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The Lived Experience of Inpatients With Acute Recurrent Pancreatitis

A Qualitative Research Study From West China

ABSTRACT

The incidence of acute pancreatitis (AP) has increased year by year. Approximately 20%–30% of these patients will have further subsequent attacks, described as acute recurrent pancreatitis (ARP). Patients who are repeatedly admitted to hospitals suffer significant psychological problems and mental hardships. In the current study, we aimed to illuminate the lived experience of inpatients with ARP from Chongqing, China. A purposive sample of 13 ARP patients was recruited from the First Affiliated Hospital of Chongqing Medical University. Semistructured and in-depth qualitative interviews were adopted in this phenomenological research. Data were analyzed by Colaizzi's Method of descriptive phenomenology and feedback on early findings from the participants. All interviews were audio-recorded and transcribed with the permission of the participants. Five themes presented in the study: anxiety and fear, lack of related knowledge, inevitability and helplessness, guilt and shame, hope, and perseverance. Overall, the ARP inpatients showed complexed experience, both active and positive. They also performed poor compliance during their hospitalization but wished for professional knowledge. Nurses should pay attention to their psychological changes to take effective interventions for them.

Acute recurrent pancreatitis (ARP) generally refers to a clinical entity characterized by two or more discrete episodes of acute pancreatitis (AP) with complete or relatively complete resolution of symptoms between episodes (Deng, Wang, Wu, Tang, & Chen, 2015; Levy & Geenen, 2001; Safari, Miri, Ebadi, Shahrokh, & Mohammad, 2016; Testoni, 2014). Studies from Chinese researchers showed that hyperlipidemia was the predominant risk factor for ARP (Guo et al., 2017; Zhang, 2017), with reporting that the incidence rates of ARP ranged from 20% to 30%.

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Background

Acute recurrent pancreatitis could lead to pancreatic pseudocysts, multiple organ failure (Gao et al., 2006), or even chronic pancreatitis (CP) if the causes persist (Mariani & Testoni, 2008). Epidemiologic studies have shown that 20%–30% of patients with AP experienced recurrence (AI-Haddad, & Wallace, 2008; Kapetanos, 2010; Roberts & Romagnuolo, 2013; Sankaran et al., 2015). Alcohol abuse, dietary excess (Gao et al., 2006), and gallstone diseases were proven to be the most common etiologies of ARP, as well as smoking (Ahmed et al., 2016), pancreas divisum, sphincter of Oddi dysfunction, obstructive lesions, and hyperlipidemia (Kapetanos, 2010; Khurana & Ganguly, 2014). However, ARP still poses diagnostic difficulties. Approximately 30% of cases of ARP remain undiagnosed after a routine evaluation (Petrou et al., 2011).

Cancers were also shown to be associated with ARP. Acute recurrent pancreatitis might represent early manifestations of pancreatic cancer, which is not

clinically apparent until several years later (Karlson et al., 1997). Petrou et al. (2011) demonstrated that ARP might be the original presentation of primary ampullary carcinoma, as well as a relationship with ampulla of Vater carcinoma showed by Tanasijtchouk, Vaisbein, Lachter, and Nassar (2004).

Acute recurrent pancreatitis is the prerequisite for the development of CP, and CP is considered an end-stage feature of ARP (Whitcomb et al., 2008). Chronic pancreatitis is characterized by chronic abdominal pain, frequent disease exacerbations, and exocrine and/or endocrine insufficiency (Yadav & Lowenfels, 2013); the association between CP and pancreatic cancer appears to be strong. Attention has focused on the prevention of repeated episodes of pancreatitis. We continue to gain familiarity with an understanding of the etiology, diagnosis, and therapy of ARP. However, the lived experience of ARP inpatients remains unclear.

Nursing care often overlaps with medical management (Johnstone, 2018). As recurrent attacks ultimately progress into CP or pancreatic cancer, which is the fourth most common cause of death from cancer, it is important that nurses develop a comprehensive knowledge of the management of ARP. Health education is imperative from nurses for ARP patients. There are long-term care considerations on pain management, provision of fluids, and nutritional care for ARP patients.

