

## Experience of living with symptom clusters in postoperative pancreatic cancer patients

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### ABSTRACT

**Objective:** The purpose of this study was to describe symptom clusters (SCs), and symptom experiences in early postoperative patients with pancreatic cancer who are recovering at home.

**Methods:** From October 2021 and April 2022, 15 patients following pancreatic cancer surgery were recruited from a tertiary hospital in Jiangsu Province by maximum variation sampling. Semi-structured interviews were performed to collect data and thematic analysis was conducted to analyze the data.

**Results:** Three themes were extracted from the data. The first theme “difference in symptom perception and cognition” illustrated factors such as patient knowledge, expected recovery status, and risk perception could influence patient symptom experience. Most patients actually reported fewer and less severe symptoms than previous studies. The second theme “the results of symptom cluster” demonstrated anorexia-distress SC, bowel-digestive related SC and sleep disturbance related SC, and anorexia-distress SC should be considered as the priority SC given its multidimensional significance for patients. The last theme described the patient’s positive attitudes, behaviours and barriers to coping with symptoms, namely “symptom self-management experience”.

**Conclusion:** There are differences in the perception and interpretation of SCs in postoperative pancreatic cancer patients. Understanding the meaning of individual differences in the experience of symptoms can assist patients in the management of SCs. Medical staff should combine patient self-management strategies and evidence-based data to provide appropriate support at different stages to improve patient symptom management and quality of life.

### 1. Introduction

Pancreatic cancer is one of the malignant tumors with high incidence and mortality rate, as well as rapid progression (Bray et al., 2018). Surgical resection combined with chemotherapy is an essential treatment modality for patients with pancreatic cancer to achieve a cancer-free survival outcome (Khorana et al., 2016). The most common surgical operation is pancreaticoduodenectomy, which involves the removal and reconstruction of several digestive organs, and patients experience severe and multiple symptoms after the operation (Allen et al., 2018). A longitudinal survey reported that pancreatic cancer patients could experience 17 symptoms such as fatigue, pain, and loss of appetite during the postoperative recovery period (Burrell et al., 2018). Symptom severity stabilizes at a level after decreasing overtime in the first three or six months but remains more severe than preoperative. These symptoms have serious negative consequences such as low quality of life, reduced food intake, malnutrition, delayed post-operative

chemotherapy, etc. (Yamada et al., 2017; Allen et al., 2018; van Dijk et al., 2018).

Analysis of large data suggests that symptoms don’t work alone, but interact with each other (Dodd et al., 2004; de Rooij et al., 2021) and may lead to lower quality of life (Nho et al., 2017). In an expert recommendation, the phenomenon of symptoms multiple coexisting and not independent of others, may sharing mechanisms and outcomes is described as symptom clusters (SCs) (Miaskowski et al., 2017). The use of symptom complex relationships within SCs provides new perspectives for interventions to manage the symptom (Kwekkeboom, 2016). Several studies have tested the effectiveness of interventions on a specific cancer SC. Most studies target the pain, fatigue and sleep disturbance symptom cluster and found beneficial effects through massage (Tarrasch et al., 2018), acupressure (Yeh et al., 2016) or cognitive-behavioural strategies (Kwekkeboom et al., 2012). In a randomized controlled trial on advanced cancer, Kwekkeboom et al. (2018) found potential factors mediated the extent of intervention effects on the pain, fatigue and sleep

