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Beyond Legal Boundaries: Public and Clinician Perspectives on Treatment Withdrawal in Infants With Poor Neurological Prognosis

In Gyu Song [1*], **Jung Lee** [2*], **Min Sun Kim** [2,3,4], **Ji Weon Lee** [2], **So Yeon Jeon** [5,6], **Shin Hye Yoo** [4] and **Hye Yoon Park** [4,7]

[1]Department of Pediatrics, Severance Children's Hospital, Yonsei University College of Medicine, Seoul, Korea
[2]Integrative Care Hub, Seoul National University Hospital, Seoul, Korea
[3]Department of Pediatrics, Seoul National University Hospital, Seoul National University College of Medicine, Seoul, Korea
[4]Center for Palliative Care and Clinical Ethics, Seoul National University Hospital, Seoul, Korea
[5]Department of Psychiatry, Chungnam National University Hospital, Daejeon, Korea
[6]Department of Psychiatry, Chungnam National University College of Medicine, Daejeon, Korea
[7]Department of Psychiatry, Seoul National University Hospital, Seoul National University College of Medicine, Seoul, Korea

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Address for Correspondence:
Min Sun Kim, MD, MS
Department of Pediatrics, Integrative Care Hub, and Center for Palliative Care and Clinical Ethics, Seoul National University Hospital, 101 Daehak-ro, Jongno-gu, Seoul 03080, Korea.
Email: mskim81@snu.ac.kr

*In Gyu Song and Jung Lee contributed equally to this work as first authors.

ORCID iDs
In Gyu Song
https://orcid.org/0000-0002-3205-9942
Jung Lee
https://orcid.org/0000-0001-8074-105X
Min Sun Kim
https://orcid.org/0000-0001-5323-9857
Ji Weon Lee
https://orcid.org/0000-0003-4012-0843
So Yeon Jeon
https://orcid.org/0000-0002-3656-1593
Shin Hye Yoo
https://orcid.org/0000-0001-7473-1082
Hye Yoon Park
https://orcid.org/0000-0003-4114-5102

ABSTRACT

Background: Despite medical advancements in neonatal survival rates, many children have poor neurological outcomes. Because the law in Korea restricts the withdrawal of life-sustaining treatment to only cases of imminent death, treatment discontinuation may not be an option, even in patients with poor neurological prognosis. This study investigated the opinions of the general population and clinicians regarding life-sustaining treatment withdrawal in such cases using hypothetical scenarios.

Methods: We conducted a cross-sectional study on the general population and clinicians using a web-based questionnaire. The sample of the general population from an online panel comprised 500 individuals aged 20–69 years selected by quota sampling. The clinician sample comprised 200 clinicians from a tertiary university hospital. We created hypothetical vignettes and questionnaire items to assess attitudes regarding mechanical ventilation withdrawal for an infant at risk of poor neurological prognosis due to birth asphyxia at 2 months and 3 years after the incidence.

Results: Overall, 73% of the general population and 74% of clinicians had positive attitudes toward mechanical ventilator withdrawal at 2 months after birth asphyxia. The proportion of positive attitudes toward mechanical ventilator withdrawal was increased in the general population (84%, $P < 0.001$) and clinicians (80.5%, $P = 0.02$) at 3 years after birth asphyxia. Religion, spirituality, the presence of a person with a disability in the household, and household income were associated with the attitudes of the general population. In the multivariable logistic regression analysis of the general population, respondents living with a person with a disability or having a disability were more likely to find the withdrawal of the ventilator at 2 months and 3 years after birth asphyxia not permissible. Regarding religion, respondents who identified as Christians were more likely to find the ventilator withdrawal at 2 months after birth asphyxia unacceptable.

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Disclosure

The authors have no potential conflicts of interest to disclose.

Author Contributions

Conceptualization: Song IG, Yoo SH, Park HY, Kim MS. Data curation: Lee J, Yoo SH. Formal analysis: Lee J. Funding acquisition: Yoo SH, Park HY. Investigation: Song IG, Lee J, Yoo SH, Park HY, Lee JW, Jeon SY, Kim MS. Methodology: Song IG, Lee J, Yoo SH, Park HY, Kim MS. Validation: Song IG. Visualization: Lee J. Writing - original draft: Song IG, Lee J. Writing - review & editing: Yoo SH, Park HY, Lee JW, Jeon SY, Kim MS.

Conclusion: The general population and clinicians shared the perspective that the decision to withdraw life-sustaining treatment in infants with a poor neurological prognosis should be considered before the end of life. A societal discussion about making decisions centered around the best interest of pediatric patients is warranted.

