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Parents' Experience with Surrogate Decision-Making Dilemmas for Mechanically Ventilated Children in the Paediatric Intensive Care Unit: A Qualitative Study

Daoping Yang [1] and Zhihong Ni [1,2,*]

[1] Children's Hospital of Soochow University, Suzhou 215025, China; sdfeyhlb@163.com
[2] School of Nursing, Medical College of Soochow University, Suzhou 215006, China
* Correspondence: nizhihong8888@163.com; Tel.: +86-13862137170

Abstract

Background: With continuous improvements in critical life support technology, the number of children receiving mechanical ventilation has significantly increased worldwide. The variable and urgent nature of the condition of children necessitate difficult management decisions by medical providers and families. Among these, the most difficult decision is often whether to pursue or continue mechanical ventilation. This study exploredthe experiences of parents with the dilemmas of surrogate decision-making for mechanically ventilated children in the paediatric intensive care unit (PICU). **Methods:** A qualitative study was conducted using semi-structured interviews between October and December 2025. Data were transcribed verbatim and analysed using thematic analysis. Eighteen parents of mechanically ventilated children hospitalised in the PICU of a children's hospital in Suzhou, China, were recruited through purposive sampling. **Results**: Nine sub-themes were identified and synthesised into three primary themes: diverse decision-making behaviours, complex inner activities in decision-making, and multidimensional challenges faced in decision-making. **Conclusions:** Parents demonstrated complex experiences regarding dilemmas in surrogate decision-making for mechanically ventilated children. In the process of promoting parents' participation in medical decision-making, healthcare providers should not only pay attention to the dilemmas and needs of parents as surrogate decision-makers but also strengthen communication with them and promote mutual trust.

Keywords: hospitalisation; surrogate decision-making; paediatric intensive care unit; qualitative study

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1. Introduction

Mechanical ventilation, a life-support technique assisted by a ventilator, aims to maintain airway patency, improve ventilation and oxygenation, prevent hypoxia and hypercapnia, and create conditions for treating underlying diseases by enabling the body to overcome respiratory failure [1]. With continuous improvements in critical life support technology, the number of children receiving mechanical ventilation has increased significantly worldwide, particularly for cases of acute neurological injury, respiratory failure, or cardiac arrest [2]. These children relied on ventilators for life support and required continuous monitoring. Consequently, mechanical ventilation is ubiquitously used in paediatric intensive care unit (PICU) [3].

Mechanical ventilation is an essential supportive measure for the treatment of children with critical illness. The variable and urgent nature of children's condition necessitates

difficult management decisions by medical providers and families [4,5]. The most difficult decision is whether to pursue or continue mechanical ventilation [6].

Children admitted to the PICU often present with varying degrees of potentially life-threatening organ failures. Given the uncertain disease trajectory and complex medical decisions, children in the PICU often lack the capacity for medical decision-making because of their young age [7,8].

From a family perspective, mechanical ventilation therapy involves considerable financial investment, can disrupt family dynamics, and often affects parental employment due to prolonged hospitalisation [9]. The enormous burden of medical expenses and the associated psychosocial stressors have the potential to negatively affect the long-term quality of life and mental health of children and their families [10,11]. The literature suggests that young children must rely on their parents as surrogate decision-makers to represent their wishes and interests in medical decision-making [12]. Consequently, the authority to make treatment decisions shifts to surrogate decision-makers. The scope of these decisions includes the bout starting ventilation, continuing treatment, tracheostomy, and withholding or stopping treatment.

Medical surrogate decision-making varies across sociocultural and legal contexts, particularly in the allocation of decision-making authority, underlying legal and cultural norms, and institutional safeguards. In many Western countries, including those in Europe and North America, a strong emphasis on patient autonomy has led to advance care planning being integrated into routine practice [13].

Influenced by traditional Chinese family ethics, the choices of surrogate decision-makers are often shaped by the entire family unit [14]. In China, owing to the profound influence of Confucian philosophy on doctor–patient relationships and family models, family members are expected to share life's challenges, such as health issues, with patients. Therefore, Chinese people attach great importance to harmonious decision-making centred on the family, often with family members taking on the role of decision-makers.

