

# The Surrogate Decision Making Participation Experience of Severe Acute Pancreatitis Patient In ICU: A Phenomenological Research In China

Ting Fang (✉ [ft6201@163.com](mailto:ft6201@163.com))

Wuhan University People's Hospital: Wuhan University Renmin Hospital <https://orcid.org/0000-0002-2520-9586>

**Shasha Wang**

Wuhan University People's Hospital: Wuhan University Renmin Hospital

**Yiyu Zhuang**

Zhejiang University School of Medicine Sir Run Run Shaw Hospital

**Xiuwei Zhang**

Huzhou Teachers College: Huzhou University

---

## Research

**Keywords:** Intensive care unit, Decision making, Surrogate, family member, Qualitative study, Phenomenological research

**Posted Date:** August 23rd, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-827735/v1>

**License:**  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

---

# Abstract

**Background** Patients with severe acute pancreatitis mental state, tissues and organs function severely affected, patients themselves unable to effective participation in decision making, they have to rely on their family members to participate in clinical decision making, when the patient was admitted in ICU. However, it is unclear what factors influence the surrogate involved in decision making during anxiety, depression, post-traumatic stress disorder and other adverse psychological reactions. To describe the experiences of ICU patient's family members with severe acute pancreatitis during decision making process.

**Methods** Husserl's phenomenology was applied in this study. This study was conducted in a critical care unit of a China tertiary hospital. They used Semi-structured face-to-face interviews with 12 surrogates of people with severe acute pancreatitis patient to explore the influencing factors of decision participation. This study followed the Colaizzi's phenomenological method guided.

**Results/Finding** Our sample consisted of 12 participants. Data analysis revealed four main themes: (i) ICU family surrogate cognitive self-role, (ii) ICU family surrogate consider of uncertainty, (iii) ICU family surrogate Communication and consulting, (iv) Decision-making attitude of ICU surrogate.

**Conclusion** A framework of 4 themes of decisional involvement of family members of patients with severe acute pancreatitis in the ICU was constructed, and the interrelationship of the 4 themes was revealed. Psychological and somatic experience of the family as an outward expression of participation in decision-making, self-ability cognition is the internal cause of decision-making participation, consulting experience and considering uncertain factors are the external cause of decision-making participation. It is very important for ICU professionals to consider family members' decision-making participation. The suggestion that the family members of ICU patients participate in the intervention plan was initially formed ICU professionals should respect the values of patients' family members, to improve the disease awareness of the patient's family, to improve the support of the medical care system, and to improve Communication and emotional support skills for health care workers.

## Background

Acute pancreatitis is a common clinical emergency abdominal condition with an incidence of 13–45/100 000[1], of which 20% are severe and dangerous, and Severe Acute Pancreatitis (SAP) has a morbidity and mortality rate of 5%-20%[2]. Patients are often sedated, unconscious and unable to participate in decision making communication, therefore, patients rely on their families to participate in decision making discussions[3] and are unable to participate in clinical decision making themselves[4, 5]. However, when patients are admitted to the ICU it can lead to emotional distress, anxiety, depression, adverse psychological reactions such as post-traumatic stress disorder, family role conflict, intense stress, disruption of daily life and potential changes in relationships between family members, with the families

reporting qualitative research of ICU patients experiencing even more distress than the patients [6]. One study showed that family members experienced up to 70.0% symptoms of anxiety and 35.0% symptoms of depression in the first few days of a patient's ICU admission, and 50.0% of family members reported that they did not fully understand the medical explanations [7].

Due to the specificity of SAP and the long duration of the disease, which places a large financial burden on society and families[8], its treatment reflects the contradiction between high-tech, high-cost, high-efficacy modern treatment modalities and society's low affordability, and patients and families expect someone to respond to their needs and assist them in decision-making participation[9, 10]. In the modern environment of highly specialised medicine where there is an ever-increasing competition to find more clinical space, healthcare professionals need to advocate strongly that provide a therapeutic space not only for patients but also for their family support network. This support comfort and rest throughout their ICU experience may improve satisfaction levels and enhance person-centred care.

