

# The Impact of Pediatric Tracheotomy on Parental Caregiver Burden and Health Status

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**Objective:** To explore the effects of the placement of a pediatric tracheotomy tube on the degree of caregiver burden and overall health status of parents using general and disease-specific instruments.

**Methods:** Between January and July 2001, the Medical Outcomes Study Short Form 12 (SF-12) and the Pediatric Tracheotomy Health Status Instrument (PTHSI) were administered to 154 families of children requiring tracheotomy. Summary scores were generated for each of the 2 scales of the SF-12 (the Physical Component Score [PCS] and the Mental Component Score [MCS]) as well as for the 4 previously established domains of the PTHSI: domain 1, physical symptoms of the child (7 items); domain 2, medical visits and cost (7 items); domain 3, parental rating of the child's psychological health status (3 items); and domain 4, parental rating of their own caregiver burden (17 items). Correlations between responses from the individual domains and between domain 4 of the PTHSI (reflecting caregiver burden) and the SF-12 were performed.

**Results:** The mean±SD summary scores for the 4 domains of the PTHSI were domain 1, 22.7±5.3; domain 2, 24.9±6.2; domain 3, 10.5±4.4; and domain 4, 48.3±9.5 (lower scores reflect "poorer" health status). The

mean±SD summary scores of PCS and MCS were 50.5±11.3 and 35.8±11.4, respectively. There existed a significant correlation between parental caregiver burden (as expressed by domain 4) and the child's physical health status (domain 1) (0.32;  $P<.001$ ) as well as between parental caregiver burden and increasing economic costs associated with this care (0.27;  $P<.001$ ). A strong correlation was found between the domain measuring parental caregiver burden (domain 4) and the MCS-12 ( $r=0.43$ ;  $P<.001$ ), while a poor correlation existed with the PCS-12 ( $r=-0.17$ ;  $P=.14$ ). Nevertheless, in contrast to caregiver burden, the health status of the caregivers as measured by the SF-12 did not alter according to the severity of illness for the children ( $P=.17$ ).

**Conclusions:** Parents caring for children with tracheotomy tubes experience significant caregiver burden. These parents appear to experience increased burden with respect to the child's severity of illness and increased costs associated with caring for their children. Overall, the mental health status for an adult caring for a child with a tracheotomy tube is significantly reduced and appears to be more affected than physical health status.

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**T**RADITIONAL DISCUSSIONS of pediatric tracheotomy-related issues report morbidity and mortality figures in terms of deaths and physical health-related sequelae. The mortality rates have decreased from early figures of 5% to 10% in the 1940s and 1950s<sup>1,2</sup> to the current range of 0.5% to 2.0%.<sup>3,4</sup> Morbidity has been reported as consisting of airway obstruction, decannulation, bleeding, and infection; contemporary rates of morbidity range from 24% to 58%.<sup>4,5</sup> "Functional" morbidity regarding the functional status or the health-related quality of life (HR-QOL) of the child or caregiver has been poorly described. This change in HR-QOL is at once physical (in terms of physical demands on the caregiver with increased home care responsibilities), economic (in terms

of increased costs required for medical visits and follow-up), psychological, and emotional. This is in line with the definition of HR-QOL as "the subjective and objective impact of dysfunction associated with illness or injury, medical treatment, and health care policy."<sup>6</sup>

To date, the evaluation of HR-QOL in technology-dependent children such as those requiring tracheotomy has relied on qualitative measurements principally derived from focus groups and nonvalidated surveys.<sup>7,8</sup> Although generic health status instruments can be used to explore the effect of a particular illness on health status, the health status changes due to specific disease states may be more adequately described by focusing on particular issues affected by that disease state such as unique symptoms and stressors. To explore more