China's health insurance system achieves broad coverage, and there are differences in the deductible, reimbursement ratio, and reimbursement cap of medical insurance in different regions. By 2025, Suzhou is estimated to have 1.67 million children. The enrolment rate for children's medical insurance among school-aged children exceeds 98%, and the reimbursement rate for inpatient care under this insurance scheme starts at approximately 75%. Essential advanced medications and equipment fall outside reimbursement catalogues or receive limited coverage, resulting in substantial out-of-pocket expenses. Combined with prognostic uncertainty, these financial pressures create profound anxiety among surrogate decision-makers regarding potential emotional and financial devastation.

As the conditions of children change, the complexity of surrogate decision-making increases significantly [15], and both the content and timing of these decisions can directly affect health outcomes [16]. Consequently, surrogate decision-makers face substantial pressures and challenges, potentially leading to psychological issues such as anxiety, depression, and post-traumatic stress.

Existing studies have not incorporated the perspectives of surrogate decision-makers in the paediatric intensive care unit (PICU), nor have they delved into the complex emotional experiences these individuals endure, the multifaceted challenges they encounter, and the diverse support needs they have across different contexts [17]. Consequently, evidence regarding the perspectives of surrogate decision-makers in varied cultural settings remains limited [18].

To address this gap, this study explored the dilemmas and emotional experiences encountered by parents of children undergoing mechanical ventilation in the PICU during surrogate decision-making. This study provides evidence that family consultation, financial

constraints, and uncertain treatment outcomes are interrelated, extending the findings of prior research. It aimed to provide a foundation for analysing diverse parental behaviours in various surrogate decision-making contexts, thereby facilitating improved communication between healthcare providers and parents and ultimately promoting enhanced child health outcomes.

2. Methods

2.1. Design

A qualitative study in thematic analysis was conducted. This involved engaging in dialogue with parents of mechanically ventilated children hospitalised in the PICU, exploring their experiences, observing related phenomena, and understanding their interpretations and the effects of these experiences, which collectively served as data sources [19]. This study adhered to the Consolidated Criteria for Reporting Qualitative Research checklist [20].

2.2. Setting

Data were collected from the PICU of a children hospital in Suzhou, China. The hospital operates a 45-bed PICU, reflecting a significant institutional commitment to and capacity for paediatric intensive care.

2.3. Participant Recruitment

Purposive sampling techniques were used to recruit parents of children hospitalised in the PICU who were receiving mechanical ventilation.

The inclusion criteria for the children were as follows: (1) requirement for mechanical ventilation; (2) age between 1 and 16 years; and (3) mechanical ventilation for at least 48 h.

The inclusion criteria for parents were as follows: (1) adults aged 18 years or older; (2) being identified as the primary decision-maker for the child's medical care; and (3) having normal communication and expression skills. Parents diagnosed with mental illnesses were excluded from the study.

The demographic characteristics of the children and their parents are presented in Tables 1 and 2.

Table 1. Demographic data of the mechanically ventilated children in the paediatric intensive care unit PICU.

Variable	N	%
Gender		
Male	11	61.1
Female	7	38.9
Age (years)		
1–8	10	55.5
9–12	5	27.8
13–16	3	16.7
Diagnosis		
Pneumonia	5	27.8
Encephalitis	4	22.2
Craniocerebral injury	3	16.7
Respiratory failure	6	33.3
Severe neurological impairments (before admission)		
Yes	7	38.9
No	11	61.1
Duration of ventilation (days)		
2–4	4	22.2
5–8	8	44.5
>8	6	33.3

Table 2. Demographic data of the parents.

Variable	N	%
Education		
Middle school	5	27.8
Junior college	8	44.4
University	5	27.8
Age		
<30	4	22.2
31–40	8	44.4
>41	6	33.4
Occupation		
Unemployed	2	11.1
Company worker	7	38.9
Agricultural worker	4	22.2
Office clerk	5	27.8
Residence		
City	12	66.6
County	6	33.4
Surrogate decision-maker		
Mother	7	38.9
Father	11	61.1

2.4. Data Collection

From October to December 2025, NZH and YDP conducted in-depth face-to-face interviews using a semi-structured interview guide. The questions aimed to explore the experiences of parents whose children were hospitalised in the PICU and required mechanical ventilation.

