



## Family surrogate decision-makers' perspectives in decision-making of patients with disorders of consciousness

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### ABSTRACT

To explore and describe the experience of decision-making for patients with disorders of consciousness (DOC) from the perspectives of family surrogate decision-makers. A total of 21 face-to-face interviews with family surrogate decision-makers from a tertiary hospital in Shanghai, China were conducted from January 2021 to February 2021. Thematic analysis was used for data analysis. Four main themes were identified and were included in this study: (1) a tough choice between life and dignity, (2) a major responsibility for patient's voice, (3) complex considerations between ethics and morals, and (4) the importance of realistic basis. The surrogate decision-making of DOC patients in China has been affected by the Chinese cultural context and several practical roots. And the family surrogate decision-makers shared their experiences of trade-offs during the decision-making process. Moreover, family surrogate decision-makers realized their serious responsibility to make a decision that would be in the best interest of DOC patients.

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Surrogate decision-making; experience; neurological intensive care unit; disorders of consciousness; qualitative

### Implications for clinical practice

- The findings may motivate healthcare professionals to understand family surrogate decision-makers' experience of decision-making in more depth.

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- The healthcare professionals should take family surrogate decision-makers' concerns during the decision-making into attention and provide them with timely and effective assistance.
- Intensive care unit nurses can provide family surrogate decision-makers with decision aids during the surrogate decision-making process.

## Introduction

Ten million cases of traumatic brain injury (TBI) are reported worldwide each year (Barman et al., 2011). TBI is one of the leading causes of mortality and disability and has become a worldwide public health issue (Stålnacke et al., 2019). According to an epidemiological survey (Huo et al., 2015), the incidence of TBI in China is about 240 cases for every 10 million people. However, because of the advances in critical medical technology, more patients with severe brain injury survive, leading to a growing number of patients with disorders of consciousness (DOC) in China (Xia et al., 2018). DOC are a collection of transitory syndromes, encompassing coma, unresponsive wakefulness syndrome, and the minimally conscious state (Graham, 2020). Patients with DOC, caused by severe brain injury, pose a great financial strain on their families, increase burnout rates in nursing, and give rise to ethical discussions (Schnakers & Monti, 2017).

Normally, healthcare professionals often inform patients of their condition and treatment plan through informed consent, and the patients decide whether to continue treatment. However, DOC patients remain in a life-threatening state with an uncertain prognosis for a long time, which can render them incapable to provide informed consent or refuse medical treatment (Long et al., 2011). Moreover, cognitive impairments prevent DOC patients from communicating effectively (Landsness et al., 2011). Research indicates that 95% of them lack the ability to make decisions and express preferences (Cai et al., 2015). For these reasons, their family members are regarded as their surrogates and assist with medical decision-making (Sequeira & Lewis, 2017). Surrogate decision-makers may make clinical decisions about diagnostic and surgical procedures, including life-sustaining interventions and end-of-life care. In addition, healthcare professionals will solicit them for guidance on the patient's treatment preferences (Hickman & Pinto, 2014).

However, it is the first time for most surrogates to encounter such an accident, and they are unsure of the desired health outcome their loved ones will consider acceptable (Turnbull et al., 2016). Decisional dilemmas and conflicts are inherent in the decision-making process and present tremendous challenges to the family surrogate decision-makers. Since many surrogates are unprepared to serve in this role, they are at risk for long-term adverse psychological outcomes such as decision regret, decision fatigue, and symptoms of post-traumatic stress disorder (PTSD) (Zahuranec et al., 2018). It is reported

that 14%~81% of the family members have symptoms of PTSD after participating in the decision-making process (Petrinec & Daly, 2016). The prevalence of PTSD exceeded 80% when the decision involved end-of-life decisions (Azoulay et al., 2005).