**Table 1. Individual Items Within Domain 4 of the PTHSI Reflecting Parental Caregiver Burden**

1. How would you describe your overall quality of life?
2. How often are you able to perform activities to manage your home?
3. How often are you worried or concerned about your child's safety when you perform a tracheotomy tube change?
4. How often are you worried or concerned about your child's safety when you suction the tracheotomy tube?
5. How often are you worried or concerned about your child's safety with regard to your child's overall ability to breathe?
6. How often over the past week have you been able to take your child out of the house (eg, to run errands or for recreation)?
7. During the past 4 weeks, how often have you been worried or concerned about your child's physical health?
8. During the past 4 weeks, how often have you been worried or concerned about your child's emotional well-being or behavior?
9. During the past 4 weeks, how often have you been limited in fulfilling your own needs because of your child's physical health?
10. During the past 4 weeks, how often have you been limited in fulfilling your own needs because of your child's emotional well-being or behavior?
11. During the past 4 weeks, how often has your child's condition affected your health?
12. During the past 4 weeks, how often has your child's condition affected your emotional state?
13. During the past 4 weeks, how often has your child's condition affected your sleep?
14. During the past 4 weeks, how often has your child's condition affected your relationship?
15. During the past 4 weeks, how often has your child's condition interrupted various everyday family activities (eg, eating meals, watching television, or going out)?
16. Over the past 4 weeks, how often did you need help from skilled medical personnel?
17. Over the past 4 weeks, how often did you get help from skilled medical personnel?

Abbreviation: PTHSI, Pediatric Tracheotomy Health Status Instrument.

formally the health status of the children necessitating tracheotomy and their caregivers, a specific parent-proxy instrument (the Pediatric Tracheotomy Health Status Instrument [PTHSI]) has been developed and pilot tested.<sup>9</sup> The instrument is designed as a disease-specific instrument; it has been scaled from 0 to 100 for ease of interpretation (and oriented in a traditional manner in which low scores reflect "poor" HR-QOL). The details of the development and pilot testing of the PTHSI have been reported elsewhere and will not be reported here.<sup>9</sup>

Attention to the caregiver's experience is also an essential part of a pediatric model, which is inclusive both of patient and family alike. There exists a body of literature supporting the theory of a caregiver burden. Although most literature regarding caregiver burden focuses on adult care of the geriatric patient, there also exists a body of literature regarding the caregiver burden for adults who attend to the pediatric population.<sup>10-12</sup> This burden can have both objective and subjective dimensions<sup>13</sup>; it may vary according to age,<sup>14</sup> race,<sup>15</sup> and economic situation.<sup>16</sup> Although there have been reports of caregiver burden producing physical vulnerability,<sup>17</sup> most reports on caregiver burden have linked such burden with depression and other psychiatric disorders.<sup>18</sup> In this study, we describe the results of preliminary evaluation of the relationship between caregiver burden and health status among the caregivers of children who have undergone tracheotomy.

## METHODS

### STUDY POPULATION

Parents and caregivers of children who have undergone tracheotomy were contacted via an active Web site that exists to provide information, counsel, and support to such families<sup>19</sup> or by direct mailing to families whose children had received a tracheotomy tube at the Children's Hospital Medical Center in Cincinnati, Ohio. The Web site chosen (<http://www.tracheostomy.com>) is specifically designed for families in which a child has received a tracheotomy tube. Currently, several hundred families access this Web site as a source of information.

This study received prior approval from the Children's Hospital Medical Center of Cincinnati's institutional review board. An introductory paragraph was placed on the first page of the Web site for purposes of informed consent and a link established for the parent or primary caregiver to receive the instrument itself. The parent or primary caregiver then completed the instrument online or e-mailed the completed instrument to the primary investigator (C.J.H.), or she or he downloaded the instrument for completion and then sent the form directly to the primary investigator.

## INSTRUMENTS

All participants completed the following 2 instruments: the PTHSI and the Medical Outcomes Study Short Form 12 (SF-12). Permission was obtained prior to the use of the generic instrument (SF-12; QualityMetric Inc, Lincoln, RI).

