

BMJ Open Psychological experience of inpatients with acute pancreatitis: a qualitative study

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ABSTRACT

Objective This study aimed to better understand the psychological experiences of inpatients with acute pancreatitis (AP).

Design We used a qualitative descriptive study design to capture patients with AP's thoughts, feelings and behavioural responses.

Setting We conducted this study in the gastroenterology departments of two tertiary hospitals in Eastern China.

Participants We used a convenience sampling approach to recruit 28 inpatients with AP from 1 August 2020 to 25 December 2020. The interviews were audio-recorded and transcribed verbatim. We employed an adapted version of Colaizzi's qualitative analysis approach to examine the data.

Results We extracted three themes and eight subthemes regarding the participants' psychological experiences: (1) feeling that their disease is unpredictable (the inability to recognise the disease, uncertainty about the illness and fear of progression or recurrence); (2) various kinds of stress and support (feeling different degrees of stress, perceiving social support, seeking and craving social support); and (3) developing self-adaptability in the disease process (treating one's illness negatively or positively).

Conclusions Cognitive and emotional responses vary in patients with AP during hospitalisation. Moreover, patients with distinct conditions demonstrate significant differences in their responses and coping mechanisms. Healthcare providers need to mobilise social support and formulate comprehensive intervention strategies according to patients' individual characteristics.

INTRODUCTION

Acute pancreatitis (AP) is an inflammatory disorder of the pancreas associated with pain, physical limitations and changes in visceral function.¹ The annual incidence of AP is 34 cases per 100 000 people in the general population.² After the initial onset of AP, 21% of patients experience relapse. Nearly 36% of recurrent AP (RAP) cases progress to chronic pancreatitis, which is a significant health burden,³ and is associated with pancreatic cancer.^{2 4} Regardless of the severity of the illness, 40% of patients will develop new-onset pre-diabetes or diabetes after their first

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first qualitative descriptive study that has explored the psychological experiences of inpatients with acute pancreatitis (AP).
- ⇒ The feelings and behavioural responses captured from different types of patients with AP have led to a deeper understanding of their psychology.
- ⇒ The study's qualitative descriptive design ensured a broader picture of the patients' inner world as generated from their perspectives.
- ⇒ One limitation might be the convenience sampling technique used.
- ⇒ Each patient was interviewed only once, which could not capture the process of change in psychological experiences.

episode of AP.⁵ About 29% of patients with AP will develop exocrine pancreatic insufficiency, and the incidence of osteoporosis in patients with AP is 1.27 times higher than that in patients without AP.² Systemic or local complications and sequelae result in substantial medical, personal and social burdens. These burdens affect patients' mental state, especially during an AP attack.^{6 7}

A meta-analysis indicated that the prevalence of anxiety among patients with AP is 29%, and incidence of depression is 35.7%.⁸ Gupta *et al* reported that anxiety levels in patients with severe AP (SAP) were high and did not change significantly during the first 7 days of hospitalisation, while depression levels first increased and then decreased.⁶ Patients with RAP may experience several negative emotions including helplessness, inevitability, guilt and shame.⁹ A nationwide case-control study also revealed that AP can increase the risk of suicide.¹⁰ Mental disorders are associated with increased 30-day readmission, length of stay and cost of hospitalisation.¹¹ It is essential to ascertain patients' psychological experiences after developing AP, as they involve

the psychological impact of the disease on patients, including their thoughts, attitudes, feelings, emotions, needs and changes.

Patients usually have inaccurate perceptions of AP. In a previous study, most patients lacked basic knowledge of AP; they did not know what pancreatitis was, how it progressed or how to prevent recurrence.¹² They felt that the occurrence of AP was simply terrible luck rather than physiologically induced.⁹ Pezzilli *et al* found that a kind of mental impairment progressively develops in the follow-up period, which may be linked to fear of another disease attack.¹³ Although they have many negative emotions, patients can use positive techniques to cope with their illness; for example, in one study, patients wished to gain more knowledge about RAP to prevent recurrence, and some patients showed astonishing perseverance in maintaining appropriate dietary habits.⁹ They used social networks and social support to increase their confidence in response to the disease.¹² However, additional coping mechanisms have not been reported.

Although AP is severe, there is little literature on the psychology of patients with AP. Moreover, these studies do not emphasise patients' psychological experiences.^{9,12}

To highlight the demands and challenges of patients with AP and to obtain a holistic understanding of the AP journey, we conducted a qualitative study to expand knowledge of patients with AP's psychological experiences, and to provide new data to support future targeted interventions to improve their quality of life during hospitalisation.