The caregivers were asked to respond to the following:

(1) Please describe the specific situation in which you decided on mechanical ventilation treatment after your child entered the PICU. (2) What were your experiences concerning the communication process with healthcare professionals when making decisions regarding mechanical ventilation therapy for your child? (3) How would you describe your perspective on the changes in your child's condition after receiving mechanical ventilation treatment? (4) What kind of support or assistance would you find helpful in facilitating medical decision-making regarding your child's mechanical ventilation treatment? The interviews lasted 30–60 min and were recorded with the participants' informed consent. The researcher also collected non-verbal cues through participant observation and took field notes to enrich the interview data for subsequent analyses. All research data and interview contents were handled with strict confidentiality protocols to protect the participants' privacy and rights. Interviews with the parents of children receiving mechanical ventilation continued until data saturation was achieved, indicating that no new themes or insights had emerged [21]. Data saturation was defined as the point at which subsequent interviews yielded no new themes or sub-themes relevant to the research questions and was assessed by maintaining a saturation grid to track the emergence of themes across consecutive interviews. During the interviews, the researcher began to encounter recurring themes and similar responses, indicating that data saturation had been reached. The interviews were audio-recorded for data collection, and field notes were logged after each interview.

2.5. Research Team and Reflexivity

The research team comprised experts in child health, qualitative research, and health services research. All interviews were conducted by the same two interviewers: a paediatrician with experience in qualitative research (NZH) and a paediatric nurse trained in

qualitative interviewing (YDP). Both researchers subsequently participated in coding and the initial development of themes. Retaining the same two researchers across data collection and preliminary analysis supported continuity in interviewing, contextual understanding, and engagement with the data. Neither interviewer was involved in the clinical care of participants. The researchers acknowledged, however, that their clinical backgrounds might shape the topics explored in interviews, the formulation of follow-up questions, coding, and the interpretation of participants' narratives. A shared semi-structured interview guide was used by both interviewers to ensure consistency in core inquiry topics, while permitting participants to elaborate on issues they deemed important. The interviewers also debriefed their interview practices during data collection to reflect on potential discrepancies in probing and questioning style.

Recognising that researchers inevitably exert influence over qualitative inquiry, reflexivity was embedded throughout the study. Reflexive field notes and analytical memos were completed immediately after each interview to document contextual observations, interviewer reflections, emergent interpretations, and researchers' assumptions and positionalities relative to the data. These records were revisited iteratively during analysis to facilitate critical self-reflection and strengthen analytical transparency. Rather than seeking to eliminate or fully bracket these assumptions, the researchers aimed to articulate them explicitly and critically examine their influence across the analytical process.

During coding and initial theme development, NZH and YDP discussed their coding decisions and emergent interpretations, and collaboratively refined the developing analysis through repeated engagement with the data. Where their preliminary interpretations diverged, discrepancies were explored through discussion and re-examination of the relevant data until a consensual analytical interpretation was reached. This collaborative process served to broaden and deepen the interpretive analysis. Preliminary themes were subsequently discussed within the wider research team to interrogate assumptions, consider alternative interpretations, and refine the conceptual boundaries and meanings of themes.

2.6. Data Analysis

Data collection involved recording and organising interview content, transcribing interviews verbatim, and integrating these transcripts with the researcher's notes to comprehensively recall non-verbal cues and participant interactions. We conducted a thematic analysis [22] following six established steps.

Familiarisation with the data. Both interviewers (NZH and YDP) repeatedly read all transcripts while reviewing field notes and reflexive memos to develop an in-depth understanding of participants' narratives.

Generation of initial codes. Transcripts were analysed using NVivo software v15 (QST International, Cambridge, MA, USA). NZH and YDP were actively involved in the inductive coding of the dataset. The coding decisions and interpretations were also discussed collaboratively and refined through joint engagement with the data. This process was used to explore different interpretations rather than to assess inter-coder reliability or establish coding agreement as a measure of analytic validity.

Searching for themes. The researchers iteratively examined the codes and developing interpretations to generate candidate themes representing broader patterns of shared meaning across the datasets. Candidate themes were subsequently discussed, with differing perspectives used to question the assumptions, consider alternative interpretations, and refine theme development.

Reviewing themes. Candidate themes were reviewed against a complete dataset, focusing on internal coherence, clear distinctions between themes, and consistency with participants'

narratives. The themes were modified, merged, or separated through iterative discussions among the research team.