### The PTHSI

The PTHSI is a 34-item measure, the content of which was generated from focus groups and semistructured interviews with parents and providers. Most questions are designed according to a 5-point Likert scale, with high scores signifying "better" health status; 4 items required scoring reversal to suit this direction of scoring. The instrument also contains a series of items designed to allow for population characterization. The instrument relies on parent report, given the age of the affected population. The items are divided into 4 domains: (1) physical symptoms of the child, (2) medical visits and costs, (3) caregiver's viewpoint of child's psychologic health status, and (4) parent's perspective of caregiver burden.

The individual items of domain 4, representing caregiver burden are summarized in **Table 1**. The PTHSI has been examined for properties of validity and reliability, which have been reported elsewhere. Principal component analysis supports its design and internal structure. The mean  $\pm$  SD raw scores for the 4 domains are as follows: domain 1, 20.6  $\pm$  5.8; domain 2, 25.0  $\pm$  5.6; domain 3, 8.7  $\pm$  2.7; and domain 4, 48.9  $\pm$  11.9.

### The SF-12

The SF-12 is a validated, generic measure of health status that has been widely used to assess diverse populations and has been

used for the purpose of population cross correlations.<sup>20</sup> The SF-12 contains 12 items that represent 8 broad concepts of mental and physical health. The scoring of the SF-12 consists of 2 scores, a physical component summary (PCS) scale and a mental component summary (MCS) scale. Both of these scales are scored using norm-based methods whereby the mean score for the US population is 50 with a SD of 10. Normative data are available from a number of diverse populations, several of which are published in the SF-12 manual. The results from these populations are presented within this article to represent comparative populations.

### STATISTICAL ANALYSIS

Completed instruments were entered into a Microsoft Access (Microsoft Inc, Redmond, Wash) database, and analysis was performed by linking the database to the SAS 8.1 (SAS Institute Inc, Cary, NC) software package. To gain some measure of understanding of the meaning of the scores for the PTHSI with reference to the caregiver's burden and caregiver's health status, cross correlations between the PTHSI (with particular focus on domain 4) and SF-12 were performed.  $P \leq .05$  was considered significant.

### RESULTS

Overall, 154 families completed the instrument. Missing data were handled by assigning "0" values as missed entry values. Overall, there was less than a 0.001% incidence of missing data points. The population characteristics for the respondents and their children are delineated in the tabulation below.

Characteristic	No. (%) (N = 154)
Respondents who are the mother of the child	136 (88)
Boys	89 (59)
Girls	65 (41)
Underwent tracheotomy at age <2 y	128 (83)
Had the tracheotomy tube for <2 y	94 (60)
Major comorbid medical problems*	109 (70)
No major comorbid medical problems	45 (30)

\*Comorbid problems are defined as other major cardiopulmonary, craniofacial, or neurological pathologic conditions.

Of the children with a major comorbid pathologic condition, 40% had neurological illness and 35% had cardiopulmonary issues significant enough to necessitate the tracheotomy. Other comorbid pathologic conditions included significant gastrointestinal tract complications (10%) and pediatric neoplasms (15%).

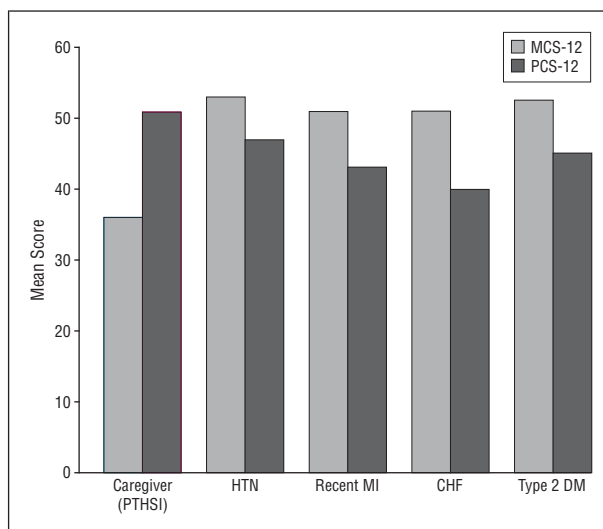
Individual raw domain scores from the PTHSI were calculated, where low values connote a relative "low" HR-QOL and higher values an improved HR-QOL. These scores and their distributions are reported in **Table 2**. Caregiver burden (domain 4) was significantly correlated with parental perceptions of the child's physical health (domain 1) ( $0.32; P < .001$ ) as well as increasing economic costs associated with this care ( $0.27; P < .001$ ). When the degree of caregiver burden was dichotomized by whether parents thought that their children had other major medical problems, the resulting differences in the mean domain 4 scores were significant ( $P = .004$ ). Caregiver burden (domain 4) bore a significant correlation with the costs associated with care ( $r = 0.41; P = .008$ ). The economic costs in turn correlate significantly with the child's overall severity of illness ( $r = 0.45; P = .003$ ).