METHODS

Design

We used a qualitative descriptive design, as our main objective is to explore and describe patients with AP's psychological experiences.¹⁴ We employed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist as a guideline.¹⁵

Participants

From 1 August 2020 to 25 December 2020, we recruited individuals diagnosed with AP who were hospitalised in the gastroenterology departments of two tertiary hospitals in China's eastern region. We employed a convenience sampling approach combined with the principles of data saturation—we could not obtain new information during the last two interviews. The inclusion criteria of inpatients were as follows: (a) 18 years of age or older; (b) able to speak and understand Mandarin Chinese or Jiang-Huai Mandarin; and (c) agreed to participate. The exclusion criteria were as follows: (a) diagnostic suspicion or a definitive diagnosis of severe illness, such as cancer or chronic failure of the heart, liver or other major organs; (b) pregnancy or breast feeding; or (c) cognitive impairment, impaired hearing or a history of psychiatric illness.

Data collection

The first author—a registered nurse with several years of experience in pancreatic disease care who is well trained in qualitative interviewing techniques but had no prior relationship with the participants—conducted semi-structured interviews. Before enrolment, we compiled a list of patients who met the inclusion criteria through the hospital's information system and consulted their doctors about their condition. If a patient's condition was stable and suitable for an interview, we distributed information leaflets. If patients were interested in participating, they would actively contact us. To avoid memory bias, we held the interviews as soon as possible. The time and place were deliberately confirmed in advance; interviews were carried out in the afternoon, at the patient's bedside, or in the physicians' on-call room when there was less treatment activity occurring.

We developed the interview questions based on previous research. Before the formal interviews, these questions were tested in two interviews with patients with AP and confirmed by us. The questions revolved around the following topics: (1) experience of onset; (2) perceptions of AP; (3) thoughts and emotions regarding the disease process; and (4) coping style. Each interview began with 'everyday conversations' with the aim of creating a relaxed atmosphere. The interviews lasted for 30–45 min. All interviews were audio-recorded, and the participants' body language was noted. The second author transcribed the recordings verbatim within 24 hours.

Data analysis

We compared the transcripts with the digital recordings to verify accuracy. We analysed the data using an adapted version of Colaizzi's qualitative analysis procedure. We read these records individually and repeatedly to grasp each patient's experience and overall understanding, and to identify and extract important units. Each author independently assigned a preliminary code to each important statement. Subsequently, we reached a consensus regarding themes, subthemes and detailed descriptions through discussion. We also discussed the essential structure of the participants' experiences. Finally, we returned the interpreted data to them for verification.

Patient and public involvement

No patients were involved in the development of the research questions, the study design or the analysis.

RESULTS

Participants' characteristics

In total, we recruited 28 participants. [Table 1](#) presents the participants' demographics traits.

Themes

Three themes emerged from the data: *feeling like the disease is unpredictable, experiencing a variety of stressors and supports* and *developing self-adaptability* over the

Table 1 The demographic traits of the patients interviewed

Characteristics	N (%)
Age (years)	
<60	21 (75.0)
>60	7 (25.0)
Sex	
Female	8 (28.6)
Male	20 (71.4)
Education level	
Primary and below	7 (25.0)
Junior high	10 (35.7)
Senior high	4 (14.3)
College and above	7 (25.0)
Marital status	
Married	25 (89.3)
Unmarried	3 (10.7)
Occupation	
Farmer or worker	7 (25.0)
Self-employed	8 (28.6)
Chef	2 (7.1)
Driver	2 (7.1)
Businessman/businesswoman	2 (7.1)
Other	7 (25.0)
Recurrence times	
<1	11 (39.3)
≥1	17 (60.7)
Aetiology	
Biliary	12 (42.9)
Hyperlipidaemia	13 (46.4)
Alcoholism	2 (7.1)
Other	1 (3.6)
Severity classification	
SAP	7 (25.0)
MSAP	18 (64.3)
MAP	3 (10.7)
Local complications of the pancreas	
WON	3 (10.7)
APFC	13 (46.4)
ANC	5 (17.9)
IPN	1 (3.6)
PPC	4 (14.3)
None	2 (7.1)

ANC, acute necrotic collection; APFC, acute peripancreatic fluid collection; IPN, infected pancreatic necrosis; MAP, moderate acute pancreatitis; MSAP, moderately severe acute pancreatitis; PPC, pancreatic pseudocyst; SAP, severe acute pancreatitis; WON, wall off necrosis.

course of the illness. The first theme consists of three subthemes covering subjective impressions of the disease process. The second theme comprises three subthemes and describes how the patients reacted to the outside world. The third theme, which is made up of two subthemes, sheds light on how the participants adjusted their inner experience when addressing these issues.