Further, the decision-making process may differ by culture which directly affects individual behaviours (Sun et al., 2020). Traditional Chinese culture is deeply rooted in the ancient philosophies of Confucianism, Taoism, and Buddhism. As a result, its cultural landscape is diverse rather than a monolithic entity, which makes the surrogate decision-making process embody cultural characteristics. For example, filial piety has been the essence of Chinese feudal ethics since ancient times. Besides, discussing the issue of life and death of seriously ill or dying patients is still a taboo subject in the Chinese context, which poses great challenges for effective communication between healthcare professionals and family members. In addition, Chinese family culture is family-oriented, which means the family is a community of life (Wei et al., 2019). The individual's disease and survival rights are shared by the family, which plays a decisive role in making health decisions (Li & Zuo, 2016). Therefore, the cultural beliefs of family members may provide family surrogate decision-makers with more challenges and complex decisions.

Many documented studies are mainly about the accuracy of surrogate decisions (Frey et al., 2014; Shalowitz et al., 2006), the underlying factors and the relations between outcomes of surrogate decision-making (Hammami et al., 2020; Spalding & Edelstein, 2022), and the extent of preference overlap between surrogate decision-makers and patients (Frey et al., 2018). Nonetheless, little is known about the family surrogate decision-makers' experience during the decision-making process. In addition, globalization trends promote an increase in immigration and enables the spread of Chinese culture. As reported (Guo et al., 2021; Stevenson et al., 2018), Chinese individuals are the largest Asian American group in the USA and is one of the largest visible minority groups in Canada, comprising 21% of Canada's visible minority population. Thus, the purpose of this study is to explore Chinese family surrogate decision-makers' perspectives of decision-making, amidst the diversity and uniqueness of Chinese culture. We hope the findings can provide healthcare professionals with guidance regarding optimal decision-making for DOC patients with similar cultural backgrounds from different countries.

## Methods

### Aim

This study aimed to explore and describe the family surrogate decision-makers' views on the decision-making of patients with DOC.

## **Design**

The qualitative thematic analysis approach (Vaismoradi et al., 2013) was employed to identify, analyse, and report themes within the concepts that reflected family surrogate decision-makers' perceptions of decision-making of patients with DOC. Semi-structured face-to-face interviews that could allow participants to freely describe their experiences and emotions flexibly were adopted (Denzin, 2007).

## **Participants**

Participants were purposively recruited from the neurological ICU of a tertiary hospital in Shanghai, China. The researchers only contacted participants who matched the criteria to ensure voluntary participation. The inclusion criteria as follows: family members should be 18 years old or older, be represented as a surrogate decision-maker of a patient who is diagnosed with DOC for the first time and lacks decision-making capacity, and can speak and understand Mandarin. Overall, 21 of 30 eligible family surrogate decision-makers were enrolled in the study. Eight family surrogate decision-makers declined to

**Table 1.** Demographic characteristics of the participants ( $N = 21$ ).

Characteristics	<i>N (%)</i>
Gender	
Male	9 (43)
Female	12 (57)
Age group (years)	
25~30	2 (10)
31~40	4 (19)
41~50	8 (38)
>50	7 (33)
Marital status	
Married	21 (100)
Unmarried	0 (0)
Education	
College graduate	8 (38)
Some college	3 (14)
High school	5 (24)
Middle school or less	5 (24)
Relationship	
Children	11 (52)
Spouse	4 (19)
Parent	5 (24)
Other	1 (5)
Religion	
Buddhism	3 (14)
None	18 (86)
Residence	
Rural	15 (71)
Urban	6 (29)
Employment	
Employed	12 (57)
Self-employed	4 (19)
Retired	5 (24)

participate, and 1 family surrogate decision-maker withdrew during the interview. The demographic characteristics of the participants are shown in [Table 1](#). The demographic characteristics of the patients are shown in [Table 2](#).