**Table 2. Scoring Results for the Individual Domains of the PTHSI**

Domain*	Items, No.	Score, Mean $\pm$ SD	Quartile Score				
			0	25	50	75	100
1	7	22.7 $\pm$ 5.3	7	20	24	27	33
2	7	24.9 $\pm$ 6.2	7	21	25	30	35
3	3	10.5 $\pm$ 4.4	3	7	10	14	18
4	17	48.3 $\pm$ 9.5	26	41	49	55	72

Abbreviation: PTHSI, Pediatric Tracheotomy Health Status Instrument.

\*For each domain there were 154 respondents. Domain 1, physical symptoms of the child; domain 2, medical visits and cost; domain 3, parental rating of the child's psychological health status; domain 4, parental rating of their own caregiver burden.



Scoring comparison for the Mental (MCS-12) and Physical Component (PCS-12) score for adults completing the Medical Outcomes Study Short Form 12. The 4 populations represent (1) adults who are caregivers for children with tracheotomy tubes and who have also completed the Pediatric Tracheotomy Health Status Instrument (PTHSI), (2) adults with hypertension (HTN), (3) adults experiencing a recent myocardial infarction (MI), (4) adults with congestive heart failure (CHF), and (5) adults with type 2 diabetes mellitus (DM). The SD for the mean score for the caregivers is 11.4 (MCS-12) and 11.3 (PCS-12); the SDs for the other populations are not given, since the results are reported according to a normalized scoring system in which 50.0 represents the US population mean with an SD of 10.

The mean  $\pm$  SD PCS-12 and MCS-12 scores for the population who completed the PTHSI were  $50.5 \pm 11.3$  and  $35.8 \pm 11.4$ , respectively. Neither PCS nor MCS scores varied by the presence of comorbidity (ie, with and without other major medical problems [PCS:  $t = -1.3, P = .20$ ; MCS:  $t = -2.75, P = .007$ ]). While caregiver burden (PTHSI, domain 4) was significantly correlated with MCS-12 ( $r = 0.4, P = .047$ ), the relationship between caregiver burden and physical well-being, as measured by PCS-12, was not ( $r = -0.17; P = .14$ ).

The mean scores for the MCS-12 and PCS-12 were then compared with the normative data for the US population, based on normative mean  $\pm$  SD scores of  $50 \pm 10$  (**Figure**). Those families members who completed the PTHSI demonstrated scores on the PCS-12 that were within 1 SD of the normative data and were comparable with scores described for adults with a range of other disease processes. The scores for the MCS-12, however, were

greater than 1 SD below the normative data (ie, a mean MCS-12 score of 35.8 compared with a population mean of 50) and markedly decreased from those scores described for adults with a range of other disease processes.

