

Health Utility Estimation based on Parenteral Support Days for Adult Patients with Short Bowel Syndrome and Intestinal Failure in Korea

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BACKGROUND

- Short bowel syndrome (SBS) is anatomically defined as post-duodenal residual small intestine length ≤ 150-200 cm, i.e. less than half the length of the normal small intestine in adults.¹
- SBS is a rare disease in which the absorptive capacity of the intestine is reduced to a clinically significant level as a result of surgical resection or congenital disease of a significant portion of the small intestine.^{2, 3}
- SBS can lead to intestinal failure (IF), a condition in which the functioning gut mass reduces below the minimum required for absorption of macronutrients or water and electrolytes. As a result, specialized medical and nutritional support, such as parenteral support (PS), are required for survival.^{3, 4}
- For patients with SBS, PS is a life-saving or life-sustaining therapy, but long-term PS significantly impacts most aspects of their quality of life and can lead to severe complications.⁵⁻⁷
- With limited evidence, research on the quality of life of patients according to the number of days of PS is necessary to better understand patients with SBS in Korea.

OBJECTIVE

This study aimed to estimate the health utility weights associated with the frequency of PS in adult patients with short bowel syndrome and intestinal failure (SBS-IF), as perceived by the general Korean population.

METHODS

Study Design and Participants

Health utilities were estimated using vignettes depicting the health states of adult SBS-IF patients, based on PS frequency in the general Korean population aged 19-60 years.

Health States Development

We developed scenarios depicting the health states of adult SBS-IF patients based on PS frequency using previous studies, in-depth interviews with 9 SBS-IF patients, and clinical expert reviews.

Table 1. Health States

Health State	
0 days	Adult patient with short bowel syndrome with intestinal failure who is not receiving parenteral support.
1 day	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, 1 day per week.
2 days	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, 2 days per week.
3 days	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, 3 days per week.
4 days	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, 4 days per week.
5 days	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, 5 days per week.
6 days	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, 6 days per week.
7 days	Adult patient with short bowel syndrome with intestinal failure who receives parenteral support for 12 to 16 hours per day, every day.

Outcome Measurement

EQ-5D-5L

The EQ-5D-5L, a multi-attribute utility instrument developed by the EuroQol Group, is a standardized measure of health-related quality of life. It comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The utility value (EQ-5D-5L score) was calculated using the Korean value set.

VAS

The EQ-VAS is an instrument that records an individual’s preference for health states using a vertical visual analogue scale (VAS), with the endpoints labeled as 100 for ‘Perfect health’ and 0 for ‘Death’.

TTO

The time-trade off (TTO) is a choice-based method used to assess preferences for the health states. It involves asking individuals to choose between two options: living with a given health condition for a period of time t followed by death, or living in perfect health for a shorter period of time x followed by death. The utility value was estimated by identifying the period x for which individuals were willing to trade off against the period t. The utility value was then calculated as the ratio x/t. In this study, the life expectancy with a given health condition was set to 20 years to make it easier for the participants to understand.

Statistical Analysis

Mean utility values were calculated across weekly PS days groups. Subgroup comparisons were performed using t-tests and ANOVA. Multilevel analysis addressed repeated measures and controlled for sociodemographic factors.

RESULTS

- The analysis included 179 participants from the general Korean population (26.3% 20s, 24.6% 30s, 26.3% 40s, 22.9% 50s; 58.7% female). The mean health utility of the responders was measured as 0.859 using the EQ-5D-5L and 0.817 using the VAS (**Table 2**).
- Utility scores, as measured by EQ-5D, VAS, and TTO, demonstrated a negative correlation with increasing PS days in SBS-IF patients. The mean utility value for "0 days on PS" was the highest and these scores progressively decreased with each additional PS day. The mean utility value for "7 days on PS" was the lowest (**Figure 1, Table 3**).
- After adjusting for covariates, PS frequency remained a significant predictor of utility values (P < 0.001) (**Table 4**).

Table 2. General characteristics of responders (N=179)

	Category	N or Mean	% or SD
Age (yrs)	20-29	47	26.3%
	30-39	44	24.6%
	40-49	47	26.3%
	50-59	41	22.9%
Sex	Male	74	41.3%
	Female	105	58.7%
Monthly household income	≤5 million KRW	56	31.3%
	>5 million KRW	123	68.7%
Education	High school graduate or lower	11	6.1%
	University attendance or higher	168	93.9%
Employment status	Unemployed/Student/Homemaker	61	34.1%
	Employed	118	65.9%
Insurance	National Health Insurance	170	95.0%
	Medical aid	6	3.4%
	Unknown	3	1.7%
Intestinal disease (self and acquaintances)	Yes	5	2.8%
	No	174	97.2%
Health utility	EQ-5D-5L	0.859	0.050
	VAS	0.817	0.110