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disturbance symptom cluster, which provide insight into ways to strengthen future interventions to alleviate the pain SC and affirm hypothesized mechanisms (Kwekkeboom et al., 2018a). Defining the characteristics of SCs is the beginning of SCs exploration. Numerous quantitative studies identified SCs through symptom assessment tools and statistical approaches (Pozzar et al., 2021; Li et al., 2020). However, because of the diversity of symptom assessment tools and statistical methods, and the absence of a “gold standard”, little consistency exists in the characteristics of SCs (Mathew et al., 2021; Kirkova et al., 2011). In a systematic review aimed at exploring SCs in patients with head and neck cancers, the authors found that the number of SCs in such cancers ranged from 2 to 5, and the number of symptoms in a cluster ranged from 2 to 11 (Mathew et al., 2021). The lack of consistency and consensus on the components and characteristics of SCs limits the exploration of mechanisms and the effective interventions for SCs (Mathew et al., 2021; Dong et al., 2014). Qualitative research can present a new method to solve the issue. Patients experience provide meaningful data on how they view, prioritize, and evaluate SCs (Miaskowski et al., 2017). In a qualitative study of patients’ symptom experiences in lung cancer, Molassiotis identified an interacting respiratory SC, which is different from the results of quantitative studies but is reasonable in consideration of patient experience (Molassiotis et al., 2011). Qualitative methods are also useful for the evaluation of priority SCs and mechanisms (Dong et al., 2016), which provide important implications for interventions. However, studies are extremely limited in identifying priority SCs and mechanisms of SCs in cancer patients. Additionally, in an expert recommendation about advancing symptom science through symptom cluster research, the identify of SCs through qualitative research is one of the key research directions to define the characteristics of SCs (Miaskowski et al., 2017).

To date, most studies have focused on target populations of patients with breast (Li et al., 2020), lung (Maguire et al., 2014), prostate (Vayne-Bossert et al., 2017) and colorectal (Agasi-Idenburg et al., 2017) cancers, rather than pancreatic cancer groups. And most studies typically tested interventions designed to manage specific cancer SCs, such as pain, fatigue, and sleep disturbance SCs, or respiratory distress SCs (Kwekkeboom, 2016). Although Burrell et al. described 16 different SCs and four core SCs in patients with pancreatic cancer undergoing surgical resection over a 9-month period, they did not explain the mechanism of symptom clustering (Burrell et al., 2018). Lin et al. describe the experience of SCs in patients with gastric cancer in a qualitative study and provides explanations for multiple symptom relationships (Lin et al., 2020). They emphasized the importance of identification of inter-individual variability for symptom interventions but did not further explore the possible influences on variation. There is no information about the qualitative SCs experience of patients with pancreatic cancer undergoing surgical resection or Chinese cancer patients.

Understanding the inter-relationships between symptoms from the patient’s perspective will help health providers identify possible mechanisms and coordinate treatment strategies that are effective across cluster component symptoms. Therefore, this exploratory qualitative study aimed to explore SCs in patients with pancreatic cancer recovering from surgical resection. The research questions are:

1. What are the post-operative symptoms experienced by patients with pancreatic cancer?
2. How do patients describe symptom clusters after pancreatic cancer surgery?
3. How do postoperative pancreatic cancer patients cope with their symptoms?

## 2. Methods

### 2.1. Study design

This was a descriptive qualitative study using semi-structured

personal interviewing. The study protocol was reviewed and received ethics clearance through the NanJing Medical University Ethics Committee.

### 2.2. Participant selection

A purposive sample of participants was recruited from a large medical center in Jiangsu Province, China between October 2021 and April 2022. Eligible patients were those who (a) were  $\geq 18$  years; (b) were diagnosed with pancreatic cancer and undergoing first tumor resection, and (c) were informed and agreed to participate in this study. Patients with cognitive impairment, mental illness, language dysfunction and other serious physical illnesses (e.g., cancer, organ failure) were excluded. Recruitment stopped when data saturation was reached.

### 2.3. Data collection

A clinical nursing researcher (LCY) filter potentially eligible patients in the inpatient record system. Researcher and participants did not establish a relationship and knew little about each other before interviews. The researcher (LCY), with the assistance of the clinical nurse, explained the purpose and process of the study to the eligible patients. If the patient agrees to participate in the study, the researcher collects the patient’s general information and cell phone number. The same researcher will conduct telephone interviews at approximately one month after the operation while they were recovering at home. Patients were asked verbally for consent before the interview and were subsequently informed of their right to terminate at any time. A semi-structured interview guide was formed according to the literature and the results of the pre-interview. Questions included the following: a) What symptoms do you experience in the past day? b) What are the characteristics of these symptoms? c) What symptoms appear together or interact with each other? d) What factors have you found to be associated with changes in symptoms? e) How do you cope with these symptoms? The researcher (LCY) completes all interviews, audio records, and file management. To reduce bias in self-reported symptoms, participants were informed that an individual recovery plan would be developed after the interview based on the content of the interview.

