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Brief Report

Health-Related Quality of Life of Pediatric Spinal Surgery Complications

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ABSTRACT

Background: Health-related quality of life (utility) measures are essential components of effectiveness analyses. The health-related quality of life of health states in pediatric patients who underwent spinal surgery have not been reported previously. **Objectives:** To estimate the utility of complications after spinal surgeries and side effects of acetazolamide administration. **Methods:** Parent caregivers, nurses, neurosurgeons, and orthopedists were interviewed as proxies to evaluate the preference of health conditions in pediatric patients who underwent intradural surgeries. We measured the utility of spinal surgery complications (cerebrospinal fluid leakage and collection, wound dehiscence, operation site infection, and secondary repair of operation site), side effects of acetazolamide administration (loss of appetite, mild gastroenteritis, and severe acid/base and/or electrolyte imbalance), taking pills (for 10 days, 1 month, and 1 year), and 24 hours of ward or intensive care unit admission by visual analogue scale. **Results:** One hundred individuals were interviewed (pilot study: 20 individuals; main study: 40 parents, 27 nurses, 8 neurosurgeons, and 5 orthopedists). Sixty-four (80%) of the respondents were female. Taking pills for 10 days had the highest utility value (0.71 ± 0.13), whereas secondary surgical repair of the operation site and acid/base and/or electrolyte imbalance had the lowest preference (0.19 ± 0.16 and 0.23 ± 0.11, respectively). **Conclusions:** This study provides the utility measures for quality assessment of temporary postsurgical events in pediatric patients.
Keywords: acetazolamide side effects, HRQOL, spinal surgery complications, utility, visual analogue scale (VAS)

Introduction

Policy makers count on cost-benefit analyses to implement the protocols of care. Nevertheless, it is the preference and compliance of the patients that determine the outcome in clinical practice. Previously we conducted a randomized controlled trial to see whether adding acetazolamide and prone positioning to postoperative care reduces the complications of intradural spinal surgeries.[1] Despite the lower rate of cerebrospinal fluid (CSF)-related complications in patients with bed rest, keeping the prone position in pediatrics was not feasible. To quantify this discomfort, we measured the utility of prone positioning through 5 instruments—the visual analogue scale (VAS), standard gamble (SG), chain of gambles, time trade-off (TTO), and modified TTO—and proposed a model for assessment of health-related quality of life (HRQOL, utility) in pediatric temporary health states (Shahjouei et al., 2018, under review). To better picture the issue, we decided to calculate the HRQOL of all health states in the postsurgical period to enable us to carry out cost-effectiveness analysis of postoperational care protocols.

Although the utilities of several health states have been published previously,[2-4] the values of specific spinal surgery complications such as CSF leak and CSF collection are not reported in pediatric patients. In addition, the method of

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measurement and the status of responding parents affect the utility values.[5-8] We designed this study to estimate the utility of complications after spinal surgeries and side effects of acetazolamide administration.

Methods

During 2015 to 2017, three university hospitals in Tehran—Shariati Hospital, Children's Medical Center Hospital, and Imam Khomeini Hospital Center—were host to this study. These centers are end point referral center of Iran, with a 75-million population and totally diverse ethnicities and cultures. The study protocol received approval from Medical Ethics and History of Medicine Research Center of Tehran University of Medical Sciences (ID number: 2137). Because of the limitations of HRQOL assessment in children,[9-12] we interviewed their parent caregivers or responsible medical staff as proxy. We randomly selected the medical file numbers of pediatric patients (<12 years old) admitted in neurosurgical wards. Interviews were terminated because of participants' unwillingness, poor English or Persian, or medical emergency for the patient at the time of the interview.

Baseline Data and Outcome Measures

The baseline characteristics of the interviewee—sex, age, number of children, age of the index child, education, occupation or specialty, and years of expertise—were recorded. Utility values of 24 hours of hospital admission in the ward and intensive care unit (ICU), complications of the spinal surgery, and acetazolamide side effects were our outcome measures. CSF leakage (rush of fluid out of wound), CSF collection (visible subcutaneous fluid collection or subcutaneous fluctuation), wound dehiscence (wound rupture along surgical sutures), wound infection (confirmed by culture and staining of the operative site's samples), and surgical management of operation site were considered as the complications of the surgery. Mild gastroenteritis (negative stool examination result and culture), loss of appetite, and severe acid/base or electrolyte imbalance (requiring ICU admission) were considered as complications of acetazolamide administration.