Previous studies about ARP have been primarily quantitative research (Rebours et al., 2012; Shen, Xu, & Shen, 2017), case reports (Petrou et al., 2011; Tsai et al., 2017), and reviews (Khurana & Ganguly, 2014; Safari et al., 2016). A better understanding of lived experience offers detailed methodological explications and practical examples for inquiry (Van Manen, 1997). Studies related to ARP inpatients' lived experience has not been analyzed in China. Therefore, this study focuses on ARP inpatients regarding their lived experience in a phenomenological way by qualitative interviews.

Methods

The phenomenological hermeneutical design was applied to illuminate the lived experience of ARP inpatients in China.

Participants

This study consisted of 13 ARP patients (3 women, 10 men), aged 29–64 years. The inclusion criteria included four items: inpatients who received a definite diagnosis of ARP; reason for hospitalization was alcohol, high-fat diet, or overeating before ARP attack; aged 18 years and older; and agreement to the study, with a clear mind to express themselves. Patients with mental illness or those who did not agree to participate were excluded from from the study. The sample size conformed to the saturation principle. The ages ranged from 29 to 64 years, with an average age of 46.92 ± 11.05 years. To protect the privacies of the participants, we identified participants by numbers N1–N13. The demographic information of the 13 patients is presented in Table 1.

Data Collection and Procedure

Before formal interviews, three participants were recruited to revise the guide of the interviews. In formal interviews, researchers made preparation for each interview. Time and place were purposely confirmed in advance, which was chosen after supper (when the patient was not undergoing treatment) in a separate and quiet place (usually the ward or the doctors' duty room) to help all the patients express their full and lived experience as much as possible. Demographic information and basic clinical details were collected including age, nationality, occupation, marital status, education, income per year, residence, recurrent times, and causes of ARP.

Interviews

All interviews were conducted by the semistructured and in-depth method between September 13, 2016, and March 18, 2017, at the First Affiliated Hospital of Chongqing Medical University by the first author. Each interview lasted 45–60 minutes. A general interview guide was used. All interviews started with an opening question allowing participants to talk about what they had eaten before their ARP attack. Then questions for abundant information were asked.

Questions asked in the interviews were as follows: What did you eat before you were hospitalized this time? How many times have you suffered ARP? Did you have some negative emotion or just feel nothing about the symptoms, such as pain or fever? Did you feel stressed during hospitalization? If you do, would you tell me about the details? Would you tell me a little more? Would you explain? Comparing the last attack, how did you feel this time? When you were in the hospital for ARP, how did you feel at that time? What do you think of the recurrence? What's your attitude toward your health, like diet habits, especially after you experienced ARP? The entire interview was audio-recorded.

Special attention was paid to participants' facial expressions, tone, movements, repetition, pause, and other nonverbal behaviors during the process and noted in time as the series of questions were asked. Inducing or leading questions were avoided, and personal opinions and comments from the interviewer were not allowed except for appropriate probing inquiries. Expressing their true and full feelings in a natural way was encouraged among the participants. Participants were free to describe their perspectives on the lived experience during hospitalization. The interviewer would go over time