Scholar Goldstein argues that the family of ICU patients is one of the important factors as a health promoter for patients and should be widely appreciated[11]. Pochard argue that adverse psychological reactions of family members can influence the decision-making process and that different decisions, which produce different outcomes, affect the physical and mental health of patients and families[12]. There is growing recognition that high-quality care for patients and families in the ICU requires exemplary interprofessional collaboration and communication.[13] Therefore, this study explores the real thoughts, ideas and actions of family members of ICU patients with severe pancreatitis in the decision-making process from the perspective of a qualitative study, vividly reproducing the essence and meaning of decision-making participation and reflecting on the shortcomings in clinical practice.

## Methods

### Participants and setting

The study used purposive sampling to select a sample that took into account the different ages, genders, disease diagnoses and decision-making involvement experiences of the interviewees for purposive sampling. The sample size was judged by the saturation of the collected data, when no new information emerged from the data.

Family members of patients with severe pancreatitis in the ICU of a tertiary hospital in a city were used as the subjects of the initial screening interview. Inclusion criteria: (i) family members of patients with severe pancreatitis who had decision-making participation experience in the ICU this time and were the primary caregivers; (ii) patients with severe pancreatitis in the ICU were unable to participate in decision-making due to disease factors; (iii) age  $\geq$  18 years, having normal cognitive ability and language expression ability; (iv) family members who gave informed consent to voluntarily participate in this study. Exclusion criteria: (i) those who did not agree to participate in this study; (ii) family members of patients with severe acute pancreatitis who had no experience of decision-making participation; (iii) those with severe

cognitive impairment, unable to speak or who had difficulty in verbal conversation; (iv) finally, 12 cases of interviews with family members of patients with severe acute pancreatitis in the ICU who had experience of decision-making participation were collected to achieve data saturation (Table 1).

Table 1  
Socio-demographic characteristics of the participants (n = 12)

Number	Code	Gender	Age	Education level	occupation	• Relationship with the Patient
1	A	Male	35	Junior high school	self-employed	Brother
2	B	Male	29	high school	staff	son-in-law
3	C	Female	32	Master	staff	wife
4	D	Female	32	College	staff	daughter
5	E	Female	31	Bachelor	nurse	daughter-in-law
6	F	Male	43	senior high school	staff	daughter
7	G	Female	31	Junior high school	staff	wife
8	H	Male	52	Junior high school	staff	son
9	I	Female	67	Junior high school	teacher	Wife
10	J	Female	28	Technical secondary School	staff	Husband
11	K	Female	31	Technical secondary School	staff	Wife
12	L	Female	28	bachelor	staff	daughter

### Ethical considerations

This phenomenology study was reviewed and approved by Sir Run Run Shaw Hospital institutional review board (number 20160610-4). We performed Semi-structured face-to-face interviews with 12 surrogates of people with severe acute pancreatitis patient admitted to ICU at the hospital of the Sir Run Run Shaw Hospital. We used the Consolidated Criteria for Reporting Qualitative Research [14] to guide reporting in this article. The study was approved by the hospital ethics committee and the following principles were strictly adhered to: (i) Principle of informed consent: The researcher is required to explain the purpose of the study to the family and all family members who voluntarily participate in the interview are required to sign an informed consent form. (ii) The principle of respect for personal privacy and confidentiality: the audio recordings and transcribed texts must be kept confidential and the names of the participants must not appear in reports or published publications. (iii) Principle of non-harm: During the

interview, the researcher enters as a nurse or listener and does not make any judgment on the statements made by the research subject. If the interview participant experiences mood swings, adverse emotional reactions such as crying or anxiety due to the content of the interview, the interviewer will pause the interview and give the patient appropriate reassurance, and the interview participant can ask to end the interview at any time. (iv) Principle of fairness in return: The interview ends with a sincere thank you to the patient's family and a small gift.

## **Data collection**

The semi-structured in-depth interview method and participant observation method were used to collect the data. In order to help the family recall the complete decision making involvement experience and experience, the interviewer gave the family clues about the session when they were admitted to the ICU to help them recall, so the first 1 and 2 of the outline are leading questions and the 3rd-6th are the main interview questions. (i) Can you tell us about your admission to the ICU at that time? (ii) How long did you care for her? (iii) How were you considered during the decision-making process? (iv) What were the main aspects you considered in this decision making process? (v) What difficulties did you find in the decision-making process? (vi) How do you think the doctors and nurses would like to help you?

During the researcher's in-depth ICU bedside nursing work, he understood the needs of patients and families through participatory observation during nursing assessments, nursing operations, accompanying examinations, and living care, took the initiative to ask questions and did his best to care for patients and families, strengthened communication and exchange, gained a family and friend-like relationship of trust, established participatory observation record sheets, and records of observation records and reflections assisted in data analysis.