Interview Sets and Pilot Study

In all scenarios, the proxy was asked to consider the HRQOL of the pediatric patients. To decide whether to ask healthcare providers or parent caregivers to respond to HRQOL scenarios, we randomly selected 20 patients who were admitted in neurosurgical wards. To eliminate confounders on utility values, all candidates who were at 1 day before or after surgery were excluded. Neurosurgeons, nurses, and parents were asked to determine the HRQOL of the index child (1) in the current condition, (2) when the patient imaginary had a 3-day episode of mild gastroenteritis, and (3) when the patient imaginary had 1 specified complication of the surgery. We could not find any statistically significant difference between the reported utility values of the first 2 questions. We also recognized that parents cannot differentiate between different surgical complications. In addition, in critical conditions such as ICU admission or surgical repair of the wound, parents were not allowed to accompany their children. According to these findings and to optimize the number of questions in each interview, we considered 3 sets of interviewees (Fig. 1). In set 1, parent caregivers of the admitted patients in the neurosurgery ward were interviewed to evaluate the HRQOL of (1) 24-hour hospitalization in the ward, (2) mild gastroenteritis for 3 days, (3) loss of appetite for 3 days, and (4) taking pills 3 times a day for intervals of 10 days, 1 month, and 1 year. In set 2, neurosurgeons, orthopedists, and nurses with at least 1 year of experience at the neurosurgery or orthopedic operation room/ward were invited to determine the utility of (1) CSF leakage, (2) CSF collection, (3) wound dehiscence, (4) operation site infection, and (5) secondary surgical wound repair. Finally, in set 3, the utilities of (1) 24-hour ICU admission and (2) severe acid/base and/or electrolyte imbalance requiring ICU admission were asked from neonatal/pediatric ICU nurses with at least 1 year of experience.

Utility Instrument and Measure Adjustment

Utilities were measured by VAS, with the visual scale painometer application on iPad (horizontal screen size, Wong Baker schematic faces, and scale maximum value of 10). Respondents had an adequate introduction to and a trial on how the software works before narrating the scenarios. To prevent calculation error, all the preferred values in the interval of 0 to 1 were considered equal to 0.05. Similarly, values between 9 and 10 were considered as 9.95.[3] The preference values were rescaled to 0 to 1 to calculate the utilities. The utilities were reported as mean (±SD) and median (interquartile range).

Results

A total of 80 patients were interviewed in this study (set 1, 40; set 2, 20; and set 3, 20 individuals). Sixty-four (80%) of the respondents were female. Table 1 presents the basic characteristics of the participants in each set of interviewees. Estimated utility values are presented in Table 2. The highest utility value was related to taking pills for 10 days (0.71 ± 0.13). There was a significant difference between the utilities of taking pills for different periods (10 days to 1 month, $P=.008$; 10 days to 1 year, $P=.020$; 1 month to 1 year, $P=.880$). The lowest utilities were for the secondary surgical repair of the operation site (0.19 ± 0.16) and acid/base and/or electrolyte imbalance (0.23 ± 0.11).

Discussion

We provided the HRQOL of spinal surgery complications and acetazolamide administration in pediatric patients. There are some recommended instruments such as the EuroQol 5-dimensional questionnaire to evaluate the HRQOL of low back

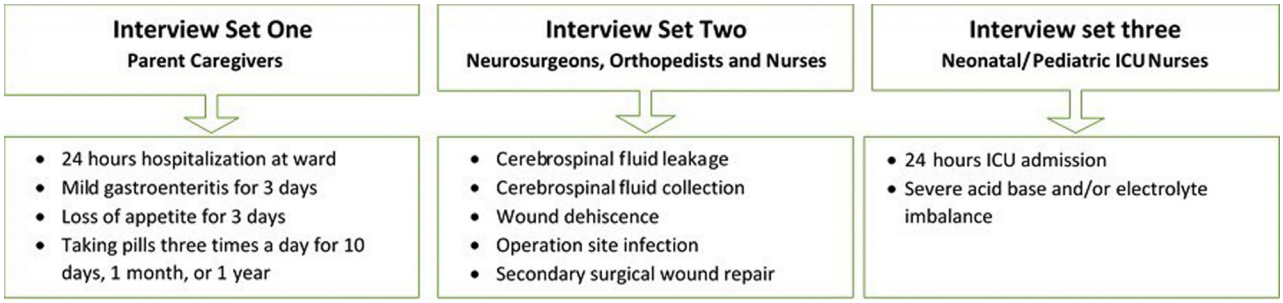

Fig. 1 – Interview sets. Three groups of respondents were invited to the study to evaluate the health-related quality of life of different health states. ICU indicates intensive care unit.

Table 1 – Basic characteristics of the interviewees.

Parameter	Set 1* (N = 40)
Parent's sex, female, n (%)	40 (100)
Parent's age (y), mean ± SD	32.45 ± 6.73
Parent's education, n (%)	
Illiterate	5 (12.5)
Primary school	8 (20.0)
Incomplete high school	2 (5.0)
High-school graduate	15 (37.5)
University graduate	10 (25)
Parent's occupation, n (%)	
Homemaker	33 (82.5)
Employee	5 (12.5)
Student	2 (5.0)
Number of children, median (IQR)	1.5 (1-2)
Index child age (mo), mean ± SD	32.71 ± 19.78
	Set 2† (N = 20)
Respondent's sex, female, n (%)	8 (40)
Respondent's age (y)	29.83 ± 1.26
Specialty, n (%)	
Nurse	7 (35)
Neurosurgeon	8 (40)
Orthopedist	5 (20)
Experience (y), mean ± SD	5.83 ± 0.46
	Set 3‡ (N = 20)
Respondent's sex, female, n (%)	16 (80)
Respondent's age (y), mean ± SD	29.67 ± 2.32
Experience (y), mean ± SD	4.21 ± 2.71

CSF indicates cerebrospinal fluid; ICU, intensive care unit; IQR, interquartile range.