TABLE 1. The Demographic Information of the 13 Patients

No.	Age	Sex	Nation	Occupation	Marital Status	Education	Income ($)	Residence	Recurrent Times	ARP Cause
N1	46	F	Han	Executive employee	Married	Specialized secondary school	723–867	Town	2	Alcohol
N2	44	M	Han	Office worker	Married	Junior middle school	723–867	Town	2	Mutton
N3	54	M	Han	Farmer	Married	Junior middle school	434–578	Town	4	Alcohol
N4	44	M	Han	Driver	Married	High school	578–722	Country	2	Greasy meat
N5	33	M	Han	Engineer	Married	College	867–1001	Town	4	Double-cooked pork slices
N6	30	M	Han	Liberal professions	Unmarried	Junior middle school	289–433	Town	6	Bacon
N7	59	M	Han	Businessman	Married	Junior college	723–867	Town	2	Dumplings
N8	51	M	Han	Teacher	Married	College	867–1001	Town	2	Alcohol
N9	45	M	Han	Maintenance worker	Divorce	Junior middle school	578–722	Town	3	Broth
N10	29	F	Tujia	Delivery woman	Married	Junior middle school	289–433	Country	3	Rib soup
N11	63	M	Han	Retired	Married	High school	578–722	Town	4	Donkey
N12	64	F	Han	–	Widowed	Primary school	145–289	Country	9	Pork
N13	48	M	Han	Office worker	Married	College	434–578	City	2	Alcohol

or increase the time according to the patients' needs to ensure the integrity of the data. Finally, researchers translated the record, word for word and sentence for sentence within 24 hours after each interview (Gale, Heath, Cameron, Rashid, & Redwood, 2013).

Quality Guarantee

All interviews were done and transcribed verbatim by the first author in the study. The researcher was familiar with the demographic information and characteristics of the 13 patients, and the participants were known to the interviewer. A familiar and trusting relationship between the nurse and the patients was built during hospitalization. To gain the patients' trust, we verified the authenticity and integrity of the data with the patients within 3 days after each interview. The patients' medical history, records, and notes were analyzed. We chose patients purposely according to their varying demographic information and recurrence frequency to ensure that the sample was representative.

Data Analysis

Colaizzi's method (Cleary & Doody, 2016; Shosha, 2012) was applied to analyze the data (Coates, 2004; Doody, 2012), which includes seven steps: reading and understanding all the interview information deeply and carefully, extracting significance of the statements and phrases, formulating meaning of the significant statements, organizing meanings into themes and clusters of themes, integrating findings into detailed and exhaustive information, formulating a structure of the phenomenon, and achieving validation from the research participants, who compare the descriptive results with their lived experience (Cleary & Doody, 2016; Doody, 2012; O' Halloran, Sweeney, & Doody, 2013; Shosha, 2012).

Ethical Considerations

This investigation conforms with the principles outlined in the Declaration of Helsinki. Informed consent was obtained from each participant. We guaranteed the participants that all the information and the audio recording, as well as their personal details, were only for scientific research and would be destroyed at the end of the project.

Findings

The Demographic Information of the 13 Patients

There were 3 females and 10 males in this study, and the mean age of participants was 46.92 years (SD = 11.05 years, range = 29–64 years). Further details are given in Table 1.

Five Themes Were Identified in the Research, Both Positive and Negative

Anxiety and Fear

In this study, the ARP patients endured higher anxiety compared with their previous attacks. The most prominent presenting symptom of ARP is abdominal pain, which may become intense and radiates to the middle of the back (Stillman & de Tornyay, 1978). Suffering severe pain, they often felt anxious, afraid, and fearful. Some patients felt panicked and flustered.

> N3: I breathed quickly, got out of breath and was unable to speak fluently in the end. My son called his mother to save me.

It seemed that women experienced more anxiety than men among all the participants because we observed that women in this study had more negative nonlanguage-reflecting emotion, such as sighing, uneasy tone, and sobbing.

> N1 (W): I felt abdominal pain suddenly when I had a night-time snack with some friends. At the time, I sweated continuously, my heart was beating so fast that they were very scared, and they took me to the hospital in a hurry. I did not dare to do it the next time, and I am afraid to eat more (sighing).

> N12 (W): Reunion with the family before the Spring Festival was common, and the dinner was sumptuous. It was the first time that I took a few pieces of donkey meat and …, ah (regretful). I guess I will not have meat now (sobbing and helpless tone).

Some patients described that their direct relatives were not beside them when recurrence happened and so they were very scared.

> N9: I had gotten divorced 5 years ago. My son is a migrant worker, so only my brother could help me. This time was more severe than the last two attacks, and we were so scared that I was transferred from the junior hospital to this senior hospital (afraid expression).