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### COMMENT

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The PTHSI, a caregiver-administered instrument, is designed to measure the parent's perception of his or her role as caregiver, including assessments of the child's health and well-being, the economic impact of the child's illness, and the impact of the illness on the caregiver. As one might hypothesize, parental caregiver burden appears to increase with the child's increasing severity of illness and the economic costs associated with caring for these children. Moreover, caregiver burden is strongly associated with parental emotional well-being (as measured by the MCS-12). These caregivers report significantly lower emotional functioning compared with normative data—a pattern of scoring that does not vary by the child's clinical illness severity and/or comorbidity. Interestingly, physical well-being is not related to caregiver burden, which bears further evaluation. One potential explanation is that the SF-12, in its construct of physical functioning, does not adequately capture the physical impact of the caregiving role. Alternatively, the comparison with other groups of adults with chronic diseases may be flawed, since the caregiving role per se, although demanding, may not be physically debilitating—especially given the young age of the children and the likely age of their parents. These issues need to be addressed in further studies to probe deeper into the particular roles played by caregivers, with their incumbent physical and mental demands.

One potential limitation of this study is its cross-sectional design, from which conclusions about change in health status or burden cannot be drawn. Further, this study cannot address the impact of discrete moments of time when events such as worsening medical condition, a change in life (eg, entry into school or day care), or a change in family status influence the health status of child and caregiver alike. In particular, how does the eventual removal of the tracheotomy tube and decannulation affect the health status of the child and caregiver? Does the health status then return to more closely reflect normative data? Finally, how is a child's health status affected by being cared for by a caregiver who is experiencing significant caregiver burden? Exploration of these questions may shed light on certain time points when the health status of the child and caregiver deteriorates owing to causes that are not related primarily to the child's medical condition, which may be helped by the development and implementation of intervention programs to enhance a caregiver's coping strategies and to maintain family stability.

Another potential weakness of this study is the use of the Internet as a means of instrument administration. There are data that support such a mode in instrument administration. One of the initial studies comparing the use of computer-administered health status instruments to standard paper-generated health status instru-

ments used the Medical Outcomes Study (SF-36), which had been previously validated and widely administered, for which normative scoring patterns had been established. To assess the ability of the SF-36 to perform when administered electronically, Bell and Kahn<sup>21</sup> evaluated the responses of 4876 individuals who anonymously completed the SF-36 via the Internet. Information collected focused on the time to complete the instrument and the overall reliability of the results. Bell and Kahn found that 66.7% of respondents completed the instrument within 5 minutes and that 90% were able to do so by 10 minutes. There existed little difficulty with interpreting missing data, since there was a 99.28% completion rate of all the items. The Cronbach  $\alpha$  values for the scoring scales ranged from .76 to .90, and these results matched the performance of the SF-36 when administered by paper. The conclusion drawn was that computer administration of health status instruments was an efficient and reliable means of collecting data from health status instruments.

The PTHSI is offered on a Web site designed for and primarily visited by dedicated parents seeking information regarding their child. Although the risk is low, given this population, there exists at least a theoretical risk that families will reply more than once and skew the data or that a family without a child who had undergone tracheotomy completes and sends the completed instrument. There is the possibility that parents who interact and glean information from an interactive Web site regarding pediatric tracheotomy may represent a biased sample in that they may be more educated and more concerned than a cross-sectional sampling of parents with children requiring tracheotomies. Nevertheless, initial pilot data as presented previously suggest that there is no statistical difference between paper- and Internet-based instrument application. We are currently conducting a longitudinal study in which we will be directly analyzing the effect of administering a questionnaire on standard paper to a cohort of parents with children at defined institutions as opposed to the Internet. It is hoped that this study allows for adequate population characterization to lend support to the methodology of Internet application.

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### CONCLUSIONS

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There is a significant impact on the caregiver following placement of a tracheotomy tube in a child. Caregiver burden is significantly affected by the child's severity of illness as well as by the increasing economic costs associated with this care. Caregiver burden appears to correlate with the "mental" aspects of a parents' own health status as reflected by the MCS-12. The caregiver's mental health status appears to be more affected than physical health status, although further studies with more specific functional activity scales are needed to better understand these relationships. Longitudinal application of the PTHSI and further cross correlations are needed to further characterize this population. By understanding the factors that influence this population, we hope to develop interventional strategies to provide rehabilitative strategies to aid the children and their caregivers.

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