effectively implemented PROs programme, it can guide interventions aimed at symptom relief, emotional support and end-of-life care planning.

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. Understanding these experiences is essential for developing patient-centred care strategies and improving the quality of life for this vulnerable patient population. Our findings could inform healthcare providers about the specific needs and challenges of patients with advanced pancreatic cancer, leading to more effective and empathetic care approaches.

METHODS

Study design

This is a qualitative phenomenological study designed to explore the lived experiences of patients with advanced pancreatic cancer. The phenomenological approach was chosen because it focuses on understanding how individuals perceive and make sense of their experiences, particularly in the context of serious illness. This approach is well-suited for examining PROs, as it allows for an in-depth exploration of how patients experience and interpret their symptoms, treatment and overall well-being.

We employed semistructured, in-depth face-to-face interviews to capture these experiences. 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.[25]

Setting

Our work was conducted at Chengdu Seventh People's Hospital, a national palliative care centre for oncology patients, renowned for our expertise in the treatment of various type of cancer and systematic palliative care for advanced patients.

We implemented a comprehensive PROs management programme for patients with advanced pancreatic cancer treated at our hospital in early 2023, and by the time of the study, over 90 patients had participated. On enrollment, patients were given brief training on how to use the PROs management system to document and report their health data, including symptoms, treatment side effects, overall well-being and other relevant daily experiences. After providing informed consent, patients were instructed to complete the PROs via an online questionnaire and participate in follow-up phone calls with their oncologists.

The PROs questionnaire, developed using the Wenjuanxing online survey platform, combined several validated instruments, such as the Eastern Cooperative Oncology Group Performance Status (ECOG PS), MD Anderson Symptom Inventory (MDASI), European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), Functional Assessment of Cancer Therapy-Pancreatic (FACT-PA) and Palliative Care Outcome Scale (POS). To tailor the questionnaire for use with patients with advanced pancreatic cancer in palliative care, we removed duplicate items, reorganised the structure and translated it for ease of use. The questionnaire consisted of structured sections for quantitative data collection, along with an optional narrative section for reporting additional experiences.

In addition to the online questionnaire, oncologists followed up with patients via phone calls, tailored to each patient's condition and treatment schedule. These calls, usually conducted 3–5 times, allowed for the collection of recent conditions and were particularly useful for capturing narrative data on patients' experiences.

Participants

We recruited participants to the current study from inpatients admitted to the Palliative Care Ward or followed up at the Oncology Clinic between 1 August 2023 and 30 November 2023, who were selected using the following criteria:

Inclusion criteria: (1) Patient has advanced pancreatic cancer (defined as stage IV, locally advanced, unresectable, or metastatic disease), currently receiving outpatient or inpatient treatment or under follow-up at our hospital; (2) Aged between 18 and 70 years; (3) Has cognitive abilities sufficient to understand the study and provides informed consent; (4) Has a Performance Status (PS) score of 0–2, based on the ECOG PS scale, which indicates the patient is physically capable of engaging in a face-to-face interview for 15–30 min.

Exclusion criteria: (1) Patient has been diagnosed with or is concurrently suffering from other malignant tumours at the time of this study; (2) Has known psychiatric illnesses such as Alzheimer's disease, autism, mood disorders, or drug addiction, and/or other mental conditions deemed unfit for the current study as assessed by investigator; (3) Has cognitive impairments that preclude understanding or participating fully in the study; and (4) Has an ECOG PS score greater than 2, indicating a higher level of physical impairment that would make enduring a 15–30 min interview ethically inappropriate due to potential harm.

Notably, the ECOG PS is a widely used scale to assess a patient's ability to perform daily activities. It ranges from 0 (fully active) to 5 (deceased), with higher scores indicating greater physical impairment.[26] We selected patients with ECOG PS scores of 0–2, meaning they were able to carry out light activities or self-care, making them physically capable of participating in interviews without undue strain. This was meant to ensure that patients were healthy enough to engage in the interview process without risking harm, as those with higher ECOG scores might be too physically debilitated to safely participate in prolonged discussions.

Sampling

Purposive sampling was used to enrol participants in this study. This method was chosen to ensure that participants met specific criteria necessary for generating meaningful data on the lived experiences of patients with advanced pancreatic cancer undergoing PROs management. The primary investigator (PI) initially screened potential candidates through the hospital's electronic medical records to verify that they met the predefined inclusion and exclusion criteria, such as having an ECOG PS score of 0–2, ensuring they were physically and mentally capable of participating in the interviews.