## **Data analysis**

Strictly using Husserl's descriptive phenomenology as the philosophical basis for analysis, and in order to increase the rigour of phenomenological research, in 2011 Australian nursing PhDs Karen-Leigh Edward and Tony Welsh extended and supplemented Colaizzi's seven-step analysis as the eight-step Colaizzi phenomenological analysis[15], (i) carefully read all interview transcripts; (ii) analyse significant statements; (iii) code recurring and meaningful ideas; (iv) assemble the coded ideas; (v) describe the phenomenon in detail and without omission; (vi) take additional steps: analyse symbolic statements and linguistic symbols such as tone of voice, gestures and metaphors; (vii) identify similar ideas and sublimate thematic concepts; and (viii) return to the interviewee for appropriate validation.

## **Results**

This study collected the experiences of family decision making involvement experiences of 12 patients with severe pancreatitis between 29 January 2016 and 25 November 2016 and distilled four themes

including: ICU family surrogate cognitive self-role, ICU family surrogate consider of uncertainty, ICU family surrogate communication consultation, decision-making attitude of ICU surrogate.

### **Theme 1: ICU family surrogate cognitive self-role**

This theme consists of three primary elements: "perceived experience of competence", "experience of psychological state" and "somatic experience".

Regarding the knowledge of the disease, the family members lacked knowledge about severe pancreatitis and their understanding was inconsistent. For example, family member A said, "There is no awareness of health care" because they were not educated and had not finished secondary school, so they had no awareness of medical care at all. The family E said "a little bit of understanding", because she worked in the hospital, the patient also had pancreatitis before. "But not very much", after all, she couldn't grasp so much, and some issues were still not understood.

The negative psychological indicators of family members' participation in decision-making are: anxiety and fear, feelings of uselessness, uncertainty and unfairness, and the positive psychological indicators are: sense of responsibility, confidence and strength.

Regarding anxiety and fear, e.g. Family B is "very anxious" because the condition has a high mortality rate and a critical illness notice has been given. Family member F feels "very worried" because the patient is very swollen, has no consciousness and he does not feel anything. Regarding the sense of uselessness, Family B feels "it's useless" because they don't understand. Family member H felt "there is nothing I can do" because the condition is very serious and there is nothing they can do. Regarding the feeling of uncertainty, family member E said that he "had doubts and thought of transferring to another hospital" because his condition was getting worse and he was already in a coma and not very conscious at that time. Regarding the sense of injustice, as family member I mentioned, "life is so unfair to me" and how everything is spread to her.

Positive psychological indicators are listed below: regarding responsibility, e.g. Family A states "go face it, you can't put the blame on your parents" because that's not what men do. Family member J stated that "couples are supposed to stay together" because two people in a couple are in trouble together. Regarding confidence, Family member A wanted to "give yourself confidence" because my brother is a good person, he will be fine with anything and this big disaster will definitely pass. About strength, Family G said "Family members have to be strong (2 times)" because you have to go and give him confidence, you also have to face the doctors, the family and all the people.

As family members became more involved in decision-making in the ICU, they began to show physical symptoms, as family member A described, "I have taken several Valium tablets, but I still can't sleep", because I was faced with all the things the doctor told me about the disease every day, plus the pressure of the internet and the financial pressure. Family member F "I can't eat or sleep well", because sometimes I wake up in the middle of the night dreaming that the patient is not being cured.

## **Theme 2: ICU family surrogate consider of uncertainty**

This theme consists of four elements: 'Considering the patient', 'Considering the economy', 'Considering the disease', 'Considering the outcome'.

The family includes four aspects when considering the patient: somatic experience, psychological state, personal characteristics, emotional support. Regarding the somatic experience, family member H felt that the patient "always suffered and our hearts ached" because she was uncomfortable, her brain was muddled and if the tubes were removed they would have to be inserted again. Family member K felt that the patient "suffered pain and was so miserable" because after the operation he was there by himself in tears, with tubes all over his body, and the tube in his mouth to keep him breathing was so thick that he must have been uncomfortable. Regarding his psychological state, family member I felt that "the patient was very agitated and scared" because he was awake and saw that he was a critical patient and that he was going to die at any moment. Family member E felt that "the patient was a bit depressed" because everyone was busy with their own work. He had been in the ICU for a long time, so he had some psychological problems and went to the mental health unit at that time. Regarding personality traits, family member L felt that the patient was "mentally well" because before he was admitted to the ICU, he was in a good state to eat and play with his mobile phone every day. Regarding emotional support, family member K said "let his will power be strong" because we had to hold on and give him a break.

