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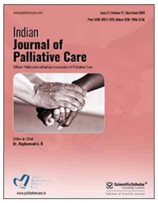

Original Article

Lived Experiences of Pancreatic Cancer Patients Undergone Whipple Procedure: A Qualitative Study

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ABSTRACT

Objectives: Pancreatic cancer is a devastating illness with significant impacts on patients' health-related quality of life (HRQoL). The Whipple procedure, a common surgical intervention for pancreatic cancer, presents numerous challenges for recovery and adaptation. This study aims to provide a comprehensive understanding of the lived experiences of patients' post-Whipple surgery. The objective of the study is to explore the lived experiences of patients having cancer of the pancreas undergone Whipple's procedures.

Materials and Methods: A qualitative phenomenological approach was employed to delve into the experiences of patients who underwent the Whipple procedure. Twenty-seven patients attending the surgical gastroenterology outpatient department of a tertiary care institution for follow-up were enrolled in the study. The patients were enrolled consecutively till the saturation of data. An interview guide was used to collect the data. The data were analysed using Colaizzi's method to identify the key themes.

Results: The participants, with a mean age of 51.61 ± 10.89 years, were predominantly male (61.7%) and Hindu (70%) by religion. Most participants had tumours of the head of the pancreas and were hospitalised for 16–30 days at the time of surgery. Thematic analysis revealed eleven themes, i.e. post-diagnosis reaction, burden of the disease, physical problems, socioeconomic burden, psychological issues, impact on social life, financial support, disturbed body image, spirituality, communication with healthcare professionals and hospital experiences.

Conclusion: This study underscores the multifaceted challenges faced by pancreatic cancer patients post-Whipple procedure, highlighting the importance of addressing physical, emotional and socioeconomic aspects to improve their HRQoL. The findings can inform healthcare professionals in developing holistic care strategies tailored to these patients' unique needs.

Keywords: Lived experiences, Pancreatic cancer, Whipple procedure

INTRODUCTION

In developed countries, pancreatic cancer ranks fourth or fifth in terms of cancer-related mortality. India is no exception to this phenomenon; variations have been noted in other regions, with the northeast exhibiting higher frequency.[1]

Pancreatic cancer is often diagnosed late due to inadequate screening methods, limited diagnostic resources and patient-related barriers such as fear and anxiety related to uncommon symptoms.[2] In around 80% of patients, it is either locally progressed or there is metastatic illness at the time of diagnosis and the patients are left only with palliative care. Hence, patients' functionality, general well-being and other aspects of their health-related quality of life are adversely affected by pancreatic cancer.[3] Patients diagnosed with pancreatic cancer have to undergo a series of treatments such as surgery, chemotherapy and radiation therapy and each treatment modality has its own side-effects.[4]

For patients with localised disease, a pancreaticoduodenectomy (Whipple surgery) is performed to remove the tumour from the head of the pancreas. Although it increases the survival of an individual with the best outcomes and potentially a cure, being a complex and extensive procedure, it is associated with

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many immediate, short-term and long-term complications impacting their quality of life.[5]

Therefore, understanding the lived experiences of pancreatic cancer patients after the Whipple procedure will provide more insight into the problems of the patients and will help plan various interventions for them.

MATERIALS AND METHODS

Study design and setting

A phenomenological study design was employed to explore the lived experiences of a pancreatic cancer patient undergone the Whipple procedure and is attending surgical gastroenterology outpatient department (OPD) of a tertiary care centre for follow-up.

Study participants

The participants who were more than 18 years of age and had undergone Whipple surgery 3 months before enrolment were included in the study. However, the patients with an inability to communicate were excluded from the study.

Sample size and sampling technique

The purposive sampling technique was used to collect the data. The interviews were continued till data saturation which was achieved at the 25th interview; however, to ensure that there was no new information, two more interviews were conducted. Hence, the total sample size was 27. The duration of the interviews was between 45 and 60 min.

