Parental Perception of Functional Status Following Tracheostomy in Infancy: A Single Center Study

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Objective To examine the functional outcomes of children who underwent a tracheostomy in the initial hospitalization after birth and to determine their correlates.

Study design We administered the validated 43-item Functional Status-II (FS-II) questionnaire by Stein and Jessop over the telephone to caregivers of surviving children. The FS-II items generated a total score, age-specific: (1) total; (2) general health (GH); and (3) responsiveness, activity, or interpersonal functioning (IPF) scores in specific age group categories.

Results FS-II was administered to 51/62 (82.2%) survivors at a median (range) age of 5 (1-10) years; 27% children were on the ventilator and 43% required devices. About 40% of children had a median of 1 (1-4) hospitalization in the previous 6 months. Scores were >2 SD below means in 55%, 24%, and 55% cases for age-specific T, GH, and R/A/IPF scores respectively. The T and R/A/IPF scales were significantly higher in those with private, rather than public, maternal insurance, as were T and R/A/IPF scores for children ≥4 years, compared with younger children. On regression analysis, FS-II T, GH, and R/A/IPF scores were independently associated with maternal private insurance (P = .02). R/A/IPF scores were also significantly associated with corrected age at FS-II administration.

Conclusions One-third of surviving children who underwent tracheostomy during their initial hospitalization remained technology-dependent. The parental FS-II questionnaires revealed low R/A/IPF scores, especially at younger ages and in those with maternal public insurance. Further research on family-level interventions to improve functional outcomes in this population is warranted. *(J Pediatr 2013;163:860-6)*.

Evolution in medical care has led to the increased survival of preterm infants to discharge from neonatal intensive care units (NICUs).[1] Survivors of neonatal intensive care, especially extremely low birth weight infants, continue to have high rates of neurodevelopmental and functional morbidities and often depend on medical devices for transition out of the hospital.[2]

In 1987, the Office of Technology Assistance estimated that up to 68 000 children in the US were dependent on medical technology.[3] Four groups of technology-dependent children were identified by the types of medical devices and services they require.[3] Children requiring tracheostomy, who may or may not be ventilator-dependent, constitute a considerable subset (groups I and III) of the technology-dependent pediatric population. The National Survey of Children with Special Health Care Needs chart book 2005-2006 reported that 11.4% of children with special health care needs required durable medical equipment and 4.4% needed mobility aids or devices.[4] In the past few decades, tracheostomy has become increasingly frequent in NICUs in tertiary care children's hospitals. In the preterm neonatal population, the common indications for tracheostomy include prolonged ventilator dependence, often as a consequence of bronchopulmonary dysplasia (BPD).[5] Other indications for tracheostomy in infancy are upper airway obstruction from craniofacial or structural airway abnormalities, and neurologic or neuromuscular disorders.

There is a scarcity of data on childhood outcomes following tracheostomy in infancy. The 2004 National Institute of Child Health and Human Development workshop statement for follow-up care of high risk infants identified an objective, alternate, and less costly methods of follow-up assessment that could be utilized by community physicians, to supplement current standardized neurodevelopmental and psychometric testing.[6] Functional status assessments are potentially useful alternative tools to evaluate outcomes and predict health care utilization. They can be performed using standardized instruments of self-reporting, with the parent as proxy. These data provide measures of outcomes of neonatal interventions from the family's perspective. Previous studies indicate that parents can be reliable and valid sources of information regarding their child's current functional and developmental status, compared with professionally administered tests.[7-9]

BPD	Bronchopulmonary dysplasia
FS-II	Functional Status-II
GH	General health
IPF	Interpersonal functioning
NICU	Neonatal intensive care unit

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Therefore, we sought to: (1) examine the parental perception of the functional status of children who underwent a tracheostomy in the initial NICU stay, using the Functional Status-II (FS-II) 43 item instrument; and (2) to determine the association, if any, between neonatal and environmental factors and functional status in childhood. Our hypothesis was that infants who undergo tracheostomy in their initial hospitalization after birth would have considerable functional impairment and that certain neonatal and environmental factors may be associated with functional status.

Methods

We undertook a prospective telephonic administration of the FS-II questionnaire to the parents or primary caregivers of eligible children. Children who underwent a tracheostomy at Children's Hospital of Michigan, while admitted in the NICU between January 1, 2001 and December 31, 2010, were included in the study. These infants were identified by the electronic NICU discharge database, using "tracheostomy" as search word. Infants who underwent tracheostomy after discharge home were excluded. The Institutional Review Board of the Human Investigation Committee of Wayne State University and the Research Review Committee of the Detroit Medical Center approved both the study and verbal parental consent.