Keywords: Public Opinion; Clinician's Opinion; Hypoxia-Ischemia, Brain; Infant; Life-Sustaining Treatment Withdrawal

INTRODUCTION

Despite advancements in medical science to enhance the survival rates of neonatal patients, many infants still experience life-limiting conditions, leading to death.[1-3] A considerable proportion of these mortalities can be attributed to complications arising from either prematurity or congenital abnormalities.[4] The need for medical professionals in the field of pediatrics to make decisions regarding life-sustaining treatment (LST) has increased. However, research on LST decisions for infants in Korea is scarce, with most studies primarily focusing on adults.[4-7]

Ethically, it is generally accepted that during end-of-life discussions, medical professionals should consider various factors, including the patient's quality of life, and they should strive to pursue the patient's best interests.[8,9] In 2007, the American Academy of Pediatrics addressed intensive care decisions for high-risk newborns. The statement discouraged intensive care when early mortality is highly probable or when survival poses an unacceptably high risk of severe morbidity. In cases of uncertain but expected unfavorable prognosis, where potential survival may diminish the infant's quality of life, the treatment approach should align with the preferences of the parents.[9] However, in Korea, discussions regarding end-of-life care are usually led by clinicians and are governed more by legal criteria than by ethical considerations. The law explicitly states that LST can only be discontinued in patients in a state of imminent death and does not allow for decisions based on the patient's best interest.[10] Furthermore, in cases where patients cannot express their preferences, such as infants, the timing of deciding on LST is restricted to imminent death, which delays the initiation of discussions. For infants with severe neurological impairments, delayed and insufficient discussions regarding LST based on the patient's best interests can result in a deterioration in the patient's quality of life and the prolongation of suffering. This often leads to continued intensive medical treatment and reliance on technology (e.g., home ventilators) for patients with permanent and profound neurological impairments. This imposes an overwhelming physical and psychological burden on patients and their families.[11]

This study explored the opinions of the general public (GP) and clinicians regarding a hypothetical case involving LST withdrawal in an infant at risk of permanent severe neurological impairment, posing ethical dilemmas in the pediatric clinical setting. The study objectives were as follows: 1) to ascertain whether there are differences in opinions between the GP and clinicians, 2) to examine potential disparities between the current practice in Korea and the perspectives of the GP and medical professionals, and 3) to lay a foundation for future improvements in pediatric end-of-life care policies.

METHODS

Study design and participants

We conducted a cross-sectional study on the GP and clinicians using a web-based questionnaire (**Supplementary Table 1**). Our research delved into three specific categories—adults in a vegetative state, individuals with advanced dementia, and infants with irreversible hypoxic-ischemic encephalopathy (HIE)—where ethical challenges arise owing to existing legal ambiguities. Our study focused on infants with severe neurological impairment. The results of our research on the other two groups will be addressed and published in separate and distinct articles.

General population

The online survey of the GP was conducted from 24 March 2022 to 30 March 2022 and comprised 500 participants aged 20–69 years. These individuals were selected from nationwide online panel members using quota sampling based on sex and age groups. All 500 participants in the online panel completed the survey.

Clinicians

The survey involving clinicians was conducted between 24 August 2022 and 23 September 2022 at Seoul National University Hospital, a 1,779-bed tertiary referral hospital in the Republic of Korea. The URL link for the survey was sent to all clinicians except interns (690 attending clinicians, 274 fellows, and 612 residents) via email and Messenger within the institution. Overall, 200 participants answered the questionnaire.

Questionnaires

To identify related factors, we collected the demographic and social characteristics of the respondents, including age, sex, religion, residential area, education level, occupation, income level, family members, disability experience (respondents and his/her family have disabilities), the illness experiences, bereavement, participation in LST decision-making, and completion of advance directives.

The clinicians' survey included additional questions regarding their medical career, current hospital position (resident, fellow, or attending physician), department, and experience in newborn treatment and in making LST decisions.

Scenarios

We created hypothetical scenarios and questionnaire items to investigate attitudes toward withdrawal of LST and related factors in neonates at risk of poor neurological prognosis due to severe brain damage. The scenarios and questionnaire items were developed on the basis of a literature review and discussion with the research team, including a neonatologist, a pediatric palliative care clinician, and clinicians working in the field of palliative care. The scenario depicted a 2-month-old full-term infant with HIE due to birth asphyxia. The infant could not be successfully weaned off the ventilator and only responded to painful stimuli, remaining unresponsive to other stimuli. Respondents were initially asked whether they would allow the withdrawal of mechanical ventilation (MV) from the infant and to provide the reasons for their decision. Additionally, respondents were asked to express their perspectives regarding the situation if the infant was to remain in the same condition at 3 years after birth asphyxia. The complete case vignette is presented in the **Supplementary Methods**.