Ethical consideration

The study was approved by the Institute Ethical Committee (IEC-INT/2023/Msc-1057). Informed written consent was sought from each participant after briefing them about the study. Confidentiality of the information was assured to them.

Data collection and analysis

A separate room was arranged in the OPD to conduct the interviews. Patients willing to participate were interviewed face-to-face using the pre-validated interview guide. The patients were made comfortable at the beginning by asking them general questions about their health and well-being, such as ‘How are you feeling after the surgery?’ and ‘How long have you been coming for follow-up etc.?’ Following this, other questions asked were related to their experiences with the procedure, any difficulties faced during recovery, their understanding of the condition and treatment and their overall satisfaction with the care received. For example, questions included ‘Can you describe any challenges you faced during your recovery?’ and ‘How well do you feel you understand your condition and the treatment you received?’ Certain probing questions were also asked during the interview. Data were analysed using Colaizzi’s steps of data analysis. Each interview was transcribed into Hindi and translated into English. The transcribed text was read and reread repeatedly to understand the meaning. Words and sentences with similar meanings were identified and coded. Codes with similar meanings were classified into subthemes, which were further grouped into themes that reflected the central content.

Data quality control

Validation processes included member checking and expert review, reinforcing the accuracy and trustworthiness of interpretations. Adherence to ethical guidelines, such as obtaining informed consent and institutional approval, safeguarded participant welfare maintained the integrity of the research. These rigorous measures underscored the study’s methodological rigour, ensuring that its findings on the impacts and obstacles faced by pancreatic cancer patients post-Whipple surgery were robust and pertinent for informing healthcare practices and policy development efforts.

RESULTS

Table 1 depicts the sociodemographic and clinical profile of the participants. The mean age of the participants was 51.61 ± 10.89 years, 35% were over 50 years old and the majority were male (61.7%). A significant portion of patients resided in rural areas (80.0%) and were married (98.3%). In terms of education, 43.3% had completed high school, while 13.3% had an intermediate or diploma level of education. The tumours were primarily located in the head of the pancreas (58.3%) and were mostly 3–5 cm in size (58.3%). Regional lymph node involvement was noted in 86.6% of the cases, while 71.6% of the patients did not exhibit distant metastasis. Treatment modalities included chemotherapy (30.0%) and radiation therapy (5.0%). The length of hospital stays for the majority of patients (60.0%) was between 16 and 30 days.

Experiences of pancreatic cancer patients after Whipple surgery

Experiences of the patients related to cancer diagnosis, management and coping mechanisms were explored. From the narration of cancer patients, eleven categories of themes emerged. These were post-diagnosis reaction, burden of the disease, physical problems, socioeconomic burden, psychological issues, impact on social life, financial support, disturbed body image, spirituality, communication with healthcare professionals and hospital experiences [Table 2].

Theme 1: Post-diagnosis reaction

The patients were asked about their thoughts and emotions immediately after they were diagnosed. The participants had significant fears about developing pancreatic cancer. These fears were primarily centred around two main concerns: The possibility of dying in pain and the prospect of burdening their loved ones. These fears were often influenced by

Table 1: Sociodemographic and clinical profile of patients undergone the Whipple procedure (*n*=60).

Variables	f(%)
Age (years)*	
<30	11 (18.3)
31–40	15 (25.0)
41–50	13 (21.7)
>50	21 (35.0)
Gender	
Male	37 (61.7)
Female	23 (38.3)
Educational status	
Illiterate	11 (18.3)
Primary	02 (3.4)
Middle	13 (21.7)
High School	26 (43.3)
Intermediate/diploma	08 (13.3)
Habitat	
Urban	12 (20.0)
Rural	48 (80.0)
Marital status	
Unmarried	01 (1.66)
Married	59 (98.3)
Site of pancreatic cancer	
Head of the pancreas	35 (58.3)
Body of pancreas	08 (13.3)
Other**	17 (11.6)
TNM classification	
Primary tumour	
T1 (>2 cm)	17 (28.3)
T2 (2–3 cm)	8 (13.3)
T3 (3–5 cm)	35 (58.3)
Involvement of regional lymph node	
N0 (no involvement)	08 (13.3)
N1 (single lymph)	35 (58.3)
N2 (more than 2 lymph node)	17 (28.4)
Distant metastasis	
M0	43 (71.6)
Mx	17 (26.66)
Types of treatment	
Chemotherapy	18 (30.0)
Radiation	03 (5.0)
Length of hospital stay	
5–15 days	11 (18.3)
16–30 days	36 (60.0)
31–45 days	11 (18.4)
>46 days	02 (3.3)