Lack of Professional Knowledge

Most patients showed poor compliance and lacked basic knowledge about ARP. They did not know what pancreatitis is, and how to prevent a recurrence.

> N2: I did not know what I can eat and not eat as an acute pancreatitis patient. I had not paid attention to it since I left the hospital last time. Why did I suffer acute pancreatitis this time (dismissive mood)? Maybe it depends on luck.

They felt that it was a matter of unlucky or by accident rather than their ignorance that led to being hospitalized. However, they wished to know how they could prevent recurrence and the diet guidance when discharged.

> N6: I do know the importance of diet for acute pancreatitis, however, it had been a long time since I had had a

piece of bacon, you know, which is one of the most traditional foods in the Spring Festival. We even feel ridiculous if we do not eat it during this special holiday. I was frustrated that I couldn't eat delicious food at the festival. I thought it was impossible for me to be sick if I had some meat, but the result was depressing. How insufferable the abdominal pain was!

N5: The nurse seemed to tell me some diet-related information for acute pancreatitis during my hospitalization last time, but I had forgotten because it was so long ago!

Inevitability and Helplessness

Several of the patients expressed feelings of passiveness and helplessness. Some of these feelings were due to their social factors, such as social engagement with workmates, cooperative partners, or clients.

"The Table and Wine Culture" is prevalent in China. A patient said that it was the work factor that resulted in recurrence.

N1: I had a very important work project last year, so it was my duty to accomplish it. I had no reason to refuse the requests of the clients, such as drinking (frowning), cup after cup. It is a custom for people to reunite at the Spring Festival.

The Spring Festival is the most important festival in China. It is a custom for people to reunite at the Spring Festival, eating and drinking.

N8: It's a conventional phenomenon that families get together and have dinner or drinking to create a warm atmosphere in China. It's hard for me to give up alcohol. I had two cups of white spirit this time since I experienced some pain (shrugging).

N13: One of my best friends came back, and it had been five years since we had seen each other. Didn't I go to dinner with him (laughing)? If he invited me next time, I would go for it too (laughing with naughty expression)!

Guilt and Shame

Guilt and shame were seen in a few patients who had a relatively bad economic condition. Medical cost is a significant expense among ordinary Chinese citizens. There were about 56.3 million impoverished people in China in 2015. The per capita disposable income was ¥23821 ($3443) in China in 2016. Patients who were poor told us that the economic stress was a barrier for them. Because some kinds of drugs and medications were beyond the medical insurance coverage, it could be a heavy burden for patients. In addition, it is common in Chinese hospitals that the patients' parents, children, or relatives were required to stay beside them to take care of them, which further increases the burdens and guilt.

N4: I suffered severe acute pancreatitis (SAP) this time, so I had hemofiltration and was in the Intensive Care Unit for 7 days before coming to this ward. It's a very heavy burden for us common people, and it is also a waste of money (laughing bitterly). My salary could afford the expense for a few months (staring, shaking his head and sighing). My son will go to university next year, but as an old man, it's a shame for me to increase the stress for my family.

N3: We are not rich (looking at the wife aside), and my condition has cost more than 20,000 RMB (almost 3000 Dollars) so far due to hospitalization. My wife and I had planned to have a trip around Chongqing, but now it is just a dream (sighing).

When asked whether they felt that they had burdened their families, especially their caregiver, because of their ARP, the answers from most patients were yes. They were all sure that the hospitalization had burdened their families to an extent, especially the three patients with severe AP.

N5: It's more severe than last time. My wife, especially, took care of me and asked for leave for me, so my son was looked after by one of my neighbors. The disease is embarrassing.

N10: I had to call my mother to care for me because my husband could not take leave for work. My mother was 72 years old, and I felt guilty (helpless mood and sobbing).