### **Data collection**

All the interviews were conducted with family surrogate decision-makers between January 2021 to February 2021. The researchers introduced the purpose of the study, confirmed each participants' voluntary participation, and established a relationship prior to study commencement. Before beginning the interviews, all participants finished a questionnaire of demographic characteristics. The semi-structured interview guide ([Table 3](#)) was developed based on the purpose of the study and modified based on one prior interview conducted. All interviews were audio-recorded with the permission of the participants. Each participant was asked several open-ended questions, according to the interview guide, by the first author and co-first author who had previously received training in qualitative research. All interviews were conducted in Mandarin. The average duration of the interviews was 38 min (range 29–59 min). Data collection continued until no new themes were identified (Bryon et al., [2010](#)). Upon reaching the 19th interview, no new themes were identified. Two other

**Table 2.** Demographic characteristics of the patients (N = 21).

Characteristics	N (%)
Gender	
Male	11 (52)
Female	10 (48)
Age group (years)	
<14	1 (5)
15~29	1 (5)
30~44	4 (19)
45~59	4 (19)
60~74	9 (43)
>75	2 (10)
Diagnosis	
Traumatic brain injury	15 (71)
Cerebral hemorrhage	5 (24)
Cerebrovascular malformation	1 (5)
Glasgow Coma Scale scores	
13~14	2 (10)
9~12	9 (43)
3~8	8 (38)
<8	2 (10)
Length of stay (days)	
<7	3 (14)
7~14	10 (48)
15~21	3 (14)
22~28	0 (0)
29~35	2 (10)
36~42	1 (5)
43~49	0 (0)
>50	2 (10)

**Table 3.** Interview guide.

## Semi-structured interview guide

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1. What kind of decision did you make for your family member?
  2. What factors would affect the decision-making of your family member?
  3. What difficulties did you have during the decision-making process? How did you handle it?
  4. What is your advice on dealing with the problems in the decision-making process?
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interviews were conducted to confirm the theoretical saturation. Still, no new themes were identified.

***Ethical considerations***

Ethical approval was obtained from the Ethics Committee of Shanghai Tenth People's Hospital (SHSY-IEC-4.1/19-163/01). All individuals voluntarily participated, and received verbal and written informed consent about the study before the interviews were carried out. The participants were informed of their right to withdraw from the interviews at any time. The audio recordings and transcripts were available for this study only, and will be destroyed once the study is finished.

***Data analysis***

Twenty-one interviews were conducted. All audio recordings of the interviews were transcribed verbatim by the first author. The authors then double-checked the transcripts for accuracy and returned them to the participants for verification. After confirming the accuracy of the transcripts, the first author translated them to English. Thereafter, the co-first author and second author checked the accuracy of the translation using a back-translation method – wherein the English was translated back into Mandarin. Finally, the co-corresponding author, who has a certificate of interpretation accreditation test and used to be a visiting scholar in the US, double-checked the translation. The English transcripts were analysed using thematic analysis (Braun & Clarke, 2006) by (1) reading the transcripts in detail several times, in order to ensure familiarity with the depth and breadth of their content; (2) formulating the meaningful statements relevant to the purpose of the study and encoding as many initial codes as possible; (3) sorting the different codes into potential themes and building a collection of themes and sub-themes; (4) reviewing the themes, collapsing some themes into others, and breaking down some themes into smaller components; and (5) defining and naming themes. In this study, two researchers carried out the coding process of transcripts independently. Thereafter, they compared and verified the themes until a consensus was reached.

## **Trustworthiness**

To ensure the trustworthiness of the study, Lincoln and Guba's (1985) study's evaluative criteria using analytical triangulation (Patton, 2015) was used. Before the data analysis, the first author translated all transcripts into English, then the second author back translated them, and the third author double-checked them to verify the accuracy of the interviews and enhance the credibility. The transcripts were repeatedly and independently analysed, compared, and verified in multiple directions by three authors. The authors then discussed and compared themes to ensure the credibility of the final themes.

## **Findings**

### **A tough choice between life and dignity**

#### Sub-theme: Sustaining life due to its sacredness (Table 4)

Different belief systems have an impact on the choice of therapeutic regimes. Some participants ( $n = 5$ ) indicated that some family surrogate decision-makers believe that life is sacred and precious, so they should provide active treatment instead of abandoning it.