Figure 1. Mean health state utilities measured by EQ-5D-5L, VAS, and TTO

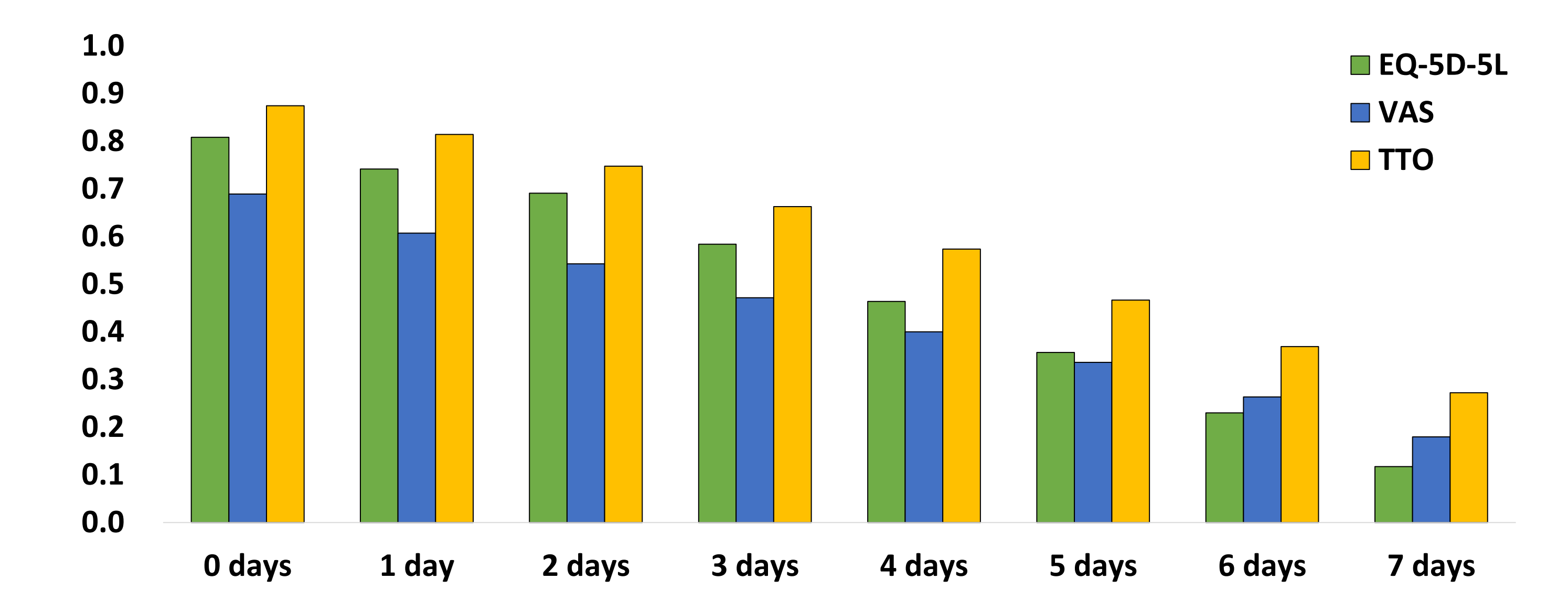


Table 3. Mean health utility values measured by EQ-5D-5L, VAS, and TTO

PS per week	0 days	1 day	2 days	3 days	4 days	5 days	6 days	7 days
EQ-5D-5L	0.808 (0.062)	0.742 (0.073)	0.691 (0.098)	0.584 (0.146)	0.464 (0.176)	0.357 (0.161)	0.230 (0.172)	0.117 (0.170)
VAS	0.689 (0.130)	0.607 (0.130)	0.543 (0.123)	0.472 (0.121)	0.40 (0.120)	0.336 (0.123)	0.263 (0.121)	0.180 (0.119)
TTO	0.874 (0.111)	0.814 (0.127)	0.748 (0.141)	0.663 (0.157)	0.574 (0.175)	0.467 (0.191)	0.369 (0.201)	0.272 (0.209)

Data are presented as Mean (Standard Deviation)

Table 4. Multivariable regression of health utility values against the number of PS days per week

Effect	EQ-5D-5L		VAS		TTO	
	Estimate	SE	Estimate	SE	Estimate	SE
Intercept	0.814*	0.054	0.642*	0.052	0.960*	0.067
0 days	ref		ref		ref	
1 day	-0.067*	0.010	-0.082*	0.006	-0.060*	0.010
2 days	-0.117*	0.010	-0.146*	0.006	-0.127*	0.010
3 days	-0.224*	0.010	-0.218*	0.006	-0.212*	0.010
4 days	-0.344*	0.010	-0.289*	0.006	-0.301*	0.010
5 days	-0.451*	0.010	-0.353*	0.006	-0.408*	0.010
6 days	-0.578*	0.010	-0.426*	0.006	-0.505*	0.010
7 days	-0.691*	0.010	-0.509*	0.006	-0.602*	0.010

* p<0.0001.
SE, Standard error
This model was adjusted for age, sex, education, income, employment status, insurance type, history of intestinal diseases (self and acquaintances)

CONCLUSIONS

This study revealed a significant increase in health-related quality of life (HRQoL) for adult SBS-IF patients with decreasing PS frequency. Interventions to minimize the number of PS days hold promise for substantially improving HRQoL in this patient population.

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