Theme 1: feeling like the disease is unpredictable

The patients were not familiar with AP, including its clinical manifestations and evolution of the course of their condition. In the early stage of the illness, *the inability to recognise the disease* led the patients to neglect and tolerate pain. During the course of the disease, they exhibited *uncertainty about the outcome of the illness*, and *fear of progression or recurrence*.

Inability to recognise the disease

In the early stages of the disease, 50% of patients did not go to the doctor immediately after experiencing pain. They thought they were suffering from cholecystitis, appendicitis, gastritis or gastroenteritis, and believed their symptoms could be relieved through rest, self-medication and keeping warm.

When I was having abdominal pain, my only thought was appendicitis. (P3)

I had neither thought nor realised that I would have acute pancreatitis. I had not urinated for 3 days before the onset. (P5)

Uncertainty about the illness

Owing to the patients' critical condition, the variable course of the disease, high mortality rate, numerous complications and symptomatic treatments, 25% of patients with AP in the present study reported uncertainty about the outcome of their illness. For some patients, it was difficult to accept changes in their condition, and expressed shock, anger and resistance:

I have been in the hospital for almost 7 months and I'm fed up; when I was admitted to the hospital, the doctor told me it was a minor problem. After more than a month in the hospital, I had developed many complications. Two weeks after discharge, I came for a follow-up and was admitted to the hospital again. Then I stayed for more than 20 days and was discharged with a drainage tube. Later, when I came in for re-examination, they admitted me to the hospital again. During this [current] hospitalisation, a total of six minimally invasive operations have been performed, and three tubes have been replaced. The tubes have become thicker than before. I do not know when I will be discharged; the doctors still have not transferred me to another hospital. (P1)

I do not know when it will end. I have undergone abdominal drainage seven times. I might need it again today. It does not hurt, but it is annoying [sighs]; three injections a day, three injections a day [speaking faster]!

It does not hurt, but it is truly annoying to receive injections every day [distressed face]. (P3)

When the doctor told me that my pancreas had a [shadowy area] that needed further examination, I did not know what to do. (P27)

Fear of disease progression or recurrence

Due to the progression and recurrence of AP, 46% of patients reported fear of aggravation or relapse. They expressed fear of recurrence of abdominal pain, ascites infection, becoming diabetic, eating food and cancerisation. Their fear was specific and caused by their uncertain future. They were worried about the physiological, psychological and social consequences of the disease.

I'm mainly worried about effusion. They also told me that it is easy to develop infection, which makes me very worried. (P3)

The night before the diagnosis, I had the heaviest psychological burden and kept thinking that if I died, there were still many things my wife would need to deal with. It is hard for my wife. I did not sleep all night. (P7)

How is my pancreas now? Is it getting worse? Is there any progression toward cancer? Albumin cannot be infused. It is a blood product that can spread diseases. If it is used, I must accept certain risks. (P27)

Theme 2: various kinds of stress and support

After developing symptoms, the patients with AP experienced abdominal pain, pain regarding dietary changes. They feared losing their jobs, family and health, and paying high medical bills. Some patients cared about the evaluations of others. During the period of illness, they felt relieved because of donations from the unit, the company of their family and the encouragement of medical staff, and worked hard to cooperate with treatment and care. At the same time, they were extremely eager to learn more disease-related knowledge to increase their confidence to overcome their ailment. Therefore, this theme is divided into three subthemes: *feeling different degrees of stress*, *perceiving social support*, and *seeking and craving social support*.

Feeling different degrees of stress

About 43% of patients experienced stress during their hospitalisation. In China, medical costs are partially borne by patients themselves. The medical expenses associated with AP vary depending on the severity of the disease, and the medical costs of patients with SAP can be as high as hundreds of thousands of yuan. According to national statistics, the per capita income of Chinese residents was ¥32 189 in 2020, while that of rural residents was ¥17 131. Moreover, family members are required to accompany patients, further reducing the source of family income. In addition, the physical pain brought about by the disease and the difficulty in managing one's diet became stressors for the patients with AP in the present study. These

stressors resulted in psychological distress, guilt, anxiety and depression. Some male patients developed a sense of stigma because they cared about the evaluations of others and their self-image.