### 2.4. Data analysis

A thematic analysis approach was used to analyze the data. The first author transcribes the recordings into texts and used Word 2016 (Microsoft Office Home and Student, 2016) software to record the transcribed text. Each verbatim file was secondarily text-checked by the second author. Coding was carried out by two authors (LCY & LLL) who were trained in oncology care and qualitative methods. Prior to individual coding, both authors read the transcripts together to avoid textual comprehension errors and repeatedly read the transcripts to fully understand the themes and patterns. Coding and coding source descriptions were performed by the annotation function of Word (2016). The two authors identify and code symptoms, relationships between symptoms, factors influencing symptoms, and coping strategies mentioned by patients. These codes were compared between the two authors and refined if conflicts occurred. The first author merged and organized the codes into themes. Next, the research team checked for thematic consistency and tightness of themes to codes. If necessary, the themes were revised until consensus was reached through group discussions. Findings were reported following the guidance of the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (See Supplementary File 1) (Tong et al., 2007).

### 3. Results

#### Demographic and clinical characteristics

Seventeen patients were recruited and two patients withdrew due to serious complications or loss of contact. The demographic and clinical characteristics of the 15 participants are detailed in Table 1. The median age of the participants was 60.9 years, and nearly half of the participants were female. A majority of the participants were married ( $n = 12$ ) and had other chronic diseases concurrently ( $n = 8$ ). The mean duration of the interviews was 25.2 min (12–47 min).

Three themes are extracted from the data (see Fig. 1). The first theme, "differences in symptom perception and cognition," described the process and factors influencing patients' assessment of symptoms. The second theme, "symptom cluster outcomes," described the content of the symptom clusters as perceived by patients. The third theme, "symptom self-management experience," described how patients cope with their symptom experiences.

#### 3.1. Theme 1: differences in symptom perception and cognition

##### 3.1.1. Differences in symptom cognition

Most patients reported fewer symptoms with an understanding of the concept of symptoms than those identified by the researcher through the patient's description of their daily life. Patient-recognizable symptoms were usually be pain, decreased appetite and steatorrhea/diarrhea, while fatigue, early fullness and negative mood were less possibly identified as symptoms. The patient's reference system is the earlier stage with more severe symptoms instead of the preoperative condition, to confirm that recovery is underway. Patients are more preoccupied with the meaning and outcome of symptoms than the uncomfortable experience itself. They believe that it is natural to be uncomfortable, and the symptoms may be a reminder of what they should not do, such as not eating too much. Provided that the symptoms are not particularly severe, they don't feel unbearable as long as the outcome is good.

"I keep waking up at night and then I don't want to sleep. There's nothing bad except being a little tired during the day, which is already better than when I was in the hospital ..... I have no other symptoms except pain."

##### 3.1.2. Individual differences in symptom perception

Patients described a total of 13 symptoms, most of which were physical, such as pain, decreased appetite, and early satiety, and only three were psychological (distress, depressed mood, and anxiety). Individuals perceived symptoms in the range of 3–7, with most symptoms generally in a mild state. Severe pain was described by one patient and was considered potentially representative of a serious problem. As he described, "I was having a lot of pain in my lower abdomen, and the doctor said he didn't know what was causing it, and I was worried about the situation."

Inter-individual differences were associated with the following psychosocial factors: expected recovery status, knowledge, and social comparison. If patients believe they meet the expected status of recovery based on their own knowledge, they are more satisfied and have lower perceptions of risk and symptoms. On the other hand, if there are high severity symptoms that do not meet expectations, patients are more concerned about their physical condition.

"I am now gradually eating more. The doctor also said that there is no rush and it will take several months to recover. I feel that I am making good progress in my recovery. Although sometimes I feel very uncomfortable, overall, I am doing well."