Defining and naming themes. Each final theme was clearly defined to reflect its central meaning and relationship with the other themes. Particular attention was paid to preserving the complexity of the participants' experiences while ensuring conceptual clarity.

Producing the final report or manuscript. Themes were generated inductively from the data.

To ensure the rigour of the study, the four general criteria of trustworthiness proposed by Lincoln and Guba [23] were employed. Regarding credibility and transferability, semi-structured face-to-face interviews were conducted with the participants by a senior researcher (NZH) in a quiet room at the Children's Hospital of Soochow University. NZH is an experienced PhD-qualified nurse. NZH trained less experienced colleagues. Neither interviewer had a prior personal or clinical relationship with the participants before study commencement, and neither was a primary physician for any of the participants. Before each interview, the interviewers introduced themselves and their roles in the study, and a brief introductory conversation was used to establish rapport and facilitate an open, non-judgmental dialogue. Reflexive field notes documenting contextual observations, interviewer reflections, and emerging analytical insights were recorded immediately after each interview.

Furthermore, the interview content and relevant contextual information were meticulously transcribed to ensure a thorough description of the research setting. This detailed description allowed the readers to evaluate the similarities between their own situations and the study context, thereby facilitating the assessment of transferability. To enhance the accuracy of interpretation and researcher understanding, the authors consulted colleagues and paediatric critical care specialists. This consultation supported the first author in gaining a more comprehensive understanding of paediatric critical care, which helped ensure that the research insights could be considered across different professional contexts.

Multiple peer discussions were conducted to establish dependability. Finally, to ensure confirmability and to mitigate bias stemming from personal values or beliefs [24], continuous in-depth reflexivity was practised throughout the study.

The translation of the original Chinese interview data into English followed a standardised procedure. A bilingual researcher familiar with domain-specific terminology performed the initial translation to ensure consistency with the standard academic English in the field. To further verify translation accuracy, a back-translation method was employed for cross-validation, and a second bilingual expert blinded to the original Chinese materials independently translated the reviewed English version back into Chinese. The research team then compared the back-translated version with the original Chinese texts to assess semantic consistency.

2.7. Ethics Statement

This study was conducted in compliance with the ethical guidelines of the Declaration of Helsinki. This study was approved by the Ethics Committee of the Children's Hospital of Soochow University (Approval No. #2025cs415). Informed consent was obtained from each participant before they were interviewed, and the data were coded to ensure anonymity.

3. Findings

We interviewed 18 parents of mechanically ventilated children in the PICU (N = 18). The general characteristics of the children and their parents are presented in Tables 1 and 2.

Nine sub-themes were extracted from the data and subsequently refined into three principal themes: diverse decision-making behaviours, complex inner decision-making activities, and multidimensional decision-making challenges (Table 3).

Table 3. Superordinate and sub-themes identified in the analysis.

Themes	Sub-Themes
(1) Diverse decision-making behaviours	Immediate decision-making
	Hesitant decision-making
	Difficult decision-making
(2) Complex inner activities in decision-making	The interaction between tension, anxiety, and fear
	The contradiction between active participation and self-doubt
	The contradiction between active treatment and forced abandonment
(3) Multidimensional challenges faced in decision-making	Cognitive challenges
	Emotional challenges
	Economic challenges

3.1. Theme 1: Diverse Decision-Making Behaviours

3.1.1. Immediate Decision-Making

In this study, six parents made choices quickly, decisively, and confidently. They were afraid that treatment delays could worsen their children's condition.

> "The doctor told me that the child needed mechanical ventilation immediately, and I thought saving the child's life was the most important thing. I immediately agreed to the doctor's advice."
>
> (Parent 6)

> "After all, I did not really understand medical knowledge, so we did whatever the doctor said."
>
> (Parent 2)

> "My child told me that she did not want to continue treatment and wanted to go home. We have also tried our best to save her, and we are ready to follow her wishes and take her home."
>
> (Parent 4)

3.1.2. Hesitant Decision-Making

In this study, five parents showed hesitation, slowness, and delays in making decisions. Parents believed that they lacked medical knowledge, had an insufficient understanding of their children's illnesses, and were afraid that they would make incorrect decisions.