Now, the decision to live or die changes by the second. More than once I climbed to the highest floor on our side of the building, and I wanted to jump off. (P10)

I stayed in the ICU of a senior hospital for 2 months, which cost approximately ¥300 000. Only my son earned money at home, so I had to borrow money from my nephew to see a doctor [crying]. (P21)

I usually keep my condition to myself, and I'm not allowed to talk about it at home or around people. (P22)

You do not know how painful it is. I cannot control myself. The temptation outside is too great. If you read today's headlines, you will see all kinds of delicious food. When you go out to dinner, you see other people eating, so how can you not eat? How can it be? No, you cannot control it [waving]. (P25)

Perceiving social support

During their illness, 14% of patients perceived varying degrees of encouragement and support from their employers, relatives and medical staff, which increased their confidence to overcome the disease.

I was sick, and my employer collected donations. They donated more than ¥10 000 and later came to visit me several times. They gave me lots of money. (P1)

At that time, the doctor told my sister that the mortality rate of this disease was very high; 5 out of 10 people [do not] survive. My sister said that they would ensure I survived, even if it broke the bank. When I was in the ICU, a young nurse was kind to me; she asked me to treat her like my own daughter and she bathed me twice a day. (P10)

Seeking and craving social support

Six (21%) of the 28 patients expressed a need for social support. The unpredictability of their condition made them lose confidence to overcome the disease, and more affirmation was needed from others. They said that family and medical staff played an essential role in their recovery. They sought help from their family members to obtain knowledge about the disease or to modify their behaviour. They desired to have the expertise of medical professionals to guide their diet, which might increase their confidence in the recovery process.

I felt too weak to learn about the disease, so I asked my wife to do it. (P3)

I do not know how to control my blood sugar. Some people say that I cannot eat noodles or rice soup. Some people say that I cannot eat porridge. Now my

blood sugar is high, and I do not know what I should eat. (P11)

At that time, there was no bed here. I was temporarily admitted to the orthopaedic ward. I had a high fever there every day. I asked the doctor to move me to the gastroenterology ward, even if my bed was in the corridor. (P15)

Theme 3: developing self-adaptability in the disease process

The patients' attitudes towards the disease are related to *treating one's illness negatively or positively*. Patients with multiple episodes of AP had lost faith in finding a cure and were indifferent to their illness. Some patients felt it is not helpful to understand the development of the disease and gain self-care knowledge. Other patients had hope, reflected on their past, and faced the future with optimism; they also expressed a willingness to change their unhealthy lifestyles.

Treating one's illness negatively

Owing to emotional exhaustion, 7 (25%) of the 28 patients tended to use a negative coping mechanism involving an escapist/avoidance coping style and self-distraction. The escapist/avoidance coping style is an emotion-focussed strategy that does not address the cause of stress; however, it can provide an immediate or short-term reduction in stress. Self-distraction entails thinking about others rather than the stressor itself.

When I'm upset, I watch TV. (P3)

When I'm sick, I see the doctor for treatment. If they cannot cure it, I let it go. (P11)

I did not take the initiative to learn about the disease. It is useless to understand it. (P20)

Treating one's illness positively

About 21% of the patients who had a positive attitude actively followed the doctor's recommended treatment, and hoped to recover quickly. Some of the patients reflected on their (unhealthy) lifestyles and were willing to change it.

I regret that I did not adjust my lifestyle habits well before this disease. After I go back home, I must adjust my lifestyle, rest and diet habits, as well as everything else. (P6)

When I was in the ICU, I actively cooperated during treatment with the hope that they would take me off the ventilator and discharge me from the ICU as soon as possible. Though I was a little asthmatic, I tried to breathe through my mouth and nose. I told myself not to be nervous and that I needed to be quiet. Although it was very uncomfortable, I made it [smiles]. (P19)

When I go home, alcohol is absolutely forbidden, and I will try to eat some light foods for 1 or 2 months. I will come back for regular check-ups and adjust my diet according to the results of the check-ups. (P23)