After preliminary screening, the PI approached eligible patients during their hospital stays or clinic visits. In these encounters, the PI further assessed patients' physical and mental status, communication abilities, and willingness to engage in the study through brief greetings and casual conversation. This step ensured that the participants could provide in-depth, reflective data during interviews without experiencing undue distress.

If the patient was suitable and expressed interest in participating, the PI provided a detailed explanation of the study's purpose and procedures. Patients who consented to participate were enrolled in the study, and face-to-face interviews were conducted immediately or scheduled during a follow-up visit. Informed consent was obtained from all participants prior to enrollment.

Although purposive sampling allowed for the selection of participants who could provide rich qualitative data, we acknowledge that this strategy may limit the diversity of patient experiences, particularly for those in poorer physical states or receiving alternative treatments. Future studies could benefit from more varied sampling strategies to capture a broader range of patient experiences.

Face-to-face interview

An interview guide was developed for the semistructured interviews (online supplemental file 1), 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, according to the methodology described by Sandelowski, where interviews ceased to provide new analytical information or generate significant variations in data.[27]

Procedure

Our multidisciplinary research team was led by a senior oncologist (PI) specialising in cancer treatment and palliative care, who had been trained and experienced in PROs management. The other team members included three oncologists and two nurses, all with at least 5 years of experience working with patients with advanced cancer, including patients with pancreatic cancer.

All team members received training in phenomenological research methods and semistructured interview techniques. After developing the interview guide and questions with the team, the PI conducted interviews. If the PI was the treating physician of a participant, another researcher would conduct the interview to avoid any potential bias or discomfort for the patient. To prevent investigator burnout and ensure adequate time for data processing, no more than three participants were interviewed on any given day. The interview sessions were recorded using two audio recorders to capture the entire conversation, from the participant's seating to the end of the interview.

A grand tour question, typically phrased as "Could you tell me about your experiences related with your disease (pancreatic cancer) recently?" or "Can you describe how your life changed after your diagnosis?" was asked to begin interview. Probing questions such as "Can you tell me more about it (or a specific topic)?" were asked to encourage deeper elaboration. Interview techniques including probing, repetition, reflective responses, and moments of silence were employed to uncover the participants' genuine feelings and experiences.

Throughout the interview, the interviewer took field notes on significant aspects such as the participant's tone of voice, facial expressions and body gestures. The recordings and notes were catalogued immediately after each session.

A different investigator transcribed the audio recordings *verbatim* and verified the accuracy of the transcriptions within 24 hours.

Participants were anonymised by replacing their names with sequential numbers, that is, P1, P2, etc. Other personal identifiers in the transcripts, notes and medical records were also anonymised. Participants' confidentiality and privacy were preserved by storing all patient data, recordings and transcripts securely on a password-protected hard drive, with restricted access within the research team.

Rigour

We took several measures to ensure quality and integrity of data. The PI maintained an impartial attitude during interviews by avoiding personal opinions or judgments. Uncertainties observed during interview were immediately clarified. Doubts and discrepancies in understanding of transcripts were resolved by discussion among researchers. If it still remained after discussion, the PI would clarify it with participant by phone.

Data analysis

In this study, we employed Colaizzi's phenomenological method for data analysis. Each transcript was thoroughly read to gain a comprehensive understanding of the participants' experiences. Significant statements directly pertained to the participants' experiences were identified and extracted. The team then formulated meanings from the significant statements by interpreting the underlying significance of each statement and translating it into a coherent understanding.

Patient and public involvement

None.

RESULTS

Demographic and clinical characteristics

The PI initially selected and approached 23 candidates. Two candidates declined to participate due to unwillingness. The remaining 21 candidates agreed to take part in a face-to-face interview. Eventually, the PI interviewed 15 participants between 1 August 2023 and 30 November 2023 before reaching data saturation.

Table 1 Demographic and clinical information of participants (n=15)

Characteristic	Categories	Frequency (n)	Percentage (%)
Age, year	<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%
ECOG PS	≤1	14	93.3%
	≥1	1	6.7%

ECOG PS, Eastern Cooperative Oncology Group Performance Status.

The participants were aged 58.7 years on average (range, 43–70 years), most of them being 50–60 years of age (n=9, 60.0%), followed by those aged over 60 years (n=5, 33.3%). Their gender distribution was almost even, including 7 women (46.7%). Most participants had an education level of senior high school or below (n=14, 93.3%). All participants were on palliative care, including 14 undergoing palliative chemotherapy (93.3%) and 1 receiving only symptomatic management (6.7%). They were in acceptable physical states by the time of study, with 14 participants having an ECOG PS score ≤1 (93.3%). The demographic and clinical information of the participants is presented in table 1.