Family K said that financially it was "simply unaffordable" as they were from another city and the daily costs were very high. Family member I said it was ok that the patient had health insurance, "it relieved a lot of the burden".

Regarding the seriousness of the illness, family member A "never dreamed of such a big illness", never thought that he had this illness, never thought he had this big illness. Regarding the danger of the disease, family member A felt that it was "very, very dangerous (with his hand over his chest)", because a normal lung is two lobes, but his lung was already squeezed out and was only as big as his fist.

The family includes two aspects when considering the outcome: uncertainty and expectation of improvement. Family A said that "no one knows", because after all, they have to rely on themselves and all the equipment to observe them, and no one is an immortal who can tell all at once. Family member G said that he "might not be there at any time", because being in the care unit is a risky situation and his condition is sometimes recurrent. Family member K said he "believes he will get better" because after all, he is young and the important thing is that he has children, so there should still be a chance.

## **Theme 3: ICU family surrogate communication consultation**

The ICU family's experience of decision making involving communication and consultation includes four dimensions: consultation with a health care provider, consultation with a friend, consultation with a network, and consultation with a family member.

There are five areas that families cover when consulting their health care provider: information about the illness, finding hope, communication about the relationship, communication time and communication effectiveness. Family member G said, "I just need the simplest information about the change between today and yesterday", because I don't understand the data on the computer, we don't know what it means.

Family members look for hope from the medical staff during consultations. Family member G said "trust the doctors, you give me the most confidence" because every day they come in and communicate the changes in his day, and several times I have come in and seen them standing there watching him again. Regarding the communication relationship, the family sometimes feels nervous when consulting with the doctor and the family feels that "the doctor is annoying me" because I am too noisy and ask him so many times every day and I am always around whenever he is there. Regarding the effectiveness of the communication, for example, family member A felt that "the condition was discussed more comprehensively" because the doctor was very good, he would tell you what would happen later, at least he had a bottom in his mind. Sometimes the communication was ineffective and family member K felt that it was "difficult to communicate" because they only accepted the visiting time to ask questions about their condition and the visiting time was only half an hour, so they could only talk briefly before leaving.

When family members consulted the internet for information about the disease, Family H repeatedly stated that "it is helpful to know the history of treatment development" because it facilitates their own analysis and handling of matters related to the disease.

When the family consulted the internet to search for hope, Family A mentioned that they were "looking forward to seeing a good thing on Baidu", as the family was looking forward to a popular comment that there was nothing in the ICU to give them confidence. There are three aspects to family members consulting their family members: concern, ambivalence and comfort.

There are three aspects to family members consulting their family members: concern, ambivalence and comfort. Family members feel worried when they consult their family members. Family member A says that "there is no way to discuss this with my parents" because they are so far away, thousands of kilometers away, so I don't want them to worry more! It's better to put everything in my heart. Family member I said "very contradictory" because the sisters are too old to take care of themselves. On the one hand, I told them that I was afraid they wouldn't be able to take the blow, but on the other hand, I didn't say anything in case something happened, so I was afraid they would blame me. Family member K feels "still comforted" because there are many sisters and they help to think of ways to finance them, so the pressure will be less.

#### **Theme 4: Decision-making attitude of ICU surrogate**

This theme consists of five elements: "trust the doctor", "actively save him", "actively cooperate", "try to cooperate" and "only cooperate". When the decision was made to "actively save him", family member G wanted to "pay the money in every day and give him as much medicine as possible, as long as he could

be saved", because the patient's fever was constantly high and low, and he was anxious because of the repetition. When the decision is "actively cooperate", family K thinks that if the condition is stable, they can be transferred to a general ward and the costs will be reduced and the pressure will be less. When the decision is "try to cooperate", family H thinks "I'll do it if I can, but there's no point in doing it again if I can't", because the family thinks the condition is so bad that they have to see if they can bear it, either mentally or financially. When the family's decision was "to cooperate", family member B said "leave it to your medical care!" Because there was nothing they could do. Family member H also repeatedly said "I can only cooperate with you" because we don't understand, but the doctor will tell us how to treat this condition later.