DISCUSSION

We aimed to investigate the psychological experiences of patients with AP. Our results highlight the inner world of patients with AP. At the beginning of the disease, half of them said they did not recognise their illness and thought it was appendicitis, gastritis, cholecystitis or another ailment. In the course of the illness, some patients experienced shock once their condition exceeded expectations. Nearly half of the patients were worried about the high medical costs and losing time from work, and felt guilty because their families were impacted. However, some patients were full of motivation and confidence during rehabilitation owing to the support they received from their employers, families and encouragement from doctors. A few patients did not know when the disease would be gone and saw no end in sight. They were angry and dissatisfied with their current treatment. Some patients also expressed that they did not dare to eat food and were afraid of abdominal pain and disease recurrence. In addition, several patients said they did not dare go outside because of their disordered self-image, and had even considered ending their lives because of pain and prolonged treatment. Faced with these problems, some patients felt their efforts were useless, and some patients said they do other things to distract themselves. However, some patients felt this was not a bad thing because the disease seemed to remind them that there was something wrong with their lifestyle.

The patients felt the disease is unpredictable, which may be for the following reasons. There are varied symptoms of AP, which means a traumatic event for patients. Trauma can influence cognitive processing and may thus promote dysfunctional interpretations of current experiences.¹⁶ Cognitive processing—including automatic threat detection, resource allocation and threat elaboration—could significantly induce and sustain emotional bias through initial automatic and subsequent strategic processing.¹⁷ In addition, the incidence of AP is low, and the public has insufficient knowledge about the disease (aetiology, characteristics, course, outcomes and recurrence prevention). Moreover, the feeling of unpredictability is determined by AP, which is characterised by abruptness, complexity, variability and susceptibility to recurrence. To improve the understanding of AP, medical staff may be able to reinforce the promotion of disease-related knowledge and offer explanations promptly based on patients' individual conditions.

When patients with AP are hospitalised, the experience is disquieting, as the usual rhythm of their lives is interrupted. Any physical or psychological homeostasis that is disrupted leads to stress. Understanding the source of patients' stress is conducive to better care. The participants in the present study experienced pressure from multiple dimensions, including physiological, economic, family, emotional and role pressure, which have been mentioned in previous studies.^{9 12} Stress causes patients to experience a myriad of negative emotions. However, support from others motivated them to overcome their illness, and they were eager to obtain support. An encouraging word or a positive look at a critical moment boosted their confidence to fight against

the disease and drove them to invest more significant effort, creating an enhanced positive affect. Any kind of support from anyone—such as financial, verbal and behavioural—is compelling. With the aid of professionally trained medical staff, patients might feel more secure and confident.

Individuals deal with a sense of imbalance using both positive and negative coping mechanisms. Coping and resilience are strongly positive, and are correlated both structurally and categorically.¹⁸ Resilience can reinforce disease-related adaptation in patients with breast cancer.¹⁹ Our results suggest that patients with AP have some degree of resilience and post-traumatic growth (PTG). However, prevalence rates of PTG or resilience are difficult to determine in our study due to the design. As it is well known, resilience entails finding or developing resources to manage stressors and may help patients thrive in the face of adversity. At present, existing research on resilience is primarily centred on patients with cancer, and there is little evidence on resilience in patients with AP. Future research should explore the framework of resilience and an assessment tool should be developed.

There are several limitations to the current study. First, we used a convenience sampling approach, and recruited participants from only two tertiary inpatient departments in eastern China, thereby limiting the representativeness of the findings. Second, we interviewed each participant only once. Although we tried to select patients with varying severity of AP, we could not capture changes in their psychological experiences over time. Consequently, longitudinal research is needed to gain a comprehensive understanding of the psychological experiences of patients from different regions and in various stages of AP.

CONCLUSION

We assessed the psychological experiences of inpatients with AP using a qualitative descriptive design. An important finding is that cognition and emotion fluctuate in patients with AP during hospitalisation. Moreover, patients with different conditions have distinct experiences and coping strategies. Appropriate guidance should be provided considering patients' characteristics. In addition to providing tailored advice to patients' psychological aspects, patients need more social support.

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data, discussed the coding throughout the analysis. SM, XY, JQ, WC and YR contributed to reviewing and editing the manuscript. All authors read and approved the final manuscript. YR is guarantor of the study.

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Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and was approved by the Ethics Committee of Clinical Medical College, Yangzhou University, Ethics Number: 2021ky188. Participants gave informed consent to participate in the study before taking part.

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