Themes

Each interview lasted approximately 17 min on average (range, 14–23 min). The interviews yielded abundant information, from which five overarching themes were generated, including 'PROs management improves communication with healthcare providers', 'PROs management improves perceived sense of care', 'PROs management is helpful for treatment decision-making', 'PROs management is instrumental for communicating with family' and 'Possible but uncertain perceived quality of living benefits'.

Theme 1: PROs management improves communication with healthcare providers

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

> Before (I) began to use the PROs, I felt like the doctors didn't fully grasp what I was feeling. Now, I can tell everything to them, our communications are more smooth, and I can explain what I feel in details… Feels like they can finally understand me. (P2)
>
> I think the (PROs) reporting has made the doctors more responsive. They see the information that I give, and (they) understand the severity of my symptoms better… This could help (them) make quicker adjustments in my treatment. (P7)

When describing their experiences as a patient:

> Very helpful for me. (The PROs programme) helps me remember all kinds of symptoms I've been having… Before (PROs) sometimes it's hard to recall some things during an appointment, but now using PROs, I can remember and tell almost everything to the doctor. (P1)
>
> I had difficulties describing my symptoms, especially how I feel, like how the pains were like and located, and how they affected me. After (I) began to use it (PROs), it feels like I could express better. (P11)

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 and attended to:

> (I) feel like I'm not just another patient, not like before (the PROs management)… It's reassuring in my heart, knowing that the doctors and nurses know what I experience every day, especially that they consider (my reports) when making (my) treatment plan. (P2)
>
> (PROs) gives me a sense of comfort. I know, at least I assume, that my feelings and symptoms are being tracked and used for my care… Reporting (PROs) makes me feel like I'm truly being looked after. (P8)
>
> Before, I used to feel like that to the doctors I am just another ordinary patient they see, but now, I feel differently. Feels like they're actually caring for me, listening to what I say, especially the details that they would otherwise not listen to. (P9)

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 organised 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. The active involvement of patient input in the decision-making process was perceived as empowering:

> The (PROs) records upgraded the level of detail about my experiences and symptoms. I can tell a lot more more quickly on my consultations… I can see my own condition more clearly and discuss my treatment decisions with the doctors. I could not do this before (PROs)… Now, it's very different. (P1)
>
> Reporting these (PROs) has directly influenced my treatment. When my symptoms worsened, I have the data to immediately show my doctor, who can make immediate adjustments… To give an example, before, it was like completely blank between treatments and consultations. I had no way to communicate with the doctors. Now, I can communicate with the doctors using the (PROs) reporting between (sessions)… I feel that they can decide better with more information I give. (P2)
>
> Yes, the recording and reporting (of PROs) are helpful. I felt more like I am actively participating in my treatment decisions… One time, my feedback through PROs informed my doctor about my symptom changes. The doctor discussed them with me and changed my medications. (P11)
>
> The doctors know more about my disease. This makes me feel confident about their judgement and treatment… I was always worried that I didn't tell them enough. (P12)

Theme 4: PROs management is instrumental for communicating with family

In addition to its roles for patient and healthcare providers, 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:

> It (PROs) is a bridge in my communication with my family. When I show them my PROs records, it is easier for them to understand what I'm going through and how they can support me. Not like before when I had lots of struggle trying to express to them how I felt. (P3)
>
> Discussing my PROs with my family is helpful for opening up conversations about my illness. We never felt like this before. (P12)

> My family sometimes couldn't believe how painful I was… They see how I feel every better now… They still underestimate the feels because they are not me feeling them, but their perspective and how they interact with me are different than before. (P13)

Occasionally, family members helped with the documentation and reporting, especially if the patient was of an older age:

> I don't know how to record these. My child always help me record. (The child) knows my disease better than I. (P4)
>
> I'm too old to understand what the doctors want exactly. It's been them (the children) helping me, documenting and answering the phone and stuff… They know everything. (P13)

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, according to our interview findings. 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:

> I think the reporting (of PROs) has helped improve certain aspects of my life, like getting my symptoms managed more quickly. But overall, I'm not sure if they've changed my quality of life significantly. (P3)
>
> Yes, my pains are definitely better managed after reporting (PROs) to the doctors. (P6)
>
> Hard to say. It's good that I communicate better with the doctors but I'm not sure how much it (PROs) has changed my quality of life. (P11)
>
> There are some benefits, like symptom relief, especially pain. I can tell more thoroughly about my conditions and the doctors can respond and make adjustments to my treatment. This could be helpful. (P12)