> "I am worried that my child's condition may not improve after endotracheal intubation, which could lead to further deterioration or cross-infection, so I have been hesitant when making decisions."
>
> (Parent 13)

> "The doctor said that my child needed to be intubated. I spent the whole night thinking about what to do in the future. Later on, I thought that my child could only survive after being intubated, which is why I decided to agree to mechanical ventilation for my child."
>
> (Parent 17)

> "Thinking that the child could only survive after being intubated, this was the determination to perform endotracheal intubation on the child."
>
> (Parent 16)

3.1.3. Difficult Decision-Making

When parents engaged in surrogate decision-making, the child's future was uncertain, and seven parents experienced difficulty in making decisions.

> "The doctor told me that my child needed emergency intubation. I was required to make an immediate decision. At the same time, I had to be prepared to face various negative outcomes for my child. Faced with this situation, I didn't know who to consult with or how to make a decision."
>
> (Parent 1)

> "If my child undergoes a tracheostomy, I'm afraid he will suffer too much pain... and I don't know whether it's good or bad for him."
>
> (Parent 5)

> "My family is poor, and I can't afford to pay for my child's hospitalization expenses. I can't borrow money from relatives either, so I have to give up on treatment."
>
> (Parent 14)

3.2. Theme 2: Complex Inner Activities in Decision-Making

3.2.1. The Interaction Between Tension, Anxiety, and Fear

Six parents exhibited tension, fear, and anxiety when faced with their child's critical condition and when making the decision to use mechanical ventilation.

> "As soon as my son was admitted to the ICU and intubated, I was very nervous, and my hands trembled when I signed the informed consent."
>
> (Parent 16)

> "After my child got seriously ill, I was very nervous. I worried about missing the doctor's communication call all day."
>
> (Parent 9)

3.2.2. The Contradiction Between Active Participation and Self-Doubt

The condition of the children was critical, and parents actively participated in surrogate medical decision-making. Five parents showed confusion and doubt about their own decision-making outcomes.

> "Although the treatment of my child was mainly decided by me, I experienced self-doubt many times. Only when my child's condition improved slightly could I continue to persist."
>
> (Parent 2)

> "The child was being rescued in the PICU. I had always been making decisions alone. My child had been hospitalized for a few days, and his condition had not improved yet. I was becoming increasingly anxious."
>
> (Parent 11)

> "Before making a decision, I would call my sister and ask her. With her support, I will felt more comforted."
>
> (Parent 12)

3.2.3. The Contradiction Between Active Treatment and Forced Abandonment

Seven parents perceived a gap between their child's treatment goals and current condition. After making this decision, the participants felt powerless.

> "I hoped my son could be transferred out of the PICU as soon as possible. The doctor said he could only be transferred out of the PICU by disconnecting from the ventilator and removing the endotracheal tube. What could I do besides waiting?"
>
> (Parent 10)

> "We expected the child to receive tracheostomy treatment for about a week, but her condition had been worsening, and I was completely at a loss."
>
> (Parent 14)

> "I hoped these positive treatment measures for the child could bring some good news, but the child's recovery was very slow."
>
> (Parent 1)

3.3. Theme 3: Multidimensional Challenges Faced in Decision-Making

3.3.1. Cognitive Challenges

Surrogate decision-makers could not directly understand the child's condition and could only rely on communication from healthcare providers, while also having concerns about the authenticity, completeness, and objectivity of the information.

> "The current status of the child's illness was all told to me by the doctor. Without seeing it with my own eyes, it didn't feel clear enough. I don't distrust doctors, but I still felt uncertain."
>
> (Parent 5)

> "The child's illness was very serious, and the effect of tracheal intubation was not very good. I was very scared and wondered whether I should not agree to intubation."
>
> (Parent 10)

Eight parents expect doctors to provide more definite and detailed information on treatment outcomes and prognosis, but they sometimes find it difficult to understand how doctors present information.

> "I hoped the doctor would explain the child's current condition and treatment plan to us every day, so that I could have a general understanding of the child's treatment situation."
>
> (Parent 18)

> "I hoped the doctor could tell me when my child could be weaned off the ventilator and transferred out of the ICU. I didn't see any hope."
>
> (Parent 11)

3.3.2. Emotional Challenges

Ten surrogate decision-makers felt isolated and helpless; they felt that healthcare providers could not empathise with them and felt that they had not received enough emotional support.