N11: My family was very worried for me, especially during the three days when I was admitted to the hospital, during which I was arranged for ECG monitoring. She (his daughter) kept me company and did not sleep for 24 hours except for a cat nap in the daytime. She has had a hard experience these days (looking at her affectionately).

Hope and Perseverance

Despite enduring such a "miserable" process, almost all the patients were hopeful for recovery, except for one. Some patients said that the medical staff played an important role in their recovery and showed trust in them.

N1: I trust the doctors and nurses who treated me, and they are responsible for me, and I believe that medical technology will be improved rapidly in the near future. So, I am hopeful for rehabilitation (smiled at interviewer).

N3: Although I have suffered acute pancreatitis four times, I think as long as I follow what the doctor and nurse told me, I will stay healthy. If I suffered it again, I would not give up but would remain positive and seek treatment.

A patient showed confidence in modern medical technology.

N7: In an era of technology, I have faith in my health (smile).

Patients also hoped to know more about the condition of AP. Patients also desired knowledge related to ARP to prevent recurrence.

> N5: I could not remember what the nurse had told me about the disease, so I hope she will tell me again.

> N6: I had recorded the telephone number of the nursing station so that I could consult them in the future if I need.

Some patients showed perseverance in maintaining appropriate diet habits. They had the confidence in keeping a balanced diet.

> N4: The nurse had given me a piece of paper that was full of disease health education information. I will develop and keep good diet habits based on that, ha-ha!

> N10: Indeed, I should keep fit to avoid getting sick. After all, as time is flying, I am getting older and older, so I cannot eat immoderately.

Discussion

The incidence rate of ARP has risen year by year in China. Therefore, this study focused on understanding and describing the lived experience of ARP patients during their hospitalization. To our knowledge, this is the first article focusing on the lived experience of ARP inpatients in China using phenomenological methods, which differs from the previous studies (Kapetanos, 2010; Khurana & Ganguly, 2014; Sajith, Chacko, & Dutta, 2010), focusing on the etiologies and clinical profiles of ARP. This study has presented both positive and negative experiences of inpatients with ARP. They suffered anxiety and fear, lack of related knowledge, inevitability and helplessness, guilt and shame, and hope and perseverance. They desired help from others, especially professional knowledge. In addition, we also showed that family and social factors could lead to heavy mental stress for ARP inpatients.

Anxiety has been proven to be a prevalent mental disorder among patients and is easy to experience regarding illness, health, or unfamiliar environments (Kessler, Chiu, Demler, & Walters, 2005). Growing evidence has indicated that abdominal pain is positively correlated with anxiety (Srinath et al., 2014; Walter et al., 2013). Acute recurrent pancreatitis inpatients with complications may feel increased pain during each attack, further resulting in anxiety, fear, and even depression. As one participant in this study said, the pain seemed increasingly severe, but the pain threshold was increasingly lower as the attacks increased. Nurses should provide priority care and interventions required for each patient (Brown, 1991). Under the circumstances, administering analgesia is needed, and reviewing its effectiveness is essential (Mcardle, 2000). All the usual medical management approaches should be used (Resnick, 2017), both pharmaceutical and nonpharmaceutical.

In this study, a lack of knowledge about ARP is one of the major reasons leading to recurrence. It is generally recognized that health education can help improve patients' knowledge and cognition of the risks of diseases (Tang, Hung, Chen, Lin, & Liu, 2015). Mcardle (2000) showed that providing educational information to alcohol-addicted patients significantly reduced their alcohol intake. Having timely access to educational information can help patients feel relaxed, indicating that nurses can create a targeted plan offering health instruction for relieving anxiety according to the educational levels, occupations, and other objective and subjective information about patients.

However, compliance should also be considered when performing lectures. Noncompliance is estimated in the United States to cause 125,000 deaths, 19% of all hospital admissions, and more than the US $100 billion in additional healthcare costs every year (Hausman, 2001). The 13 patients enrolled in this study had weak self-control, demonstrated severe physical and psychological symptoms, and one of the subjects had suffered nine attacks. Thus, improving medical compliance is very important to prevent attacks. Registered nurses can perform follow-up visits to satisfy patients' needs and implement continuing care, which seems to be helpful for reinforcing an initial period of recovery (Blodgett, Maisel, Fuh, Wilbourne, & Finney, 2014).