*Mean±SD: 51.61±10.89 years; Range (30–75) year

**Duodenal adenocarcinoma, neuroendocrine tumour D1 and D2, Distal cholangiocarcinoma, serous cyst carcinoma, TNM: Tumor, node, and metastasis

Table 2: Themes and subthemes generated from the data (*n*=27).

Sr. No.	Themes	Subthemes
1.	Post-diagnosis reaction	a. Feeling of fear and worry b. Fear of abandoning the children c. Lack of knowledge of diseases
2.	Burden of long-term treatment	a. Burden of follow-up b. Facing long distance constraints
3.	Physical problem	a. Abdominal pain b. Fatigue c. Disturbed sleeping pattern d. Side effects of chemotherapy
4.	Socioeconomic burden	a. Medication Adherence b. Financial Constraints post-surgery c. Effect on studies d. Loss of occupation
5.	Psychological issues	a. Change in behaviour b. Feeling of loneliness
6.	Impact on social life	a. Avoid social visit b. Perceived social stigma
7.	Financial support	a. From the family b. From the relatives and the friends
8.	Disturbed body image	a. Weight loss b. Loss of hair
9.	Spirituality	a. Thanking god for saving life
10.	Communication with Healthcare Professionals	a. Good communication b. Language barrier
11.	Hospital experiences	a. Dissatisfaction related to hospital b. Satisfaction with nursing care

personal or family experiences with pancreatic cancer, where they may have witnessed a loved one suffering or facing difficulties. In addition, personal concerns about their own well-being and the impact on their family played a crucial role in shaping their initial reactions.

> *My reports came in a few days ago. When the doctor examined my reports, it was revealed that my cell count had increased. I became very scared, and I started to worry a lot about how I could have acquired this illness. When I heard about my illness, my hands and body started*

> *shaking. I kept asking the doctor repeatedly if there was a cure for this illness. I was so scared that I didn't know what would happen next* (Participant 1).

Theme 2: Burden of long-term treatment

Patients were asked about the difficulties they faced with long-term treatment. The theme 'Burden of Long-Term Treatment' illustrates the challenges faced by pancreatic cancer patients over time. Participants described difficulties attending appointments due to distance and coronavirus disease-19 disruptions, leading to uncertainty about recovery. Emotional strains, including marital stress, and logistical issues managing hospital systems were also highlighted.

> *It is very difficult to come and go from such a long distance or one has to come for chemotherapy also. Here's a side-by-side follow-up. Whenever one has to wait for OPD, one has to wait in line, it is very difficult* (Participant 4).

Theme 3: Physical problem

Patients were enquired about the physical challenges; they have experienced as pancreatic cancer patients. These themes illustrate the physical challenges faced by pancreatic cancer patients: Severe abdominal pain and sleep disturbances after surgery, chronic fatigue and weakness affecting daily tasks and side effects such as hair loss and digestive problems from chemotherapy.

> *After the operation, I didn't feel anxious at all, not even one percent. I'm not someone who gets scared; I've face death closely before and was glad that my illness could be cured. The doctor said complications may arise, but there's no need to worry. I get really scared if anything happens to me. After the surgery, I experience a lot of stomach pain and weakness. If I get stomach pain, I can't sleep the whole night; I spend the entire night crying. Taking medicine provides some relief, but then the stomach pain returns.* (Participant 2).