"I haven't gotten the drain removed yet and it is causing severe pain and making me feel very bad about my whole being. "

Patients' attention to and perception of symptoms do not vary linearly. When symptoms are mild, patients are less likely to notice and perceive symptoms. Symptoms also vary erratically over time, sometimes in a severe state during a steady recovery process. When symptoms break a threshold or are suddenly severe in a steady process, the patient perceives the symptoms and assesses them. Patients also attempt to attribute and respond. If the symptom is thought to be associated with an adverse outcome, the patient pays more attention to the symptom and shortens the assessment interval.

"I feel better the whole time. I'm used to it now, and I usually don't pay attention to these. But two days ago, I suddenly lost my appetite, probably because the food was too oily. I paid attention to this next time and then I was fine."

##### 3.1.3. Low perception and cognition of symptom clusters

Patients were less likely to consider and were difficult to describe the relationship between symptoms. Patients who reported low symptom

**Table 1**

Description of study participants ( $n = 15$ ).

No.	Gender	Age (year)	Education	Marital Status	Monthly income	Hospitalization Duration (day)	Postoperative Duration (day)	Comorbid chronic diseases
P1	Male	70	Primary school	Married	low	15	30	Diabetes
P2	Female	53	Primary school	Married	medium	13	32	
P3	Female	51	Junior high school	Married	low	28	37	
P4	Male	65	Junior high school	Married	medium	18	30	Hypertension
P4	Female	66	Junior high school	Single	low	20	31	
P5	Male	62	High school	Married	high	14	40	Hypertension
P6	Female	59	Primary school	Married	low	13	31	
P7	Male	29	University	Single	high	13	36	
P8	Male	49	University	Married	high	10	31	
P9	Female	68	Primary school	Single	low	12	32	Diabetes
P10	Female	55	High school	Married	medium	14	40	Insomnia
P11	Male	57	High school	Married	medium	13	35	Diabetes
P12	Male	72	Junior high school	Single	medium	32	45	Cerebral infarction; Constipation
P13	Female	43	University	Married	high	15	34	
P14	Female	55	High school	Married	medium	32	41	
P15	Male	60	Primary school	Married	low	15	35	Hypertension

Monthly income: low < ¥3000, medium ¥3000 ~ ¥5000, high > ¥5000.