* Set 1: parent caregivers; utility measure of taking pills 3 times a day for 10 d, 1 mo, and 1 y; mild gastroenteritis for 3 d and loss of appetite for 3 d; and 24 h hospitalization in ward.

† Set 2: neurosurgeons, orthopedists, nurses of neurosurgery/orthopedics ward/operation room; utility measure of CSF leak, CSF collection, wound dehiscence, operation site infection, and secondary surgical wound repair.

‡ Set 3: nurses of neonatal/pediatric ICU; utility assessment of acid/base and/or electrolyte imbalance and ICU admission for 24 h.

surgeries.[13] But to our knowledge, utility values of specific complications are not reported, even in adults.

Carroll and Downs[4] measured utility values of some health states with TTO and SG. Their mean utility estimates of 10-day hospitalization in ward (SG = 0.94; TTO = 0.95), 10-day hospitalization in ICU (SG = 0.87; TTO = 0.91), and moderate gastroenteritis (SG = 0.93; TTO = 0.94) are higher than our values (0.60, 0.50, and 0.67, respectively). There are a couple of explanations for this difference. First, the impact of instrument on the measured utility values is significant. Our previous study demonstrated that none of the parents accept the risk of death (SG) or trading life-years (TTO) for temporary health states. We chose VAS as our utility instrument because we showed adequate reproducibility and validity of VAS even after introducing other scenarios (Shahjouei et al., 2018, under review). In addition, utility tools such as TTO and SG require adequate knowledge of statistics, and the results depend on life expectancy and the risk-taking behavior of the respondent.[5,14] In contrast, using VAS is very feasible, and participants should select a point in a scale of pictured faces. In comparison with TTO, modified TTO, SG, and chain of gambles, VAS values are lower.[5,15]

Table 2 – The result of utility values measured in this study.

Condition	Utility value	
	Mean ± SD	Median (IQR)
Taking pills		
10 d	0.71 ± 0.13	0.73 (0.61-0.80)
1 mo	0.61 ± 0.23	0.67 (0.36-0.81)
1 y	0.61 ± 0.24	0.67 (0.37-0.83)
Complications		
CSF leakage	0.51 ± 0.15	0.57 (0.40-0.59)
CSF collection	0.45 ± 0.15	0.41 (0.40-0.59)
Wound dehiscence	0.34 ± 0.15	0.40 (0.26-0.42)
Operation site infection	0.30 ± 0.09	0.25 (0.24-0.40)
Secondary surgical wound repair	0.19 ± 0.16	0.10 (0.07-0.35)
Side effects of acetazolamide		
Loss of appetite	0.63 ± 0.21	0.72 (0.39-0.78)
Mild gastroenteritis	0.67 ± 0.17	0.61 (0.59-0.76)
Acid/base and/or electrolyte imbalance	0.23 ± 0.11	0.27 (0.14-0.32)
Admission in		
Ward	0.60 ± 0.23	0.68 (0.38-0.82)
ICU	0.50 ± 0.14	0.51 (0.41-0.58)

CSF indicates cerebrospinal fluid; ICU, intensive care unit; IQR, interquartile range.

Second, multiple factors determine the perception of the preference for each health condition.[8,16] Sociodemographic characteristics of the population and nonmedical burden of the health state such as stigma, health insurance coverage, and access to rehabilitation and social services are among them. Our study was conducted in a country where hospitals are overcrowded and ICU care and advance medical services are available only for critically ill patients with severe morbidities and high mortality rates. Thus, it is not unusual that the perception of our population differs from American subjects in the study by Carroll and Downs.[4] Another example to support the impact of social factors rather than methodological difference on utility values is the preference for health conditions with minimum preference in the report by Carroll and Downs[4]: quadriplegia, cerebral palsy, and mental retardation have utility values of about 0.5. We demonstrated that a significant portion of our respondents perceive these health conditions as worse than death (Shahjouei et al., 2018, under review).

The strength of this study is that we interviewed specialists and experienced healthcare providers to determine the utilities of critical conditions. In our pilot study, we obviously recognized that even with adequate explanation of the condition, parents cannot discriminate between complications and rely on some key terms (such as surgical intervention) to judge about the preference. Asking experts limited the number of eligible participants in our study.

We evaluated the utility values in a population with diverse ethnicities and sociodemographic factors. Nevertheless, the importance of a standardized multination and multicultural study on quality of life of a wide range of health conditions, including the specific complications and side effects of surgical interventions, cannot be ignored.

Conclusions

We provided the HRQOL of spinal surgery complications, side effects of acetazolamide administration, taking pills, and ward and ICU admission for future studies.

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