Statistical analysis

The characteristics of respondents were analyzed using descriptive statistics. Continuous variables are expressed as medians with interquartile ranges (IQRs). Categorical variables are presented as numbers and percentages. The median number of households in this study was 3, and the median income for a 3-person household in 2022 in Korea was 4,194,701 KRW. Therefore, we recategorized the income data into two groups on the basis of 4 million KRW (approximately $3,000).[12]

McNemar's test was employed to evaluate differences in attitudes toward MV withdrawal at 2 time points, namely, 2 months and 3 years after birth asphyxia. χ^2 or Fisher's exact test was used to assess associations between attitudes toward MV withdrawal and the potential related factors. The association between each factor and the response was analyzed separately for the GP and clinician groups.

Furthermore, simple and multivariable logistic regression analyses were performed to evaluate the effect size (odds ratio [OR] and adjusted OR) of each factor on attitudes toward MV withdrawal. In the multivariable regression analysis, those variables that showed significant ($P < 0.05$) associations with attitudes toward MV withdrawal based on simple regression models were included. All statistical analyses were conducted using R version 3.5.0 (R Foundation for Statistical Computing, Vienna, Austria).

Ethics statement

This study protocol was reviewed and approved by the Institutional Review Board of Seoul National University Hospital (number: 2202-081-1301). The survey was conducted after obtaining consent from the participants to disclose their information and participate in the study.

RESULTS

Participant characteristics

Table 1 presents the characteristics of the general sample. Among the 500 respondents in the GP, 50.8% (n = 254) were male, and their ages were evenly distributed from their 20s to their 60s. Eighty-five percent (n = 425) had a college education or higher, and 59.4% (n = 297) reported a household monthly income of 4 million KRW or more (approximately $3,000). Additionally, 27.6% (n = 138) of the participants lived with children (age, ≤ 19 years), and 13% (n = 65) indicated either having a disability or living with a person who has a disability.

The response rate of clinicians was 12.7%. Among the 200 clinician respondents, 54.5% (n = 109) were male, the median duration of clinical experience was 6.5 (IQR, 3.9–10.6) years, and 47% (n = 94) were residents. The two most common specialties were internal medicine (n = 37, 18.5%) and pediatrics (n = 34, 17%). Sixty-seven (33.5%) respondents indicated having experience caring for neonatal patients. Most had experience in caring for patients on MV (n = 140, 70%) and participating in decision-making on LST (n = 150, 75%) (**Supplementary Table 2**).

Attitudes toward MV withdrawal

Notably, 73% of the GP and 74% of clinicians exhibited positive attitudes toward MV withdrawal at 2 months after experiencing birth asphyxia (**Fig. 1**). Regarding the reasons for supporting withdrawal, most respondents selected "excessive suffering when the comatose

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Table 1. Characteristics of participants in the general population (N = 500)

Characteristics	Values
Age group, yr	
20–29	89 (17.8)
30–39	90 (18.0)
40–49	110 (22.0)
50–59	114 (22.8)
≥ 60	97 (19.4)
Sex	
Male	254 (50.8)
Female	246 (49.2)
Religion	
Christian: Protestant	127 (25.4)
Christian: Catholic	41 (8.20)
Buddhist	67 (13.4)
Other	7 (1.4)
None	258 (51.6)
Residential area	
Capital area (Seoul/Gyeonggi/Incheon)	258 (51.6)
Non-capital area (others)	242 (48.4)
Education	
High school or less	75 (15.0)
College or more	425 (85.0)
Job	
Practitioner/Technical worker/Management worker/General office worker	288 (57.6)
Self-employed/Sales worker/Production worker/Agriculture, forestry, and fisheries	79 (15.8)
Homemaker/Student/Not employed	133 (26.6)
Household monthly income, KRW	
< 4 million won	197 (39.4)
≥ 4 million won	297 (59.4)
Not specified	6 (1.2)
Household size: number of household members	
1	71 (14.2)
≥ 2	429 (85.8)
Presence of a spouse: Yes	288 (57.6)
Living with children aged ≤ 19 yr: Yes	138 (27.6)
Living with a person with a disability (physical or mental) or having a disability: Yes	65 (13.0)
Experience with suffering from a disease or an accident for a month or more: Yes	111 (22.2)
Experience with a household member suffering from a disease or an accident for a month or more: Yes	104 (20.8)
Experience with bereavement: Yes	216 (43.2)
Completion of advance directives (for myself or a household member): Yes	48 (9.6)
Experience with participating in decision-making on life-sustaining treatment for family member(s): Yes	53 (10.6)

Data shown are number (%) not otherwise specified.

patient is reliant on MV," "concerns about the potential for reversibility," and "burdensome care for the family." Regarding the reasons for objecting to withdrawal, most respondents cited the "possibility of survival for several years" and the "potential for regaining consciousness despite the clinician's opinion" (**Fig. 2**).

The proportion of positive attitudes on MV withdrawal at 3 years after birth asphyxia was increased among the GP (84%, McNemar's $\chi^2 = 42.6$, $P < 0.001$) and clinicians (80.5%, McNemar's $\chi^2 = 5.5$, $P = 0.02$) (**Fig. 1**).