## Discussion

Identifying the relationship between the intrinsic and extrinsic elements in the interaction between ICU families and healthcare professionals' decision-making involvement is an exploration of the nature of the meaning of family action. In the phenomenon of family decision-making in the ICU, the "family self-role" consists of three dimensions: "competence cognitive experience", "mental state experience" and "somatic experience". The "ability cognitive experience" plays a decisive role as an intrinsic factor in the decision-making process, while the "mental state experience" and the "somatic experience" are the family's experiences. "Somatic experiences" are the post-decisional expressions of the family. The "consideration of uncertainties" and "communication and counseling" as external factors of the phenomenon in turn influence the family's cognitive, psychological and somatic experience as a necessary condition for the family's decision making. Among the "uncertainties to consider" are "illness", "finances", "patient", "family" and "hospital". "family" and "hospital" as external factors of the phenomenon that the family cannot change. "For ICU families, the "consultation with medical and nursing staff" as an external factor is a crucial part of the phenomenon for decision making and participation.

The family of the ICU patient finally decided that "I will save my brother even if I have to sell my pots and pans, and I will accept that loss of life and property", because in the eyes of the family "kinship" is better than "money". The "sense of responsibility" is the support of the inner strength of the subconscious, and the "culture of filial piety", "moral conscience" and "good intentions and good rewards" play a leading role. The "culture of filial piety", "moral conscience" and "good intentions" play a leading role. The "advanced medical equipment" is the objective basis for the family's decision making, the "friends" of the doctors are trustworthy, and the high cost of the ICU is a problem. The lack of knowledge about the disease is reflected in the words "nothing at all about health care" and "I don't know much about it after all". "There is a sense of fear and dread", "I'm really scared" and "I can't eat or sleep well". The family suffers a great deal of psychological and physical pain, but it is difficult to cope with it (Fig.1).

Traditional Chinese culture influences the values that families choose when making life and death decisions for their loved ones, and healthcare professionals should understand the values that families follow and thus respect the choices that families make for their patients. Hospital treatment does not only depend on developed medical equipment and skilled doctors, but also on the public health care

coverage of the cost of treatment and the improvement of the health care system. In the modern environment of highly specialized medicine where there is an ever-increasing competition to find more clinical space, healthcare professionals need to advocate strongly that provide a therapeutic space not only for patients but also for their family support network. This support comfort and rest throughout their ICU experience may improve satisfaction levels and enhance person-centered care [16]. Autonomy of choice, especially of those who are incapable of discernment, can be seen as a relational faculty jointly constructed that could contribute to maintain and foster humanisation in critical care [17]. Enhancing the frequency and quality of communication between ICU caregivers and the patients' family with a standardized format improves the decision-making process for continuing versus limiting life sustaining treatment of ICU patients [18]. Medical and nursing care should pay attention to communication skills that can explain the condition clearly and easily, as well as enhance the level of knowledge and hope related to the illness of the family. ICU medical and nursing staff should understand the performance of the family's emotional feelings and provide the necessary emotional support to alleviate the family's adverse experience and enhance coping skills in decision-making participation.

## **Limits**

Due to regional limitations, the research object of this study is the family members of ICU patients with severe pancreatitis in a third-class A hospital. In the future, the sample can be further expanded to select other regions for further study. Patients with severe acute pancreatitis have been treated for a long time, and their surrogate families have rich experience in decision-making. Therefore, this study only selected the families of patients with this disease as the interview object, and it is uncertain whether the families of patients with other types of diseases have the same results.

## **Conclusion**

This study reproduces the elements of family members of ICU patients with severe pancreatitis in the decision-making participation process, vividly describes the real feelings of family members in the decision-making participation process, and enables healthcare professionals to understand more deeply the values, emotional feelings and behavioral norms of family members of ICU patients with severe acute pancreatitis.

Based on the understanding of decision making involvement of family members of ICU patients, a preliminary proposal for an intervention program for decision making involvement of family members of ICU patients was developed. (i) Endogenous intervention recommendations: Firstly, healthcare professionals should obtain the values followed by the family so that they can better respect and understand the choices made by the family for the patient. Secondly, provide families with knowledge of the diagnosis, progression, treatment options and prognosis of severe acute pancreatitis on a micro level, and improve the system of multi-dimensional disease information support on a macro level. (ii) Recommendations for exogenous interventions: Firstly, encourage and support the community to provide compassionate assistance and improve the support system of the medical security system to relieve the

financial pressure of the family. (iii) Pattern of manifestation intervention suggestions: ICU health care staff should understand the performance of the family's emotional feelings, provide the necessary emotional support, alleviate the family's adverse experience, empower the family, and enhance coping skills in decision-making participation.