> "I hoped the doctor could pay more attention to my child. My child already felt uncomfortable with a tube inserted in his mouth. We should praise and encourage him more so that he could cooperate better with the treatment."
>
> (Parent 3)

> "I was worried about losing my child. My parents were gone (his eyes were red and his voice was choked). Fortunately, I had my wife and colleagues to discuss things with."
>
> (Parent 9)

> "This was the first time I had encountered such a situation, and I hoped the doctor could consider the parents' feelings more."
>
> (Parent 8)

3.3.3. Economic Challenges

In this study, all children required mechanical ventilation support, and 11 surrogate decision-makers stated that medical expenses were one of the top concerns in surrogate decision-making.

> "I hoped doctors could choose the most effective and least expensive drugs and treatments, ensure their efficacy, and maximize reimbursement whenever possible."
>
> (Parent 17)

> "My child's medical expenses were high. After my colleague and friends learned about my child's illness, they mobilized nearby people to donate money to help us. I was very grateful."
>
> (Parent 7)

4. Discussion

The qualitative study presented here yielded novel insights into the parental experience of the dilemma of surrogate decision-making for mechanically ventilated children in the PICU. Our results indicate that parents' surrogate decision-making is highly context-dependent. This finding is consistent with those of previous studies [10,11]. In this study, parents demonstrated a multifaceted experience of this dilemma, characterised by diverse decision-making behaviours, complex inner decision-making activities, and multidimensional challenges faced in decision-making.

The study revealed that decision-making behaviours were diverse, and the types of decisions made by surrogate decision-makers for mechanical ventilation varied with the decision content. Immediate decision-making typically occurs when high trust in medical personnel allows surrogate decision-makers to quickly align their choices with the child's interests and wishes. This is further facilitated by shared understanding and consistent direction between healthcare providers and surrogate decision-makers. Hesitant decision-making is characterised by slowness and delay. Surrogate decision-makers often seek additional information, which can lead to treatment delays or missed opportunities for optimal patient care. Difficult decision-making is characterised by significant psychological and emotional distress in surrogate decision-makers, necessitating increased decision-making support and psychological support. These challenges stem primarily from factors such as uncertainty regarding the impact of decisions on children's life outcomes and quality of life, the time-sensitive nature of decisions, and insufficient medical knowledge [4]. Therefore, this study focused on the decision-making dilemmas faced by surrogate decision-makers and aimed to identify timely intervention strategies. Our findings suggest that when encouraging parental participation in medical decision-making in the PICU, healthcare

providers must consider the context and timing of hesitant and difficult decisions, assess parents' decision-making capacity, and provide tailored support [7].

This study found that surrogate decision-makers faced complex inner decision-making activities and experienced various negative emotions during the decision-making process, such as tension, anxiety, fear, self-doubt, sadness, and helplessness. Surrogate decision-makers experienced tension, fear, and anxiety when confronted with their child's critical condition and the decision to initiate mechanical ventilation. While the children were in critical condition and surrogate decision-makers actively engaged in surrogate medical decision-making, they also expressed confusion and doubt regarding the consequences of their decisions. They perceived a conflict between pursuing active treatment and the perceived necessity of forgoing treatment. Surrogate decision-makers reported experiencing feelings of powerlessness as they waited for their child to be extubated and transferred out of the PICU.

They worried about the correctness and helpfulness of their decisions for the child, as well as potential opposition or criticism from other family members. This suggests that healthcare providers should attend to the emotional well-being of surrogate decision-makers, establish a relationship of mutual trust, encourage them to express their inner feelings, and promptly identify and alleviate their negative emotions [6]. Collaboration among PICU doctors, nurses, psychotherapists, and medical social workers can provide personalised psychological interventions for surrogate decision-makers [16]. Research has shown that multidisciplinary conversations, family meetings, and other methods can help surrogate decision-makers make informed decisions that align with the best interests of the child and family [25]. Support from relatives is an important source of comfort and emotional support for surrogate decision-makers [26]. This suggests that healthcare providers may reduce surrogate decision-makers' negative emotions and improve their decision satisfaction by refining the PICU visitation policy and facilitating diverse forms of interaction between surrogate decision-makers and mechanically ventilated children [27].