Associated factors with attitudes toward MV withdrawal

Among the GP, religion ($\chi^2 = 4.7$, $P = 0.031$) and disability experience ($\chi^2 = 4.7$, $P = 0.031$) were related to attitudes toward MV withdrawal at 2 months after birth asphyxia (**Table 2**). After

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adjustment, respondents living with a person with a disability or having a disability were more likely to find MV withdrawal at 2 months after birth asphyxia unacceptable (adjusted OR, 1.88; 95% confidence interval [CI], 1.06–3.28; $P = 0.028$). Similarly, respondents who

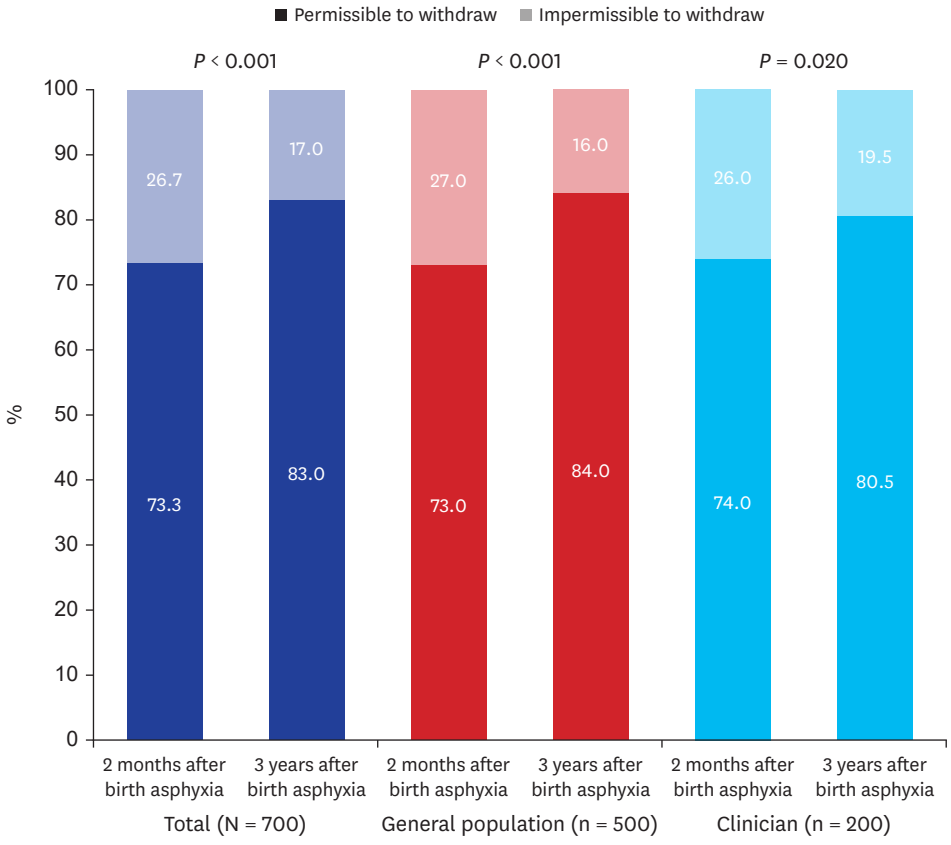

Fig. 1. Attitudes toward mechanical ventilator withdrawal at 2 months and 3 years after birth asphyxia stratified by the general population and clinicians.
P values in the figure were derived from McNemar's test.