A retrospective chart review of eligible infants was performed to obtain demographic data such as gestational age, sex, and age at tracheostomy. Pulmonary and otorhinolaryngology clinic visit charts were accessed to assess survival and pulmonary outcomes, which were then confirmed with the parent during the administration of the questionnaire. Data on follow-up visits to various clinics and for therapy were abstracted from the electronic medical records registration information and were limited to our center. The charts of the Developmental Assessment Clinic were reviewed to obtain growth data as close as possible to the 18-month corrected age. Growth percentiles were derived from the sex-specific World Health Organization growth charts. Parents and caregivers of eligible survivors were contacted to seek telephonic consent to administer the 43-item version of the FS-II questionnaire. Only parents who provided verbal consent were administered the questionnaire by a single investigator (S.R.). Data on insurance type was collected at the time of FS-II administration from the respondent parent and at the time of initial hospitalization from the medical records. The respondents were also asked about whether they had available partner help, defined as the help of a married or cohabiting partner in the care of the study child. Questionnaires were then independently scored by two investigators (G.N. and S.R.).

FS-II Instrument

The FS-II instrument, developed by Stein and Jessop, is a validated parent report of the child's functioning in the physical, psychological, social, and cognitive domains, categorized by age.[10,11] (The Functional Status-II (R) Measure is copyright by R. E. K. Stein, C. K. Riessman, and D. J. Jessop, 1981, 1991). It addresses elements such as communication, mobility, mood, energy, sleeping, eating, and impact of chronic illness (defined in our study as tracheostomy-related illness). It can be administered by a trained layperson in less than 30 minutes and consists of the long 43-item and short 14-item versions. Examples of questions include whether the child can eat well, sleep well, is content, can communicate, is interested in the environment, has temper tantrums, and has trouble with tasks, among others. Parents respond to each question on a 3-point categorical Likert scale. The FS-II is administered in two parts; in the first part, the parent rates the functional limitation of the child or the extent of difficulty with specific behaviors; in the second part, the parent rates the extent (fully, partly, or not at all) to which the difficulty with specific behaviors is due to ongoing illness. The purpose of this order is to minimize a response set. Scores are the points obtained by the child as a percent of possible points for that scale and age group. Scoring is based on the subset of items chosen by the parent indicating that the child's functional status was partially or fully impacted as a result of illness, which we defined as "tracheostomy-related" in this study. Higher scores indicate a more favorable functional status. The FS-II questionnaire generates a total score and 2 component scores—general health (GH) in all age groups and responsiveness, activity or interpersonal functioning (IPF), depending on the age group. The manual provides means ± SD for the total score for all ages (14 items, 86.8 ± 15.7), for children <1 year (19 items total 87.9 ± 18.3; 10 items GH 86.9 ± 19.2; 13 items responsiveness 90.7 ± 18.2), for children 1 year-23 months (22 items total 86.9 ± 18.3; 17 item GH 84.8 ± 20.3; 11 item responsiveness 90.3 ± 17.0), for children 2-3 years (24 item total 91 ± 15.2; 12 item GH 85.1 ± 18.3; 20 item activity 91 ± 16.7), and for children 4 years and older (26 item total 87.4 ± 13.8; 18 item GH 89.1 ± 13.9; 13 item IPF 88.4 ± 14.3).

Stein and Jessop have validated the instrument using data from 732 children aged 2 weeks to 16 years who were either chronically ill or well.[10] Principal component analysis determined the factor structure associated with the questionnaire items for four age groups (≤1 year, 1 year-23 months, 2-3 years, ≥4 years). The strengths of the questionnaire are that it includes a large age span, 0-16 years, divided into 4 age groups, is available both in English and Spanish, has good psychometric properties, and is designed to assess child health status in children with a wide variety of ongoing illnesses.

Statistical Analyses

Descriptive statistical analyses were performed using the SPSS software v. 17.0 (SPSS Inc, Chicago, Illinois). Results were expressed as mean (SD), median (range), or n (%) as appropriate. Bivariate comparisons of FS-II scores were performed using the t test for continuous variables and χ^2 test for categorical variables between the two sexes, for subgroups of infants born extremely premature <28 weeks and others, private and public insurance, BPD as an indication for