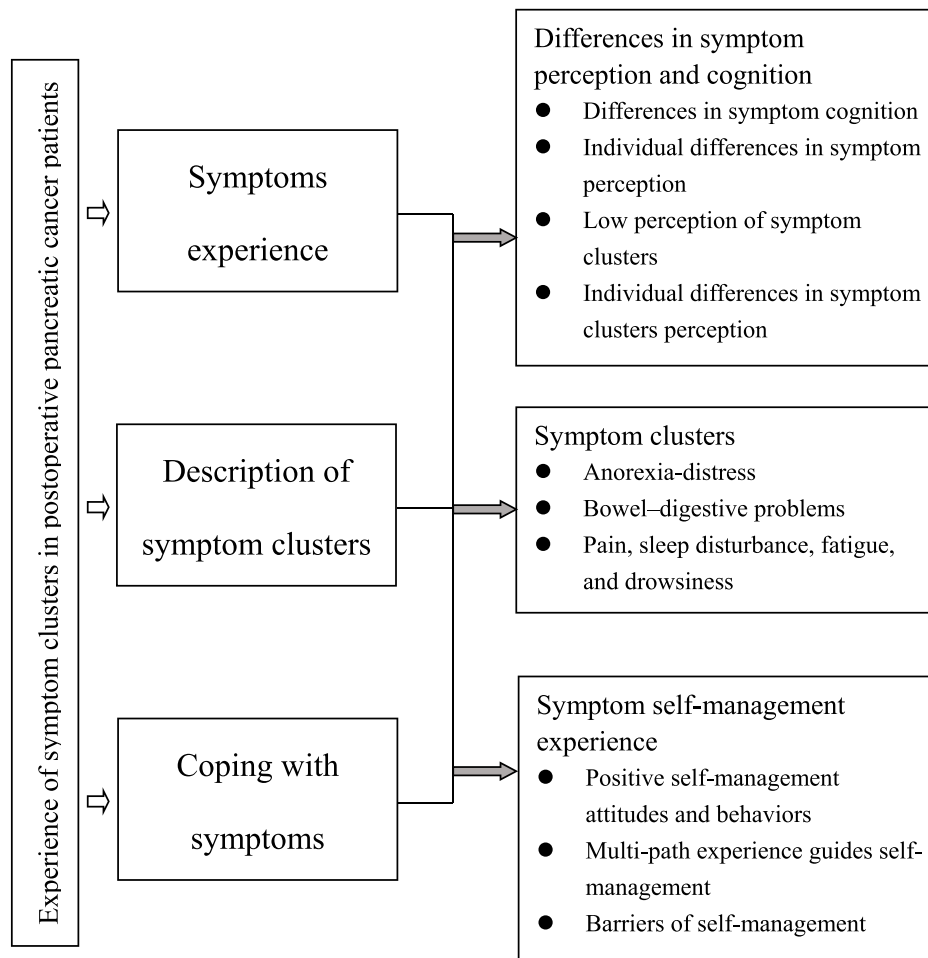


Fig. 1. Study themes and subthemes.

severity reported fewer symptom clusters and had poorer descriptions of symptom associations. Patients focused their narratives on specific individual symptoms. Patients recognize the association of symptoms according to the order in which they change. The patients perceive a complex of gastrointestinal symptoms. Since they often appear together, the patient does not perceive that they affect each other and believes that it is a problem of digestive organ function. But patients can experience more serious consequences resulting from the synergistic effect of the presence of symptoms.

"I can feel discomfort in my abdomen, like belching, but not really, I'm not very good at describing it. These feelings make me want to eat even less ... I don't really know how they affect each other, it's just all at once, I think it's due to the organ removal"

"I feel good in most cases. Sometimes I can feel them, but I don't pay attention to them because I will get better soon. And it doesn't help to focus on them since I don't know them. "

#### 3.1.4. Individual differences in symptom clusters perception and cognition

There were inter-individual differences in the number of symptom clusters and the composition of symptom clusters described by patients. The most frequent symptom clusters were the gastrointestinal symptom cluster and the pain symptom cluster. If the severity of symptom clusters varies greatly, the more severe symptom clusters should be prioritized; In general, the Anorexia-distress symptom cluster was described by patients with the highest frequency and priority.

"I don't want to eat either, but I have a worse stomachache. I'm worried about this situation and I want to solve this problem more quickly."

#### 3.2. Theme 2: symptom cluster results

Patients had fewer cognizable symptoms and symptom clusters. In addition to integrating patient-reported symptom clusters, the researcher extracted symptom cluster results by identifying logical statements from patient descriptions to form the following results.

##### 3.2.1. Anorexia-distress symptom cluster

This is the priority symptom cluster and contains symptoms such as loss of appetite, nausea, belching, acid reflux and distress. This group is most significant for patients, as it can lead to inadequate nutritional intake, weight loss, and thus ineligibility for chemotherapy and shortened survival. More patients focus their narrative on decreased appetite. They describe difficulty in eating after discharge from the hospital due to loss of appetite and nausea. The loss of appetite was worsened by restrictions on food types and changes in eating habits. However, they would force themselves to eat, resulting in a reduced sense of well-being in life. Some patients expressed distress. The main reasons for patients' distress include the inability to improve symptoms, discomfort from compulsive eating and concern about inadequate nutritional intake.

"I have no appetite, so I force myself to eat. How can I gain weight for chemotherapy if I don't eat?"

"Drinking soup is supposed to be good for me, but I don't like it, especially when I smell it. My food is prepared separately. My family gets nervous if I act like I don't have an appetite, and it makes me feel very stressed."

### 3.2.2. Bowel-digestive problems symptom cluster

This group contains symptoms such as early satiety, abdominal pain, nausea, diarrhea/steatorrhea, depression, and anxiety. Although patients describe eating amounts consistent with early satiety diagnostic criteria, fewer patients report this symptom on their initiative, mainly because their reference is to the previous stage, where symptoms are more severe. Abdominal pain is mostly associated with patients overeating.