Theme 4: Socioeconomic burden

Patients were asked about their experiences with financial support. Patients' discussion on the 'Financial Support System' theme showed a range of experiences: Gratitude for strong family support in managing cancer-related financial burdens contrasted with frustration over lack of support and criticism post-surgery, alongside reflections on the impact on relationships with relatives and friends.

> *Experiencing some financial difficulties, especially after being at home for 2 months. I'm facing financial issues now. I'm not receiving any pay, and my medical benefits have run out. Previously, I used to receive pay along with medical benefits, but now that I've been at home for 2 months, my medical leave has also expired* (Participant 19).

Theme 5: Financial support system

Patients were asked about the people who helped them during their treatment. The financial support system reveals different experiences among participants: Some were thankful for strong support from family, especially from spouses and parents, in dealing with the financial challenges of pancreatic cancer treatment. Others mentioned the lack of family support and facing criticism for their financial decisions after surgery. Participants also discussed the impact on relationships with relatives and friends.

> *There are no problems; my family is providing support in every possible way. My father and my wife are helping me completely. There are no issues, but it would be even better if my body recovers soon* (Participant 15).

Theme 6: Psychological issue

Patients described how their psychological experiences evolved during treatment, revealing significant behavioural changes and feelings of loneliness among participants. These changes included disruptions in daily routines and social discomfort, especially with women. Feelings of profound loneliness were prevalent, with one participant expressing a dependency on their spouse's presence, while another noted a positive shift with increased family support.

> *I feel very lonely. I don't let my husband go far; I ask him to come back to me after finishing his work* (Participant 16).

Theme 7: Impact on social life

Patients described how these issues influenced their social lives. Participants avoided social events due to dietary restrictions, frustration with repeated health enquiries and perceived social stigma. One participant expressed feeling particularly frustrated by constant questions about their condition. They also experienced significant weight changes, including notable weight loss during illness and fluctuating weight post-surgery.

> *After the surgery, I have stopped attending wedding functions because I need to be mindful of what I eat and drink there. I also avoid going because everyone asks the same question about what happened, which frustrates me.* (Participant 2).

Theme 8: Disturbed body image

The patients were asked how their cancer treatment has influenced their body image. Participants in Theme 8, i.e. disturbed body image, discussed the impact of chemotherapy. One of the participants described initial hair loss during treatment, which later resolved as their hair regrew. Another noted ongoing side effects such as hair loss and digestive issues despite multiple chemotherapy cycles. These insights highlight the challenges individuals face in maintaining their physical appearance and well-being during cancer treatment.

> *When I had chemotherapy, I had a lot of side effects, my hair fell out. Now my hair has come back again* (Participant 19).

Theme 9: Spirituality

Patients were asked about expressing gratitude to God for preserving their lives. Participants talked about thanking God for keeping them alive. One felt better after discussing their illness and thanked God for saving their life. Another said that they are alive because of God, despite their health issues. This shows how important faith is for them in dealing with illness and valuing their life.

> *It seems as if you are asking all the questions related to my illness. I felt better after talking to you and my mind has become lighter. Thank God for saving my life* (Participant 1).

Theme 10: Communication with healthcare professionals

Patients were asked about their experiences with communication with healthcare professionals. In theme 10, Communication with Healthcare Professionals, participants had varied experiences. Some participants praised the clear and supportive communication; they received from nurses and doctors, highlighting effective care and understanding (Participants 5 and 6). However, others noted occasional challenges with medical terminology and language barriers, despite generally positive interactions (Participants 12 and 17). These insights underscore the critical role of effective communication in healthcare, ensuring patients feel informed and supported throughout their treatment journey.

> *Yes, there is a lot of caring here, everyone cares and explains everything well which is why I am fine here* (Participant 5).

Theme 11: Hospital experiences

The patients were also asked about their hospital experience. According to the participants, hospital experiences were mixed. Satisfaction with nursing care was high, with participants praising the attentive and caring staff. However, there was significant dissatisfaction with the hospital facilities, particularly due to the inconvenience of daily visits and long wait times, which were especially challenging for patients such as Participant 10 and Participant 21 after surgery.