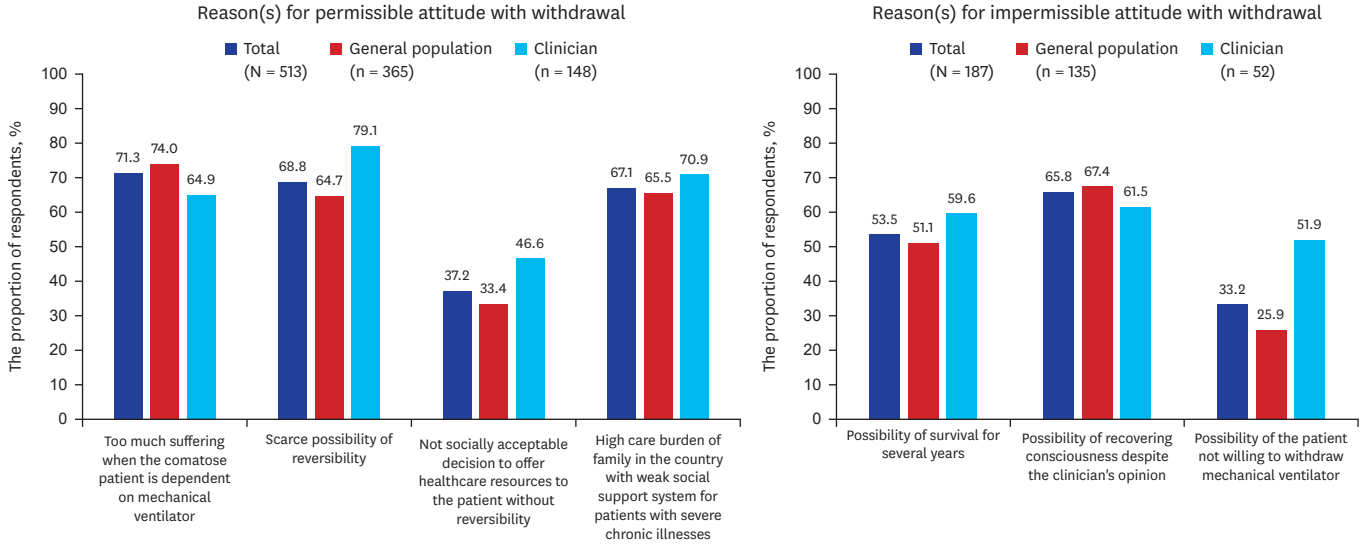

Fig. 2. Reasons for the response for mechanical ventilator withdrawal at 2 months after birth asphyxia stratified by the general population and clinicians.

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identified as Christians were more likely to find MV withdrawal at this stage unacceptable (adjusted OR, 1.56; 95% CI, 1.02–2.38; $P = 0.039$) (**Table 2**).

Attitudes toward MV withdrawal at 3 years after birth asphyxia among the GP showed associations with religion ($\chi^2 = 3.9$, $P = 0.049$), disability experience ($\chi^2 = 13.4$, $P < 0.001$), and

Table 2. Attitudes toward mechanical ventilator withdrawal at 2 months after birth asphyxia and related factors in the general population

Characteristics	Permissible to withdraw (n = 365)	Impermissible to withdraw (n = 135)	χ^2 test *P*	OR (95% CI)	aOR (95% CI)[a]
Age group, yr			0.554		
20–29	63 (70.8)	26 (29.2)		Ref.	
30–39	67 (74.4)	23 (25.6)		0.83 (0.43–1.61)	
40–49	78 (70.9)	32 (29.1)		0.99 (0.54–1.85)	
50–59	80 (70.2)	34 (29.8)		1.03 (0.56–1.90)	
≥ 60	77 (79.4)	20 (20.6)		0.63 (0.32–1.23)	
Sex			0.306		
Male	191 (75.2)	63 (24.8)		Ref.	
Female	174 (70.7)	72 (29.3)		1.25 (0.85–1.87)	
Religion			0.031		
Christian (Protestant/Catholic)	112 (66.7)	56 (33.3)		1.6 (1.06–2.41)*	1.56 (1.02–2.38)*
Others (Buddhist/Other/None)	253 (76.2)	79 (23.8)		Ref.	Ref.
Residential area			0.663		
Capital area (Seoul/Gyeonggi/Incheon)	191 (74)	67 (26)		Ref.	
Non-capital area (others)	174 (71.9)	68 (28.1)		1.11 (0.75–1.65)	
Education			0.526		
High school or less	52 (69.3)	23 (30.7)		Ref.	
College or more	313 (73.6)	112 (26.4)		0.81 (0.48–1.40)	
Job			0.599		
Practitioner/Technical worker/Management worker/General office worker	215 (74.7)	73 (25.3)		Ref.	
Self-employed/Sales worker/Production worker/Agriculture, forestry, and fisheries	55 (69.6)	24 (30.4)		1.29 (0.73–2.20)	
Homemaker/Student/Not employed	95 (71.4)	38 (28.6)		1.18 (0.74–1.86)	
Household monthly income, KRW			0.122		
< 4 million won	136 (69)	61 (31)		1.4 (0.94–2.10)	1.25 (0.81–1.91)
≥ 4 million won	225 (75.8)	72 (24.2)		Ref.	Ref.
Household size: number of household members			0.124		
1	46 (64.8)	25 (35.2)		1.58 (0.91–2.67)	1.50 (0.84–2.65)
≥ 2	319 (74.4)	110 (25.6)		Ref.	Ref.
Presence of a spouse			0.378		
Yes	215 (74.7)	73 (25.3)		Ref.	
No	147 (70.7)	61 (29.3)		1.22 (0.82–1.82)	
Living with children aged ≤ 19 yr			0.864		
Yes	102 (73.9)	36 (26.1)		Ref.	
No	263 (72.7)	99 (27.3)		1.07 (0.69–1.68)	
Living with a person with a disability (physical or mental) or having a disability			0.007		
Yes	38 (58.5)	27 (41.5)		2.15 (1.25–3.68)**	1.88 (1.06–3.28)*
No	327 (75.2)	108 (24.8)		Ref.	Ref.
Experience suffering from a disease or an accident for a month or more			0.279		
Yes	86 (77.5)	25 (22.5)		Ref.	
No	279 (71.7)	110 (28.3)		1.36 (0.84–2.26)	
Experience with the household member suffering from a disease or an accident for a month or more			1.000		
Yes	76 (73.1)	28 (26.9)		Ref.	
No	289 (73)	107 (27)		1 (0.62–1.66)	
Experience with bereavement			0.437		
Yes	162 (75)	54 (25)		Ref.	
No	203 (71.5)	81 (28.5)		1.2 (0.8–1.79)	