Patients' descriptions of negative emotions are mostly cryptic, such as unhappiness and bad mood. Nausea and diarrhea/steatorrhea are mostly associated with postoperative pancreatic enzyme deficiency and excessive consumption of lipids. The incidence of diarrhea/steatorrhea is high in the short term. Patients generally believe that steatorrhea means they have a problem with their organism and that it can lead to weight loss. Because of the uncontrolled nature of steatorrhea, patients are more likely to experience a sense of loss of control. The sense of uncontrollability and poor outcome of steatorrhea can be closely associated with emotional symptoms.

"I have to diarrhea not long after I finish a meal, maybe three or four times a day. I've lost a little weight. I'm frustrated but I don't know what to do."

"I have to control myself and find the balance. I accidentally ate too much and my stomach felt too full and uncomfortable, and a little sore, like a wound about to split open. "

### 3.2.3. Pain, sleep disturbance, fatigue, and drowsiness symptom clusters

Pain is usually the antecedent symptom. It occurs at the site of abdominal wall incision, gastrointestinal incision, drainage tube related and unexplained pain. The first three sites have a high incidence and low severity, mostly due to sudden changes in position, eating and prolonged walking. The pain caused by prolonged walking limits the patient's range of motion making them less likely to engage in outdoor and social activities. They, therefore, spend more time sleeping and resting. Unexplained pain is not only a painful experience at the moment, but patients are unable to attribute it and are concerned that it will cause adverse outcomes as well as anticipated pain experiences. Many patients describe pain making it difficult to fall asleep and interrupting their sleep, so they feel tired the next day.

"The wound will hurt if I sleep in one position for a long time, and I have to wake up and change the position."

## 3.3. Theme 3: symptom self-management experience

### 3.3.1. Positive self-management attitudes and behaviors

Patients consider it their responsibility to manage their symptoms and actively seek strategies for faster recovery. Self-management is effective in reducing the sense of burden and increasing self-efficacy with reduced family responsibilities. And, they usually follow the advice on medication, diet, and exercise.

"I don't do much else at home now, but I can take care of myself according to my doctor's advice. "

### 3.3.2. Multi-path experience guides self-management

The main experience comes from the hospitalization history. When life changes after discharge, they assess the changes and try to respond experimentally based on what they learned during their hospitalization. Even when strategies are effective, they may remain doubtful due to the

lack of professional supervision and worry whether there may be errors leading to adverse outcomes. They also absorbed the knowledge from their peers about the diet based on TCM that is useful for cancer patients. This makes food access more difficult due to the strict restrictions on food types.

"If I'm a little up after eating, I'll walk around like I'm in the hospital. But one time I increased the amount of my rice and then it was very hard. I want to know how I can add to my meal quantity"

### 3.3.3. Barriers of self-management

Because of the poor knowledge of medication, patients are failed to adapt the dose of pancreatic enzyme supplements to relief their symptoms according to their GI symptoms and dietary content. No one tells them what to do if they are running out of medication. Chronic diseases that are comorbid in some patients make it more difficult to attribute symptoms and manage them. All patients described their unmet needs, including: confirmation of recovery progress, help with new problems, guidance on diet and activity, and preparation for follow-up treatment.

"I don't know if (my situation) is considered normal, I can't find a professional to ask."

## 4. Discussion

This qualitative study of patients recovering at home early after pancreatic cancer surgery provides insights into patients' experiences with multiple concurrent symptoms, as well as how they cope with the symptoms. Patients' perceptions and cognitions of symptoms and symptom clusters vary due to a variety of factors, consistently all less than what they have experienced. In addition, this study revealed patients' attitudes, strategies, and support needs for symptom self-management, which could be a step toward developing individualized symptom interventions.