## **Abbreviations**

### **ICU**

Intense care unit

## **Declarations**

### **Availability of data and materials**

The data are available from the corresponding author on reasonable request.

### **Acknowledgements**

The authors deeply acknowledge all the staff members of Sir Run Run Shaw Hospital for their support and cooperation. The authors also thank all the research participants and who supported and facilitated this research.

### **Funding**

Open access funding provided by Renmin Hospital of Wuhan University, This study was in part funded by the Project of nursing in the people's Hospital of Wuhan University.

### **Author information**

#### **Affiliations**

Department of Critical care medicine, Renmin Hospital of Wuhan University, Wuhan, Hubei, China

Ting Fang, Shasha Wang

Nursing department of Sir Run Run Shaw Hospital, Zhejiang University School of Medicine, Hangzhou, Zhejiang, China

Yiyu Zhuang

Huzhou University, Medical college of Huzhou University, Huzhou, Zhejiang, China

Xiuwei Zhang

### **Contributions**

Both TF and SSW contributed equally to the writing and revising of the manuscript and both approved the final manuscript. TF: Conceptualization, Methodology, Validation, analysis, Resources, Data curation, writing-original draft. SSW: Formal analysis, Supervision, Resources. YYZ: Methodology, Resources, Project administration, Supervision. XWZ: Conceptualization, Methodology, analysis, Supervision, writing-review.

### **Corresponding author**

Correspondence to Ting Fang or Yiyu Zhuang or Xiuwei Zhang

### **Ethics declarations**

Ethics approval and consent to participate

The study was approved by Sir Run Run Shaw Hospital institutional review board (number 20160610-4). The participants were informed about the study and about the handling of personal data and were informed that personal information would be kept confidential. Written informed consent was obtained.

### **Consent for publication**

Not applicable

### **Competing of interest**

The authors have no conflict of interest to declare.

### **Additional information**

Publisher's Note

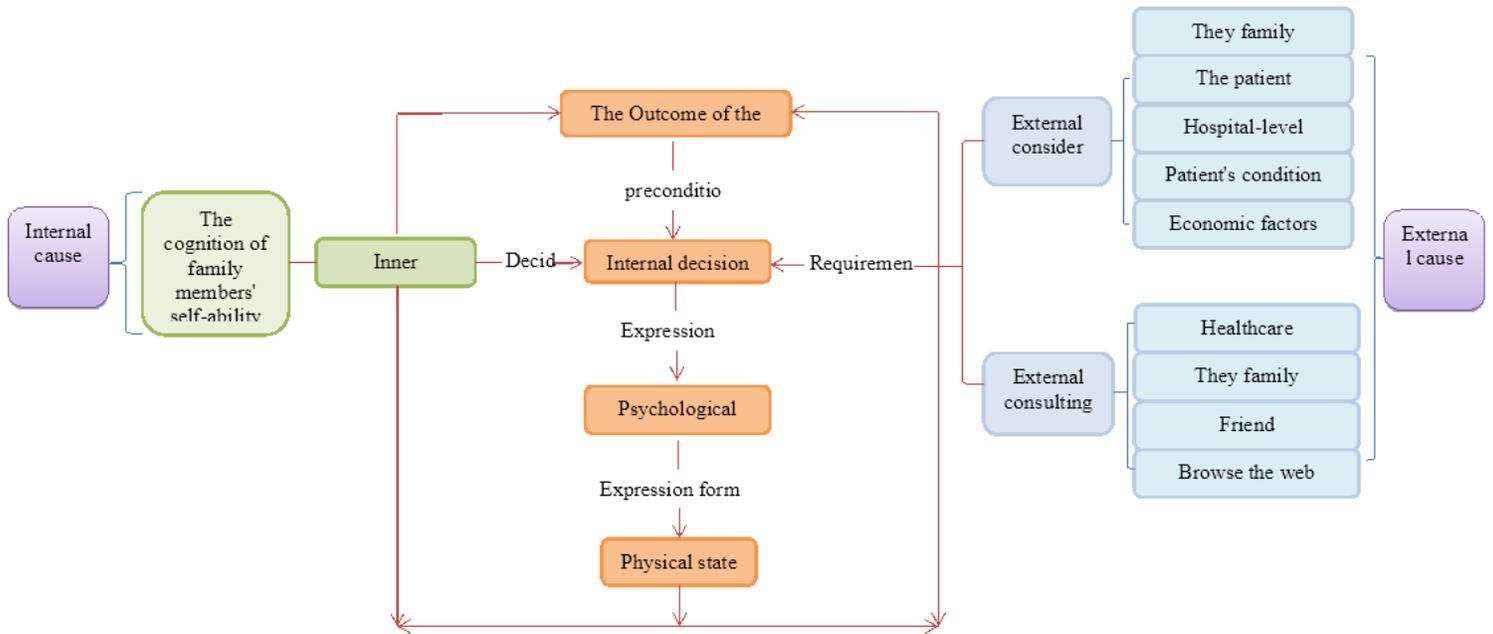
Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## **References**