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Table 2. (Continued) Attitudes toward mechanical ventilator withdrawal at 2 months after birth asphyxia and related factors in the general population

Characteristics	Permissible to withdraw (n = 365)	Impermissible to withdraw (n = 135)	χ^2 test *P*	OR (95% CI)	aOR (95% CI)[a]
Completion with advance directives (for myself or a household member)			0.385		
Yes	32 (66.7)	16 (33.3)		Ref.	
No	333 (73.7)	119 (26.3)		0.71 (0.38–1.38)	
Experience with participating in decision-making on life-sustaining treatment for family member(s)			1.000		
Yes	39 (73.6)	14 (26.4)		Ref.	
No	326 (72.9)	121 (27.1)		1.03 (0.55–2.03)	

Data shown are number (%) not otherwise specified.
OR = odds ratio, aOR = adjusted odds ratio, CI = confidence interval.
[a]Adjustment was made for religion, household income, number of household members, and disability experience.
$^{*}P < 0.05$; $^{**}P < 0.01$; $^{***}P < 0.001$.

household income ($\chi^2 = 6.2$, $P = 0.013$) (**Table 3**). After adjustment, respondents living with a person with a disability or having a disability were more likely to consider MV withdrawal at 3 years after birth asphyxia not permissible (adjusted OR, 2.71; 95% CI, 1.39–5.16; $P = 0.003$). Conversely, respondents aged > 60 years deemed MV withdrawal more permissible than respondents who were aged 20–29 years (adjusted OR, 0.21; 95% CI, 0.06–0.62; $P = 0.008$) (**Table 3**).

Table 3. Attitudes toward mechanical ventilator withdrawal at 3 years after birth asphyxia and related factors in the general population

Characteristics	Permissible withdraw (n = 420)	Impermissible to withdraw (n = 80)	χ^2 test *P*	OR (95% CI)	aOR (95% CI)[a]
Age group, yr			0.075		
20–29	70 (78.7)	19 (21.3)		Ref.	Ref.
30–39	77 (85.6)	13 (14.4)		0.62 (0.28–1.34)	0.69 (0.29–1.59)
40–49	90 (81.8)	20 (18.2)		0.82 (0.4–1.66)	0.93 (0.40–2.15)
50–59	93 (81.6)	21 (18.4)		0.83 (0.42–1.67)	0.90 (0.38–2.12)
≥ 60	90 (92.8)	7 (7.2)		0.29 (0.11–0.69)**	0.21 (0.06–0.62)**
Sex			1.000		
Male	213 (83.9)	41 (16.1)		Ref.	
Female	207 (84.1)	39 (15.9)		0.98 (0.61–1.58)	
Religion			0.049		
Christian (Protestant/Catholic)	133 (79.2)	35 (20.8)		1.68 (1.03–2.73)*	1.66 (0.96–2.85)
Others (Buddhist/Other/None)	287 (86.4)	45 (13.6)		Ref.	Ref.
Residential area			0.356		
Capital area (Seoul/Gyeonggi/Incheon)	221 (85.7)	37 (14.3)		Ref.	
Non-capital area (others)	199 (82.2)	43 (17.8)		1.29 (0.8–2.09)	
Education			0.864		
High school or less	64 (85.3)	11 (14.7)		Ref.	
College or more	356 (83.8)	69 (16.2)		1.13 (0.59–2.36)	
Job			0.665		
Practitioner/Technical worker/Management worker/General office worker	242 (84)	46 (16)		Ref.	
Self-employed/Sales worker/Production worker/Agriculture, forestry, and fisheries	64 (81)	15 (19)		1.23 (0.63–2.31)	
Homemaker/Student/Not employed	114 (85.7)	19 (14.3)		0.88 (0.48–1.54)	
Household monthly income, KRW			0.013		
< 4 million won	156 (79.2)	41 (20.8)		1.91 (1.17–3.12)*	1.64 (0.92–2.92)
≥ 4 million won	261 (87.9)	36 (12.1)		Ref.	Ref.
Household size: number of household members			0.072		
1	54 (76.1)	17 (23.9)		1.83 (0.97–3.30)	1.57 (0.73–3.34)
≥ 2	366 (85.3)	63 (14.7)		Ref.	Ref.