> *Yes, there is a lot of caring here, everyone cares and explains everything well which is why I am fine here* (Participant 5).
>
> *Yes, it was very comfortable. The nurses and doctors took very good care of me, unlike the hospital where neither the nurses nor the doctors cared* (Participant 14).

DISCUSSION

The study provides significant insight into the aim of the study by explaining the lived experiences of the patients after the Whipple procedure. Since the study was done 3 months after the Whipple surgery, this period can provide great insight into the immediate outcome after the Whipple procedure. Following Colaizzi's steps of data analysis, eleven main themes emerged. These were post-diagnosis reaction, burden of the disease, physical problems, socioeconomic burden, psychological issues, impact on social life, financial support, disturbed body image, spirituality, communication with healthcare professionals and hospital experiences.

The current findings reported that these patients often face a lot of emotional and physical challenges as they struggle with managing symptoms, lack a support system and have limited communication with healthcare providers, which can make them feel stressed and isolated. These challenges impact their overall well-being and quality of life, showing the need for more support. Similar findings of difficulties in managing the patient's symptoms, limited communication with healthcare providers and a lack of adequate support have been reported by Chong *et al.*[6] It has been further reported that the patient's caregivers also reported high levels of anxiety and sadness highlighting the need for personalised support interventions to improve caregiver well-being and enhance their quality of life.

The post-diagnosis reactions among individuals facing potential health challenges, particularly cancer, reveal profound emotional and cognitive responses. Participants expressed intense fear and worry upon receiving test results indicating health abnormalities, with concerns ranging from the treatability of their condition to the uncertainty of their future health. One of the participants verbalised '*I got my test reports today. When the doctor examined my reports, it was revealed that my cell count had increased. I became very scared, and I started worrying a lot about how I could have acquired this illness. When I heard about my illness, my hands and body started shaking. I kept asking the doctor repeatedly if there was a cure for this illness. I was so scared that I didn't know what would happen next.*' The results are consistent with the findings of a study by Conley *et al.*[7] that pancreatic cancer patients experienced emotions such as shock and fear when they got to know about their cancer diagnosis. Hence, it stresses the significance of patient-focused communication in delivering bad news and suggests incorporating their viewpoints to enhance support.

The current study also brought out the burden associated with treatment where they expressed uncertainty about recovery, the burden of follow-up and long-distance constraints. These findings are in line with Prinja *et al.*[8] wherein the mean direct out-of-pocket expenditure per outpatient consultation and an episode of hospitalisation were estimated as INR 8053 and 39085, respectively, and per annual treatment cost as INR 331,177.

In the present study, the participants reported significant pain in the stomach after surgery, affecting their ability to work. Weakness is experienced after surgery, affecting the individual's ability to work and engage in daily activities. One of the participants verbalised that after *the surgery, I experienced a lot of stomach pain and weakness. If I get stomach pain, I can't sleep the whole night; I spend the entire night crying. Taking medicine provides some relief, but then the stomach pain returns.* A similar study was conducted by Coveler *et al*.[9] reported abdominal pain among the patients which disturbed their sleep quality and also affected their day-to-day life.

Participants in the current study reported a profound impact of the diagnosis and treatment on their lives, including physical weakness, anxiety and various side effects such as hair loss and fatigue from chemotherapy. Burrell[10] has reported that fatigue, difficulty sleeping, loss of appetite, difficulty digesting meals and weight loss were consistently identified as the most common and severe symptoms. Fatigue, the most common symptom experienced by participants can occur because of the treatment of cancer and cancer itself. Pancreatic cancer can cause fatigue due to inflammation, metabolic changes, anaemia, pain, sleep disturbances, nutritional challenges secondary to digestive problems and emotional stress. Treatment-related fatigue may be associated with chemotherapy, radiation therapy, anxiety about treatment outcomes, weight loss, muscle wasting and emotional distress.