DISCUSSION

PROs are self-assessments provided by patients about their health status, symptoms, and the impact of disease and treatment on their daily lives. This patient-centric approach has been employed in various domains in clinical care, such as chronic disease management, postoperative recovery and mental health treatment.[28–31] However, its application in managing patients with pancreatic cancer, especially those in their advanced stages, has not been reported. In this study, we explored the lived experiences of patients with advanced pancreatic cancer who were enrolled in our PROs management programme, where they were required to regularly document and report their symptoms, side effects and disease-related experiences directly to their oncologists.

Our interviews with 15 enrolled participants uncovered five significant overarching themes, which seem to reveal multiple aspects of the impact of PROs on these patients' care and treatment experience. The first theme focused on the improvement in communication with healthcare providers 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.

The perceived improvements were on both sides of healthcare providers and patients according to the participants' feedback. It aids healthcare providers in understanding of patients' conditions, which is significant for informing their decision-making. This echoes with theme 3 where participants indicated PROs management to be helpful for treatment decision-making, and aligns with the findings of other scholars.[32 33] By having access to detailed and systematic patient reports, healthcare providers can gain a deeper insight into the severity and impact of symptoms, especially the dynamics of changes, and be more responsive to make timely adjustments in treatment. Similar impact was also reported by other researchers who studied the effects of PROs in other clinical domains.[34 35]

Participants also highlighted the impact of PROs management from patient perspective, where PROs reporting aided them in recalling and articulating their symptoms more effectively. This benefit is particularly relevant for patients with complex conditions, such as advanced pancreatic cancer in our case, whose symptom burden can be high and varied.[5 36] The ability to accurately convey their experiences is essential for patients, as noted in previous research about patient articulation's key role in personalised care.[37]

Theme 2 reflected a profound shift in the participants' perception of the care that they receive, which is central to patient-centred healthcare models. Patients expressing feelings of being "more than just another patient" (P2) or feeling "truly being looked after" (P8) demonstrates a critical aspect of successful healthcare delivery, which is the need for patients to feel valued and heard in their care process, especially such vulnerable individuals as patients with advanced cancer. The finding is consistent with Ingersoll's work, which emphasised the psychological benefits of patients feeling recognised and understood by their healthcare providers.[38] By regularly documenting and sharing their experiences, patients likely perceive an increased attentiveness to their individual needs.

Another important aspect is the patients' act of participating in PROs management. This empowers the patients as they become active contributors to their care, evidenced by statements such as feeling reassured that their reports are considered in treatment planning (P2) and the sense of comfort in knowing their experiences are tracked (P8). This observation was also reported by numerous previous studies, which suggest that patient involvement in care processes can enhance their sense of agency and improve the overall experience of care.[39–41]

The participants' experiences suggest a shift in the dynamics of their relationship with healthcare providers. As noted by P9, the feeling that doctors are "actually caring" and "listening" to the details reflects a move towards a more empathetic and patient-focused approach in clinical interactions. This shift is crucial, as indicated by previous studies which find that a strong patient-provider relationship could positively impact patient satisfaction and adherence to treatment plans.[37 42]

Theme 3 reveals a crucial role of PROs management in enhancing patient involvement in treatment decision-making with their perceptions of improved communication and empowerment in their care, which also resonates with themes 1 and 2. As noted by P1, the use of PROs significantly improved the level of detail and clarity in communicating their experiences and symptoms. The ability to convey more information quickly and effectively allows patients to have a clearer view of their condition, facilitating more informed discussions about treatment options. According to P2's experiences, PROs even resulted in direct impact on treatment adjustments because timely reporting of symptom changes enables healthcare providers to make immediate and more precise treatment modifications. These findings are consistent with the study by Stabile *et al*, where they found that timely symptom reporting can lead to quicker therapeutic adjustments and decision-making.[43]

Furthermore, 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 and address concerns promptly. On the patient side, 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. This confidence stems from the knowledge that their healthcare providers are well-informed and responsive to their needs. 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.[44]

Theme 4 reveals a significant yet often overlooked aspect of patient care, the role of PROs management in enhancing communication between patients and their families. According to our interview findings, PROs management caused changes in how family understand and support the patients. The use of PROs as a communication bridge, as described by P3, is instrumental in enhancing family members' understanding of the patient's experiences. By providing a tangible record of the patient's symptoms and struggles, PROs help family members to visualise and comprehend the realities of the patient's condition. Thomson and Bujoreanu reported similar findings which emphasised the importance of effective communication in improving family support for patients with chronic illnesses.[45] P12's experience of PROs opening up conversations about their illness demonstrated another critical function of PROs management, which is initiating dialogues that might not otherwise occur.