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Table 3. (Continued) Attitudes toward mechanical ventilator withdrawal at 3 years after birth asphyxia and related factors in the general population

Characteristics	Permissible withdraw (n = 420)	Impermissible to withdraw (n = 80)	χ^2 test *P*	OR (95% CI)	aOR (95% CI)[a]
Presence of a spouse			0.052		
Yes	251 (87.2)	37 (12.8)		Ref.	Ref.
No	167 (80.3)	41 (19.7)		1.67 (1.03–2.71)*	0.87 (0.41–1.78)
Living with children aged ≤ 19 yr			0.874		
Yes	117 (84.8)	21 (15.2)		Ref.	
No	303 (83.7)	59 (16.3)		1.08 (0.64–1.90)	
Living with a person with a disability (physical or mental) or having a disability			< 0.001		
Yes	44 (67.7)	21 (32.3)		3.04 (1.67–5.43)***	2.71 (1.39–5.16)**
No	376 (86.4)	59 (13.6)		Ref.	Ref.
Experience suffering from a disease or an accident for a month or more			0.339		
Yes	97 (87.4)	14 (12.6)		Ref.	
No	323 (83)	66 (17)		1.42 (0.78–2.73)	
Experience with a household member suffering from a disease or an accident for a month or more			0.732		
Yes	89 (85.6)	15 (14.4)		Ref.	
No	331 (83.6)	65 (16.4)		1.17 (0.65–2.21)	
Experience with bereavement			0.794		
Yes	183 (84.7)	33 (15.3)		Ref.	
No	237 (83.5)	47 (16.5)		1.1 (0.68–1.80)	
Completion with advance directives (for oneself or a household member)			0.625		
Yes	42 (87.5)	6 (12.5)		Ref.	
No	378 (83.6)	74 (16.4)		1.37 (0.6–3.69)	
Experience participating in decision-making on life-sustaining treatment for family member(s)			0.433		
Yes	47 (88.7)	6 (11.3)		Ref.	
No	373 (83.4)	74 (16.6)		1.55 (0.69–4.17)	

Data shown are number (%) not otherwise specified.
OR = odds ratio, aOR = adjusted odds ratio, CI = confidence interval.
[a]Adjustment was made for age group, religion, household income, number of household members, presence of spouse, and disability experience.
*P < 0.05; **P < 0.01; ***P < 0.001.

In the clinician's survey, no significant associations were identified between attitudes toward MV withdrawal and potentially related factors, except for a marginal association (P = 0.046) between sex and attitudes at 2 months after birth asphyxia (**Supplementary Table 3**).

DISCUSSION

Herein, most of the GP and clinicians responded that withdrawing LST is permissible in infants with anticipated permanent severe neurological impairment. More participants supported the permissibility of discontinuation when the prognosis did not improve after 3 years of treatment.

A historical debate has unfolded regarding neonatal critical care patients with expected poor prognoses. Particularly notable is the 1970s controversy in the United States, stemming from parents of infants with Down syndrome refusing treatment for duodenal atresia. The response to this was the establishment of the Baby Doe Rules in 1984. Consequently, doctors were obligated to provide maximal treatment to almost all patients under this law, triggered by neglect reports if adequate treatment was not provided to children with disabilities. However, the President's Commission criticized the law, urging consideration of factors such as the baby's suffering and severity of dysfunction in treatment decisions, emphasizing patient

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quality of life and parental authority.[13] Ongoing challenges persist in LST-related decisions; however, in numerous Western countries, such decisions are increasingly guided by ethical principles, with factors such as medical diagnoses, prognosis, quality of life, suffering, and futility being considered.[14] Accordingly, 50–80% of infant deaths in neonatal intensive care units (NICUs) occurred following LST withdrawal, whereas approximately 10% of patients received continued intensive treatment and underwent cardiopulmonary resuscitation before death.[15,16] This pattern was similar in patients with HIE, with 87.6–100% of infant deaths involving withdrawal or withholding of LST.[17-19] One study characterizing the circumstances of death in encephalopathic neonates reported that 81% of infants underwent LST withdrawal owing to considerations of prognosis and quality of life despite physiological stability.[17]