1. Wu HS. Minimally invasive intervention in severe acute pancreatitis. *Journal of Clinical Emergency(China)*. 2016;17(2):85–8.
2. Lankisch PG, Apte M, Banks PA. Acute pancreatitis. *Lancet*. 2015;386(9988):85–96.
3. Cheryl, Holly. Susan Salmond: Families' Experiences of Having an Adult Family Member in a Critical Care Area: A Systematic Review of Quantitative Evidence. *The JBI Database of Systematic Reviews and Implementation Reports* 2012:237–250.
4. Cai X, Robinson J, Muehlschlegel S, White DB, Holloway RG, Sheth KN, Fraenkel L, Hwang DY: Patient Preferences and Surrogate Decision Making in Neuroscience Intensive Care Units. *other* 2015, 23(1).

5. Harvey S, Adenwala A, Lane-Fall M. Defining Familial Interactions and Networks: An Exploratory Qualitative Study on Family Networks and Surrogate Decision-Making. *Critical Care Explorations*. 2021;3:e504.
6. Liu XJ, Yu JH. A Qualitative research on the Impact factors of ICU patients' family members. *Journal of Nursing Science*. 2012;27(17):74–6.
7. Azoulay E, Chaize M, Kentish-Barnes N. Involvement of ICU families in decisions: fine-tuning the partnership. *ANN INTENSIVE CARE*. 2014;4:37.
8. Han TQ, Feng FL, Lei RQ: Life Value of Severe Acute Pancreatitis: Study on Treatment Cost and Quality of Life. In: *The 11th National Symposium on Pancreatic Surgery*.; 2006.
9. Sainio C, Lauri S, Eriksson E. Cancer patients' views and experiences of participation in care and decision making. *NURS ETHICS*. 2001;8(2):97–111.
10. Walker E, Dewar BJ. How do we facilitate carers' involvement in decision making? *J ADV NURS*. 2001;34(3):329–37.
11. Goldstein WM, Hogarth RM. *Research on judgment and decision making:current,connections,and controversies*. Cambridge University Press; 1997.
12. Pochard F, Azoulay E. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *CRIT CARE MED*. 2001;29(10):1893–7.
13. Michalsen A, Long AC, Ganz FD, White DB, Jensen HI. Interprofessional Shared Decision-Making in the ICU: A Systematic Review and Recommendations From an Expert Panel. *CRIT CARE MED*. 2019;47(9):1258–66.
14. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative Research. *ACAD MED*. 2014;89(9):1245–51.
15. Edward K, Welch T. The extension of Colaizzi's method of phenomenological enquiry. *CONTEMP NURSE*. 2011;39(2):163.
16. McLennan M, Aggar C. Family satisfaction with care in the intensive care unit: A regional Australian perspective. *AUST CRIT CARE*. 2020;33(6):518–25.
17. Grignoli N, Di Bernardo V, Malacrida R. New perspectives on substituted relational autonomy for shared decision-making in critical care. *CRIT CARE*. 2018;22(1):1–6.
18. Kerckhoffs MC, Kant M, van Delden JJM, Hooft L, Kesecioglu J, van Dijk D. Selecting and evaluating decision-making strategies in the intensive care unit: A systematic review. *J CRIT CARE*. 2019;51:39–45.

## Figures



**Figure 1**

The relationship between intrinsic and extrinsic elements in the interaction between ICU families and healthcare professionals' decision-making involvement

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Supplementaryinformation.docx](#)