The special culture of the Chinese Spring Festival is another factor associated with the incidences of ARP. The Spring Festival is a time when families and friends get together to eat and drink, analogous to Christmas in Western countries. Furthermore, wine culture is very popular in China for everyone, young and old. Six subjects enrolled in our study were patients hospitalized during the Spring Festival because of overeating and drinking, though they had suffered from ARP before, indicating the important roles of medical workers as good educators for patients and to influence patients' perspectives on alcohol and dietary habits.

Furthermore, some patients told us that they felt ashamed, even guilty, for their families because of economic factors and caregiver burden, which has been previously demonstrated to be higher in China (Zhou et al., 2016). Longer hospitalization time was associated with higher medical costs (Huang, Vemer, Zhu, Postma, & Chen, 2016; Wang et al., 2015), which explained why the participants were worried. The costs paid by co-payments of insured patients and uninsured patients were quite different (Zhang et al., 2017). Despite the medical reform in China, some people are uninsured (Wu, Huang, & Lu, 2016). For

uninsured people, the total fees during hospitalization seemed to be unbearable. For insured people, employee medical insurance and resident medical insurance are the main types of insurance in China, and the payments differ according to the type. Although the population with medical insurance has been expanded and individual payments for medical expenses reduced from 52.2% in 2005 to 32.0% in 2014 (Wu et al., 2016), numerous people still face heavy economic burdens and low incomes, especially for country residents. So, some of the inpatients in this study still suffered a heavy expenditure burden.

However, almost all the participants expressed confidence and hope in terms of recovery. These emotions seemed to be associated with the spirit of the Chinese nation that has been handed down for thousands of years, with self-strengthening and tough character. Previous studies have suggested that Chinese people tend to hold onto their negative emotions to avoid adding to others' burden (Ho, Chan, & Ho, 2004; Ho et al., 2016). They would rather show their positive emotions than negative ones to others. The national spirit is the spiritual support for a nation to exist and develop. These national traits include feeling strong, tough, hopeful, and persistent, which are always valued by Chinese individuals.

Limitations

There are several limitations within this study. First, the study recruited only 13 ARP inpatients from one hospital in southwest China for interviewing. The findings may differ between other regions and races, so multicenter studies and larger samples are needed to better understand other experiences of ARP inpatients. Second, there are only three females in the study, and this may be inappropriate to generalize our findings to other populations. Third, we focused only on inpatients and did not explore the psychological factors of the patients when they discharged. However, this is a qualitative study to focus on the lived experience among ARP inpatients. We hope that our findings provide useful information for related departments and, hopefully, promote considerably more work.

Conclusion

This study was the first performed using qualitative methods to focus on the lived experience of ARP inpatients, thus presenting a chance for us to learn about the inner world, mental activities, and basic needs of them. Most of the patients in our study showed strong negative thoughts, such as anxiety, fear, helplessness, guilt, and shame. Our findings also showed that although some patients suffered repeated recurrences, they still tend to be full of hope and perseverance, as well as expressing active attitudes toward gaining professional medical information. It seemed that low compliance levels among ARP inpatients were major reasons for many of their recurrences in China. Future study is needed to validate the results of our study. ✪

Implications for Practice

This qualitative study was the first one to discuss the lived experience of ARP inpatients in west China by phenomenological methods. The findings showed complex emotions in ARP inpatients, which have clinical implications. We also learned of the poor compliance but a strong desire for professional knowledge among the participants. The medical workers should have access to understand the inner world for ARP inpatients to take effective measures for them.

Health education and patients' compliance can both benefit from collaboration with other related departments. The ARP patients' psychology should be recognized and understood by nurses. Further studies can be focused on how to prevent ARP patients suffering recurrent attacks.

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