Although it's very painful for comatose patients, in my opinion, life is so precious that we can't abandon it. (N18)

Participants ( $n = 7$ ) highlighted that the family members' belief that nothing is more important than human life would influence the decision-making process as well. Participants also mentioned ( $n = 3$ ) that most family members were eager for the extension of their relative's life.

I strongly want to keep the patient and prolong his life, even if he only has breathing. (N6)

#### Sub-theme: Foregoing treatment to save the patient's dignity

Some family surrogate decision-makers give priority to quality of life. When DOC patients have a low quality of life, the family members will reject painful invasive manipulations and choose to let the patients die with great dignity.

**Table 4.** Themes and sub-themes.

Themes	Sub-themes
A tough choice between life and dignity	Sustaining life due to its sacredness Foregoing treatment to save the patient's dignity
A major responsibility for patient's voice Complex considerations between ethics and morals	The impact of kinship and filial piety on clinical decision-making Different understanding of illness experience Medical technology Prognosis
The importance of realistic basis	

Our family said that they didn't want their family to suffer a lot and live without quality at the terminal stage. So, we decided to give up. (N8)

Moreover, participants ( $n = 10$ ) indicated that when faced with patients in critical condition, they prioritised quality of life, as they believed that instead of allowing patients to continue accepting advanced life support and maintain life without quality, it was better to let them pass away peacefully.

The quality of life is poor. DOC patients have no quality of life and are, from my side, unconscious and helpless. (N10)

However, some participants ( $n = 3$ ) indicated that selecting the communication style to have other immediate family members make a rational judgment about giving life without quality up, has become an issue currently considered in family meetings.

My mother has neither dignity nor quality of life. I have told my father and sibling that if she can't bear it, then give up, but I don't know how to talk to them. (N4)

### ***A major responsibility for patient's voice***

Since DOC patients lack decision-making capacity and cannot choose clinical treatment autonomously, family surrogate decision-makers should make decisions on behalf of them, which makes the family surrogate decision-makers shoulder the heavy responsibility of speaking out for the patients.

If you don't decide, who will make the decision? Only you can make the decision, you have to bear it. (N14)

This heavy responsibility is also reflected when family surrogate decision-makers need to conceal the patient's condition to certain members, such as family members who have poor resilience, because they fear that the patient's condition will deal a heavy blow to these family members. Family surrogate decision-makers often make decisions alone under these circumstances, and they will be under more pressure and assume more responsibilities.

I didn't tell my sister [mother's condition] because she was going to take the entrance examination for high school, and I made the decision by myself. (N3)

The surrogate's decision is usually related to the patient's subsequent recovery, even their lives. Therefore, this is also a huge challenge for the family surrogate decision-makers.

This is my mother's second chance to live. This decision is of great help to her later treatment. (N6)

### ***Complex considerations between ethics and morals***

Sub-theme: The impact of kinship and filial piety on clinical decision-making

Family bond was one of the factors that influenced surrogate decision-making. This emotional belief has not only become the main motivation for family members not to give up, but has also become an indispensable part of their lives. To this end, several family surrogate decision-makers show a reluctance to let the patient go.

Affection was the greatest strength that supports our family members. My wife is 70-year-old woman who was out of hope [for] a cure, I have let go of [my] feelings and sold our house for her treatment. (N21)

Furthermore, to guard against a perception from others that they are not showing appropriate filial piety and to gain social acceptability, family members will do anything they can to rescue their family member.

Traditional Chinese thinking focuses on filial piety. I want to give up (stop treatment) but I am afraid of being blamed [for] an ungrateful attitude. Finally, I chose to adhere to the treatment. (N15)

It is when your family suddenly becomes ill that you realize you don't do your filial piety. Then you want to do something for your family. (N17)

#### **Sub-theme: Different understanding of illness experience**

Family members have different perceptions of illness experience, especially of the decisions regarding invasive procedures. Some family members who disapprove of such procedures think that the pain caused by invasive procedures outweighs the suffering caused by the disease, while other family members believe that carrying out invasive procedures could prevent and relieve the secondary pain caused by the disease.