Following surgeries, participants described challenges such as being unable to work, financial difficulties and concerns about family responsibilities. Some relied on family support for daily tasks, while others faced business disruptions and financial strain due to their health conditions. One of the participants verbalised that '*A lot of financial difficulties have arisen after the surgery. Sometimes, there isn't even enough money for medication*'. Similarly, in a study conducted by Sun *et al*.[11] on financial stress, the findings reveal that a significant proportion of pancreatic cancer patients rated their family's financial stress as moderate (49%) or severe (36%), with higher levels of financial strain correlating with heavier caregiving burdens on pancreatic cancer caregivers.

Body changes such as weight loss resulting from illness may affect a person's self-image and confidence. One of the participants verbalised '*Yes, there has been a significant change in my body. Previously, I used to look very good, but now there's a noticeable difference. My weight has improved a bit now, but during the illness, I lost a lot of weight.*' In a study by Nayak *et al*.,[12] it was found that 85% of the surveyed people with cancer were not satisfied with their bodies. Thus, they may need support and resources to help them cope with these challenges.

The present study brought out various psychological concerns such as tension, worry, irritability, depression, low confidence and avoidance of social functions related to poor self-image. One participant verbalised '*My behaviour has changed a lot; I don't behave the same as before. I don't like talking to anyone, especially not to women.*' A similar finding was also reported in a study conducted by Yılmaz *et al*.[13] wherein the participants had a belief that cancer is a social stigma due to its poor prognosis and its associated challenges and treatment. Because it is often diagnosed at a late stage when treatment options are limited, there can be a sense of hopelessness surrounding the disease. People may feel isolated or may have misconceptions about the diseases contributing to the stigma.

In addition, in terms of spirituality, participants in the current study expressed gratitude to God for their lives being saved. This showed that spirituality brings a positive attitude to the patients during their treatment journey. Similar to our findings, a study conducted by Taylor *et al*.[14] has explored the significance of spirituality in patients undergoing chemotherapy for pancreatic ductal adenocarcinoma, emphasising the necessity of providing spiritual support, identifying and addressing negative emotions, strengthening health education, emphasising companionship and creating a positive atmosphere is crucial for enhancing spiritual well-being. Furthermore, the study underscored the critical role of managing symptoms such as anxiety, fatigue and insomnia, as these factors profoundly affect the spiritual well-being of an individual.

Social support can have a significant impact on the quality of life of the individuals facing pancreatic cancer. Having a strong support system can provide emotional support, practice assistance and a sense of belonging. It can also reduce the feeling of isolation, anxiety and depression and improve overall well-being. As per Bekele *et al*.,[15] social support has an indirect impact on the quality of life and a direct impact on the perceived health status and functional status. In the present study, the patients reported having family support and support from friends as one of the participants verbalised '*My family is fully supporting me; my daughter is more supportive and caring*'.

In terms of hospital experiences, the current study participants expressed satisfaction with nursing care while some expressed a language barrier with healthcare professionals in the OPD. Similar findings were observed in a study by Mehrnoosh *et al*.[16] on effective patient-professional communication. It has been revealed that most cancer patients were satisfied with nurse communication. Effective patient–nurse communication is vital for cancer patients' psychosocial well-being. The study reported that among 384 patients, 81.5% were satisfied with the communication and information provided by nurses while 18.5% were not satisfied.

Limitations of the study

The data were based on the subjective assessment of the patient's experiences with pancreatic surgery. Patients could have provided socially desirable responses or not accurately recalled their experiences, leading to biased data.

CONCLUSION

Despite multiple treatment options, pancreatic cancer patients who undergo Whipple surgery face numerous ongoing health problems. Their lived experiences emphasise the need for a dedicated patient care system that specifically addresses these issues to enhance their overall quality of life.

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Ethical approval: The research/study was approved by the Institute Ethics Committee at Postgraduate Institute of Medical Education & Research (PGIM, number IEC/INT/2023/Msc-1057, dated April 01st, 2023.

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