The change in family interaction, as noted by P13, reflects a shift in family members' perceptions. This shift likely results from a better understanding of the patient's symptoms and challenges, which are objectively recorded in PROs. This change in interaction is crucial for the patient's emotional well-being as empathy from family members can significantly affect the quality of life of patients with severe illnesses.[46 47] Additionally, 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. This presents a unique opportunity to channel information exchange and communication between patients and their family. Healthcare professionals may draw on this finding by tailoring and implementing strategies to enhance patient care and support. For instance, PROs reports can be integrated in care discussions and decision-making with patient families. This inclusive approach may not only educate the family but also create a shared sense of responsibility and involvement in the patient's care plan.

To our surprise, the effect of PROs management in improving quality of life was complex among patients with advanced pancreatic cancer, according to our findings under theme 5. The varied responses from participants, ranging from recognition of certain benefits to uncertainty about the overall impact, reflect the multifaceted nature of quality of life considerations, especially in a palliative care setting.

The inconsistency in perceptions, as noted by participants like P3 and P11, suggests that while PROs management may improve specific aspects of patient care, such as symptom management, its overall impact on quality of life is less clear-cut. Symptom management is crucial, but it does not always translate directly to an improved quality of life due to the complexity of factors involved.[48]

Additionally, the varied responses could also be attributable to the individual nature of experiencing and coping with a life-limiting illness. As P6 and P12 noted improvements in symptom management, it reflects that for some patients, effective symptom control can significantly enhance their daily living experience. However, as per P11's experience, this does not uniformly translate to a perceived improvement in overall quality of life for all patients. Numerous other studies have demonstrated the subjective attribute of quality of life.[49 50]

Furthermore, the uncertainty also points to the inherent challenges in assessing and improving quality of life in the context of advanced cancer. As identified in the work of McCaffrey *et al*, quality of life in palliative care is influenced by a myriad of factors, including physical symptoms, psychological well-being, social relationships and existential concerns.[49] The multifactorial nature of these influences means that improvements in one aspect, such as improved symptom management through PROs, 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.

Limitations

Our study, while offering valuable insights, is subject to several limitations. Though the sample size of 15 participants is adequate for a qualitative study design, it may not cover the full spectrum of experiences among patients with advanced pancreatic cancer. A notable aspect is the limited diversity in treatment modalities, where 14 out of 15 participants were undergoing palliative chemotherapy, with only one receiving therapy only for symptom management. This homogeneity in treatment experiences could lead to less representative findings. Additionally, our study exclusively included patients with advanced pancreatic cancer with a ECOG PS score of 0–2. This means that our participants were in relatively better physical condition. Their experiences might not accurately reflect those of patients in more advanced stages. Consequently, while our study sheds light on certain aspects of the impact of a PROs management programme and suggests future research directions, the findings should be interpreted with caution. We recommend further studies with a more varied and representative sample, particularly focusing on patients in poorer physical states, to obtain a more comprehensive understanding of PROs management in advanced pancreatic cancer care. Furthermore, while our study focused on the patients' perspectives, exploring how clinicians engaged with the PROs or how the programme influenced their decision-making processes is another worthy perspective for future studies to provide a comprehensive understanding of how PROs affect patient care from both sides.

Conclusions

PROs management plays a significant role in improving communication between patients with advanced pancreatic cancer and their healthcare providers, enhancing patients' involvement in treatment decisions, and potentially improving family dynamics. However, the impact of PROs management on the overall quality of life of patients remains complex and individualised. The findings suggest that further research with a more diverse patient population is needed to fully understand the implications of PROs management in advanced cancer care.

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Contributors PC, WH, CL and CY conceptualised and designed the study. WH and PC conducted the interviews. PC, WH, CL and QL transcribed the audio recordings. LM and XZ verified the transcripts. PC, WH, CL and QL analysed the data. PC, WH, CL, QL, XZ and CY interpreted the themes. PC, WH and CY drafted the initial manuscript. All authors reviewed and approved the final version for submission and agree to be accountable for all aspects of the work. CY is the guarantor. We used ChatGPT to translate the initial manuscript and polish the English writing. Study design, data collection, analysis, and interpretation, and drafting of the initial Chinese manuscript were all done by human researchers.

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