This study found that surrogate decision-makers faced cognitive, emotional, and economic challenges during the decision-making process. The dynamic changes in ventilator dependence, withdrawal preparation, and the uncertainty of mechanical ventilation outcomes can significantly increase the cognitive and emotional burden on surrogate decision-makers. From a cognitive perspective, mechanical ventilation withdrawal is a gradual process, and there is a lack of clear predictive indicators of whether a child can successfully leave the ventilator [28]. Prognostic information is ambiguous and there is a risk of information comprehension bias and decision-making difficulties. Emotionally, recurrent illness and unknown outcomes can lead to persistent anxiety, guilt, and helplessness. Surrogate decision-makers not only have to endure the pain caused by fluctuations in the patient's condition, but also bear the responsibility of medical decision-making under uncertain information, constantly wavering between hope and concern, exacerbating decision-making pressure and emotional friction.

In response to these challenges, parents expressed the need for support and desired more information. They hoped to receive recognition and encouragement from healthcare providers as well as emotional and economic support from society. Regarding cognitive challenges, the study indicated that surrogate decision-makers perceived the language used by healthcare providers to be difficult to comprehend. This suggests that healthcare providers should offer surrogate decision-makers sufficient guidance and explanations to facilitate their understanding of their children's conditions and treatment plans. They should align the prognosis of mechanically ventilated children with decision-makers' expectations and implement standardised communication strategies to enhance communication between healthcare providers and surrogate decision-makers [29]. Concerning emotional

challenges, surrogate decision-makers require support, communication, and respect from healthcare providers as well as guidance and comfort from other family members. Research indicates that communication programmes implemented by multidisciplinary teams can effectively improve parents' caregiving experiences and communication with healthcare providers. Concurrently, healthcare providers should consider the impact of the overall family dynamics and provide targeted communication support to families [30]. Interventions designed to address the cognitive and emotional needs of surrogate decision-makers can enhance the quality of their decision-making.

Regarding economic challenges, the study found that both sources of family income and the presence of economic difficulties influenced the psychology and behaviour of surrogate decision-makers [31]. In Chinese culture, decision-makers in life-threatening situations prioritise external factors, such as social pressures and financial concerns, rather than accurately reflecting the patient's own preferences [32].

Parental dilemmas regarding cognitive challenges and emotional challenges may also occur elsewhere, and economic challenges may be influenced by local healthcare arrangements or family practices. This suggests that healthcare providers should encourage surrogate decision-makers to draw support from family, friends, and broader social networks. They should inform surrogate decision-makers about children's uncertain prognoses, engage other family members in providing supportive care, and assist families in accessing financial resources. Meanwhile, social welfare organisations and government agencies should pay greater attention to and deliver more support for families of critically ill children.

5. Conclusions

This study used semi-structured interviews to provide an in-depth understanding of the dilemmas experienced by parents of PICU patients undergoing mechanical ventilation during surrogate decision-making. These findings highlight the various types of decision-making behaviours, complex internal decision-making processes, and multidimensional challenges faced by parents in navigating the dilemma of surrogate decision-making for mechanically ventilated children. It is recommended that, in promoting parental participation in medical decision-making, healthcare providers not only address the dilemmas and needs of parents as surrogate decision-makers but also enhance communication and trust with them.

6. Limitations

This study had several limitations. First, parents were recruited primarily from the paediatric internal medicine intensive care unit (ICU), resulting in insufficient representation of children from neonatal and paediatric surgical ICUs. Consequently, this study did not fully explore the diverse experiences of decision-makers across different PICU specialties regarding mechanical ventilation decisions. Second, this study was conducted at a single institution and did not include decision-makers from hospitals in diverse geographical regions. Third, given the variations in paediatric healthcare systems, legal frameworks, and policies across different countries, our research findings may not be generalisable internationally.

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Institutional Review Board Statement: This study complied with the Ethical Guidelines of the Declaration of Helsinki. This study was approved by the Ethics Committee of the Children's Hospital of Soochow University on 10 February 2025 (Approval No. #2025cs415). Informed consent was obtained from each participant before they were interviewed, and the data were coded to ensure anonymity.

Informed Consent Statement: All participants provided informed consent before participating in the interviews.

Data Availability Statement: The data presented in this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions relating to the protection and confidentiality of human-participant data.

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Conflicts of Interest: The authors declare no conflicts of interest.

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