I cannot accept the tracheotomy, thinking the prognosis will be bad. (N12)

The tracheotomy doesn't matter compared with her current condition. Provided there is a gleam of hope for her recovery, I will do it. (N8)

Yet another perception is reflected when comatose patients are bound by physical restraints, which is used commonly in the ICU. Since healthcare professionals pay attention to the psychological pain suffered by conscious patients, they can understand their stigma. For patients in a comatose state, however, family members are often more focused on humanistic care.

Another point is the use of restraint bands. I think it's contrary to humanity. If he is awake, he must feel that he has no dignity. (N19)

#### ***The importance of realistic basis***

#### **Sub-theme: Medical technology**

Some participants ( $n = 3$ ) believe that although there are many new treatments and theories emerging, there are still many areas that have not been

addressed regarding the treatment of DOC patients. When faced with cases that could not be solved by current medical practices, family members found themselves willing – but unable – to avail proper treatment for their family.

I feel that current medical technology can't cure him. His condition is worse off, and the current technology can only be like this. (N6)

More than half of the DOC patients in this study are from small rural towns, where the medical standards and disproportionate medical conditions are not conducive to further treatment of patients. Therefore, the family surrogate decision-makers will elect to transfer a patient to a developed area with leading advanced medical standards at any cost.

The doctor (of county town) advised us not to transfer. I said no. We said we must transfer because the medical conditions in our county town are not good. (N7)

Although participants ( $n = 5$ ) have encountered the limitations of the development of modern medicine during the treatment process, they were not discouraged from rescuing patients. On the contrary, they were motivated and believe that healthcare professionals would seek the necessary research data to further explore treatment methods.

Despite [having] tried our best, we can only go this far. I think the development of medicine still requires persistent people to overcome the problems. If we don't persist, we may stand helpless when we encounter a similar [problem] next time. (N20)

#### Sub-theme: Prognosis

Some participants described that in the decision-making process, the prognosis of DOC patients should be addressed as a priority, and subsequent decisions will be based on their recovery. In the acute phase of the disease, family surrogate decision-makers are mainly trying their best to save patients' lives.

Now we mainly focus in saving her life. The follow-up issues we will discuss later on. (N9)

In the stable period of the disease, the family surrogate decision-makers are concerned about the follow-up rehabilitation issues, so as to determine the setting of rehabilitation, personnel arrangements, and other issues.

If she can recover normally, going to the rehabilitation centre will be of great help to her later treatments. Later, I will arrange division of care after she gets home. (N7)

## Discussion

Traditional Chinese culture emphasizes that the meaning of life lies in the present world (Hao, 2010). Therefore, many family members advocate for the theory of the sanctity of life. This conception also explained why family

members were eager to prolong DOC patients' lives. However, this did not increase the chances of survival, and could cause harm and result in the over-treatment of incurable patients (Dzeng & Curtis, 2018). Moreover, the patients' family members would experience a higher symptom burden. McAdam et al. (2010) indicated that 57% of family members had moderate to severe levels of traumatic stress, and 70%~80% of them had borderline symptoms of depression. In order to address the popular perception of life support treatment and promote that of palliative care (Peden-McAlpine et al., 2015), as well as improve the quality of death of critically ill patients, healthcare professionals could provide an inpatient palliative care program. Enguidanos et al. (2014) found that communication and information received contributed to the family members' ability to make decisions. Furthermore this can make a distinct change in clinical direction, from a traditional disease-centred approach to a holistic approach focusing on quality of life and comfort.

The challenges of discussing prognosis of DOC patients among families revealed that the taboo of talking about death and dying had permeated Chinese culture. In this study, the participants realised their total responsibility to serve in the role of a surrogate decision-maker; meanwhile, they were filled with moral unease when communicating with other family members of dying patients, as they were worried that the end-of-life decision could crush other family members' spirits. A cohort study found that surrogate decision-makers' beliefs during a discussion on death could be emotionally damaging to their family members (Apatira et al., 2008). In Chinese society, people make use of implicit communication. They do not spell everything out, but leave the "unspoken" meaning to the listeners (Liu et al., 2005). In addition, some family surrogate decision-makers will think twice before talking to their relatives. Thus, it is essential for healthcare professionals to understand the cultural sensitivity in such a context, as this could strengthen supportive communication and show greater consideration for families' feelings (Tao et al., 2016).