The patient-reported symptom burden in this study appears to be inconsistent with previous studies. A large cohort not only reported a high prevalence of moderate to severe symptoms in patients following PD but tiredness and impaired well-being were the most prevalent (Tung et al., 2019). However, in this study, patients seldom described their symptoms as being moderate or severe. They also rarely reported fatigue or early satiety as a symptom when they were asked what symptoms they experienced. In previous studies, fatigue was assessed by patients through reduced stamina, muscle strength and activity level, and inability to cope with social activities (Gustavell et al., 2017). Instead, it is the researcher who identified the degree of symptoms by the variation in the intensity of physical activity and consumed food patients described. It seems that for them, the actual biological state represented by the symptom plays a more important role compared to the discomfort of the symptom itself. Therefore, to confirm the degree of physiological recovery, they are compared to a previous state where symptoms would have been more severe when assessing symptoms. For long-term symptoms such as fatigue and early satiety, patients regard them as reminders that the body has reached its threshold. Since physical limitations are unavoidable, patients appreciate that the symptoms prevent them from causing harm to their bodies. Patients may therefore stop noticing symptoms until they become severe. These may lead to lower assessment results than actual body sensations. However, three conditions may be required for the above scenario to be valid: the symptoms are not very severe, the patient knows the cause of the symptoms, and the patient believes they are safe. As Symptom and Illness Attitude Model (Petersen et al., 2011) states that the perception of a bodily sensation includes the physiological representation of afferent information (e.g., localization, intensity, or quality of a sensation) and physiological representation. The psychological representation of bodily states resulted from the interaction of beliefs on sensations and their affective evaluation. This article explores the presence in which

underreporting can occur during the process of psychological evaluation, in patients recovering from surgery. And additional study is needed to explore the role of psychological and social states that may influence the cognitive process of symptoms.

Multiple co-occurring symptoms are very prevalent in cancer patients. According to expert recommendations (Miaskowski et al., 2017), priority symptom clusters and symptom cluster mechanisms provide targets for exploiting the utility of symptom clusters. This research identified three symptom clusters that appeared to influence each other or occurred together. If the severity of symptom clusters varies greatly, the more severe symptom clusters should be prioritized; In general, the Anorexia-distress symptom cluster should be considered as the priority symptom cluster. Differently, Molassiotis et al. (2011) found that respiratory symptoms always play a central role for inoperable lung cancer patients. This is quite agreeable as the prominent symptoms of different cancers are varied. The overwhelming focus on respiratory symptom clusters appeared to derive from the fear of death among lung cancer patients. For pancreatic cancer patients, anorexia makes them worry about inadequate eating leading to weight loss and failure to meet the criteria for receiving chemotherapy, which can save them from cancer recurrence and fear of death. This provides evidence for the findings that cancer patients give different weights to symptoms based on the meanings that they ascribe to them.

This cluster is partly consistent with a quantitative study that identified fatigue, poor appetite, weight loss, and change in taste as a symptom cluster (Burrell et al., 2018). Consistent with previous studies, patients experience multiple symptoms but are fewer likely to discern symptom interactions (Ng et al., 2020). It may be reasonable for patients to attribute gastrointestinal symptoms to biological factors that they are not equipped to deal with rather than other symptoms. Decreased appetite, change in taste, nausea and belching are symptoms of pancreatic exocrine insufficiency, and there may be a synergistic effect between symptoms that aggravate decreased appetite. To maintain weight, patients force themselves to eat (Gustavell et al., 2017). The discomfort of forced eating and inadequate nutritional intake are the main causes of patient distress. Additional preparation of individual food adds burden to the caregiver and consequently may increase negative feelings in patients. Moreover, in a cultural focus on diet in China, restrictions or changes in dietary patterns may affect the patient's self-concept and social relationships (Chai et al., 2014).