The findings of the current study revealed concerns of the Korean population and clinicians about the potential suffering of the patient and the burden on the family as prominent reasons for withdrawing LST from an infant with permanent severe neurological impairment. Additionally, medical professionals frequently cited a low probability of reversibility as the key rationale for LST discontinuation. However, such opinions from the GP and clinicians have not been adequately reflected in discussions related to LST in Korea. In current practice, infants with severe HIE often receive intensive care until imminent death. Research within the Korean NICU suggested that 65–73% of death cases received excessive intensive care, including resuscitation, supporting this claim.[20,21] The current law proclaims the patients' right to make treatment decisions and their right to dignity. However, decision-making based on ethical considerations remain challenging owing to the restriction of discontinuing LST only during the death-imminent stages of terminal illness. This study observed that the GP and clinicians expressed a public opinion for comprehensive and ethical decision-making on LST, considering ethical aspects. Establishing guidelines is crucial to creating a clinical environment conducive to such discussions. In this respect, Wilkinson's "threshold view" can provide a framework for evaluating the ethical permissibility of treatment decisions in complex cases. Wilkinson argued that LST withdrawal should be discussed when the patient's condition falls below the minimum threshold of life, referred to as "restricted lives" (very severe physical and severe cognitive impairment), rather than waiting until reaching "the zero point" of "a life not worth living." This does not mean that LST for patients below the threshold must be discontinued; instead, it allows parents to make informed decisions about continuing treatment for their child.[22]

In this study, more respondents were open to LST discontinuation at 3 years after the initial point, suggesting that their perception of the patient's condition as irreversible had become more evident. Clinicians had a lower rate of attitude change than the GP, indicating that the current law influenced clinicians' preferences despite guidance to make judgments independent of the law. Additionally, the primary reason (79.1%) cited by responding clinicians was that the withdrawal of LST was permissible when their perception was that the patient's condition was irreversible, which may explain the lesser difference between the two time points compared with that of the GP.

More people with disabilities or family members with disabilities provided opinions on continuing life support with MV of the infant. This finding is intriguing, considering a previous study in Taiwan revealing that individuals with experience caring for a family member with a severe disability were less likely to want to receive LST for themselves.[23] The authors explained that the suffering of families of people with severe disabilities who were cared for and the burden on caregivers may have affected the decision. In Taiwan,

within the East Asian cultural sphere, thoughts on death and the burdens associated with being a family proxy for end-of-life decisions are similar to those in Korea.[23] However, the proportion of deceased individuals using palliative care services, including home hospice, is higher than that in Korea, with institutional differences allowing for the withdrawal of LST in cases of irreversible coma, persistent vegetative state, and severe dementia.[24,25] Differences in opinions on LST between the two studies may also depend on whether the patient is oneself or other family member, especially a child. Additionally, there may be differences in the experience of the participants in the present study compared with those in previous studies. Although the direction of the results is inconsistent, the findings of the previous studies suggest that perceptions and experiences related to disabilities significantly influence decisions about LST. When discussing decisions regarding LST, parents' perspectives on living with children with severe disabilities should be considered.

In a survey conducted among the GP, Christians (Protestants and Catholics) were more inclined to discontinue ventilator use than people practicing other religions or those not following a religion. According to the Christian principles discussed in the study by Scott-Joynt, the decision to withdraw LST from a newborn should be based on the infant's best interests and not on the quality of life or the interests of others.[26] The article suggests setting a low threshold for acceptable quality of life to safeguard vulnerable populations. The author asserts that vulnerable individuals, including infants, should be given a presumption in favor of life, and care should be provided with respect and dignity in the infant's best interests.[26] Previous studies have shown a correlation between the religious beliefs of clinicians and decisions to withdraw LST[27,28]; however, the present study did not find such a correlation.

This study has some limitations. First, although the GP provided detailed explanations, having an accurate understanding of the infant's medical condition may have been challenging. Some respondents may have struggled to fully grasp the concept of living on a ventilator after hospital discharge. Second, the survey was conducted by enrolling clinicians from a single hospital; therefore, it lacked representativeness. However, this study is the first to investigate and compare the opinions of the GP and clinicians in Korea regarding discontinuation of LST in infants. While this study did not target parents who had experience with the withdrawal or continuation of LST for their newborns, it focused on the GP. As a result, it provides a better representation of the general perceptions within the Korean population. Furthermore, the inclusion of clinicians from diverse specialties and careers enabled the study to better represent the general opinions of healthcare professionals.

This study highlights the notable disparities between the existing medical framework in Korea and the preferences of the GP and clinicians. Although the study did not ascertain the optimal timing for withdrawing LST, both clinicians and the GP recognize the necessity for discussions on its withdrawal in infants with unlikely neurological recovery. When discussing the discontinuation of LST for infants with permanent severe neurological impairment, the patient's best interest should be prioritized, considering factors such as the reversibility of the patient's condition, prognosis, and quality of life. To ensure that this occurs at the appropriate time and that the opinions of medical professionals and parents are adequately reflected, overall system improvements such as legislative amendments, guideline development, and medical staff education are necessary.

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SUPPLEMENTARY MATERIALS

Supplementary Methods

Supplementary Table 1

Survey questionnaire for public and clinicians on attitudes toward life-sustaining treatment withdrawal in infants with poor neurological prognosis

Supplementary Table 2

Characteristics of participants in clinicians (N = 200)

Supplementary Table 3

Attitudes toward withdrawal of mechanical ventilator and related factors in clinicians (N = 200)

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