Our findings highlighted that 52% of family surrogate decision-makers are patients' children. The filial piety is a major emotional factor and impetus for them to make surrogate decisions. Family ethics is vital to maintaining a family bond and is a common emotional behaviour criterion (Qiu et al., 2018) that regulates the relationship between children and their parents (Ruan & Zhou, 2019). Whether children engage in the active treatment of their parents has become a standard for moral judgment. Thus, healthcare professionals may face more challenges when telling families that withdrawing life-sustaining treatment is another way to practice filial piety. Therefore, healthcare professionals should take actions to popularise bereavement support, set grieving families free from public pressure, and promote the understanding that it is human beings' great love that turns kinship into a spirituality concern (Zhang et al., 2019).

It was revealed that family surrogate decision-makers had different understandings of illness experience. According to Confucian familyism, the holistic wisdom of the family is greater than that of the individual, since families believe that they can make the optimal decision for the patient (Sun, 2017). Rolland et al. (2017) posed that if family systems were included in medical decision-making, medical decisions could be less conflicted and less emotional suffering would be felt by both clinicians and families. However, our findings provided insight that some medical decisions would contradict the actual condition of the patient and hamper clinical operation implementation. This indicates that the perception of illness experience of family members was different, and to some extent, not sympathetic. Thus, healthcare professionals should respect the decisions of families and combine their illness experience with ethical principles and medical interests. Besides, Wong et al. (2020) found when healthcare professionals communicated with family members clearer, were more transparent and interacted with patience and empathy, and were responsive to their concerns, family members were less stressed and respected.

In this study, when patients' vital signs decreased, family members could do nothing but feel sympathy, due to the limitations of critical care technology and the uncertain prognosis. This emotional exhaustion affects surrogate decision-makers' physical and mental health. The persistent state of heightened emotional distress can destroy surrogate decision makers' internal and external flexible resource, resulting in a state of ego depletion (Hickman et al., 2018). Moreover, the psychological distress of critical illness and state of high negative emotions can influence decision-makers' ability to formulate optional decisions (Hickman & Douglas, 2010). Consequently, in order to improve the psychological resilience of family surrogate decision-makers, healthcare professionals should actively address existing psychological problems and enhance family surrogate decision-makers' abilities to react positively despite the difficulties encountered – turning these situations into opportunities for growth (Sisto et al., 2019).

### ***Limitations***

The study had some limitations. Firstly, the researchers' native language is Mandarin. This may have resulted in misinterpretations during the translation stage. Nevertheless, the researchers verified the accuracy of the translations during each step to ensure their trustworthiness. Secondly, all 21 participants were married, which could contribute to bias. The participants' perspectives on the same issue could differ due to the responsibility of family. Therefore, more diverse target groups should be enrolled in future studies. Thirdly, the hospital where the participants were selected is situated in a developed coastal city of China. Since the development of medical technology and level of consumption

may differ cross regions, further research on the medical settings of developing regions is needed. Fourthly, the participants were selected according to the state of consciousness of the patients instead of the process of the disease. Therefore, we were unable to identify participants' perspectives of decision-making about different stage of the disease, like the acute versus stable stage.

## Conclusions

In the neurological ICU, decision-making for DOC patients is significantly more difficult than for conscious patients. These findings hinted at the family surrogate decision-makers' experiences and decisional dilemmas in decision-making for DOC patients under the Chinese culture framework. The results emphasize the need for healthcare professionals to offer decision-making assistance to family surrogate decision-makers and pay attention to their psychological needs so that informed decisions could be formulated. To best protect the rights and make the surrogate decisions in the best interest of DOC patients, further research on improving the collaboration between healthcare professionals and family surrogate decision-makers in the diversity of care of DOC patients, such as the role of shared decision-making, should be conducted.

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