The cluster of pain, sleep disturbance, fatigue and drowsy investigated in this study is in line with previous studies. This cluster is the most widespread symptom cluster among cancer survivors, with more than 40% of the percentage existing (Kwekkeboom et al., 2018a, 2018b; Miaskowski et al., 2017). There are four possible mechanisms for symptom clustering, including (1) cancer treatment strategies; (2) one symptom leading to the others; (3) side effects of management strategies for one symptom leading to the others; and (4) a shared underlying etiology, such as inflammation (Kwekkeboom K L, 2018). In line with the second mechanism, possibly because of lower external environmental stimuli at night and more attention to the body, patients perceive more severe pain leading to sleep disturbances (Scott et al., 2013). They feel tired and drowsy the next day and have increased daytime sleep, which further leads to difficulty sleeping at night, forming a vicious cycle (Ng et al., 2020). In the dyspepsia-emotional symptom cluster, depression and anxiety are strongly associated with diarrhea/stiarrhea. Diarrhea is highly prevalent and difficult to control in the short term, mostly associated with postoperative pancreatic enzyme deficiency and diet (Nikfarjam et al., 2017; Pezzilli et al., 2020). But few patients know the causes of diarrhea and how to deal with it. If diarrhea is not progressively reduced, patients may feel depressed and anxious due to worries and sense of loss of control. Our findings support the symptom cluster effect by revealing the interaction of symptoms. We should also be aware that the inter-individual differences in symptom experience add variability to symptom clusters (Lin et al., 2020). In the era of precision health, eHealth applications and machine learning facilitate

investigation of personalized symptom clusters (Koleck et al., 2019; Neijenhuijs et al., 2021).

In this study, we also explored patients' attitudes, behaviors, influences and barriers to self-management. As with other post-operative cancer patients, pancreatic cancer patients who undergo the most complex surgeries believe they are responsible for their status and actively involved in self-management. They indicated that self-management reduces the burden of family caregiving, and increases self-worth and self-efficacy. We also identified barriers to patient self-management and the support they desired. Patients' unawareness of medications and dietary modifications to cope with pancreatic enzyme deficiency symptoms supports findings which indicate that patients lack adequate and specific advice at discharge (Cooper et al., 2015). However, healthcare providers emphasized that patients were given advice, but patients could not absorb all and forgot it (Gustavell et al., 2017). Patients with comorbid other diseases experience more barriers to self-management. They are confused with the source of the symptoms. Therefore, the passive strategy may be applied, which means patients giving up taking control and adopting strategies to manage the situation (Eckerblad et al., 2020).

## 5. Conclusion

This qualitative study explored the experience of Chinese patients living with symptoms after pancreatectomy. Compared to other countries, Chinese postoperative pancreatic cancer patients reported milder symptoms, which may be associated with patient knowledge, expected outcomes, and risk perception. This provides a new perspective on the effect of relief symptoms on the quality of life for postoperative pancreatic cancer patients. The identification of three symptom clusters, priority symptom cluster and barriers of self-management provides insights to streamline intervention programs and improve the efficiency of symptom management.

### 5.1. Relevance to clinical practice

This study has several implications for clinical practice and research. First, this study draws out the conditions under which patients cope with symptoms with an accepting attitude after pancreatic cancer surgery. Understanding these particular conditions helps nurses give more effective targeted interventions. For Chinese patients, the sense that they are safe is a core condition. But for other population applications, cultural differences should be appreciated. Second, we found several factors that may influence the perception and cognition of symptoms in individuals. The meaning dimension of symptoms may play an important role. Helping patients discover the meaning of their symptoms may improve the level of benefit finding and thus mitigate the impact of symptoms on quality of life (Sheikh-Wu et al., 2022). Patients tend to compare their symptoms with those of the previous period. This is useful to check the progress of recovery, and future research is needed to examine whether there are drawbacks to this comparison. Also, the nurse should give the patient adequate information in multiple ways (not limited to information that addresses the situation at the time). Finally, we extracted three symptom clusters (anorexia-distress, bowel-digestive problems and pain-related symptom clusters), and the anorexia-distress symptom cluster was prioritized. We also tried to explore the mechanisms of the symptom clusters. Overall, physical symptoms were the main influencing factor for psychological symptoms. This indicates the necessity of increasing the correct understanding of symptoms in patients. However, in the case of GI symptoms, we could only identify the influences of individual symptoms without being able to find clues to the mechanisms of inter-symptoms.

### Credit author statement

**Changying liu:** Conceptualization, Methodology, Investigation,

Data curation, Formal analysis, Writing – original draft, **Linglong liu**: Methodology, Formal analysis, Writing – review & editing, **Mingxia chen**: Conceptualization, Writing – review & editing, Supervision, Project administration, Funding acquisition.

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## Declaration of competing interest

The authors declare that they have no competing interests.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejon.2022.102266>.

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