Parents' experiences managing their child's complicated postoperative recovery

Mary Purcella, Julie Longardb, Jill Chorneya,c,d, Paul Honga,c,∗

a Division of Otolaryngology-Head and Neck Surgery, Department of Surgery, Dalhousie University, Halifax, Nova Scotia, Canada
b Department of Psychology and Neuroscience, Dalhousie University, Halifax, Nova Scotia, Canada
c IWK Health Centre, Halifax, Nova Scotia, Canada
d Department of Anesthesia, Pain Management and Perioperative Medicine, Dalhousie University, Halifax, Nova Scotia, Canada

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ABSTRACT

Objective: Tonsillectomy is commonly performed as same-day surgery and parents are heavily relied upon for management of children's postoperative recovery. The objective of this study was to provide an in-depth description of the experiences parents face when managing their child's complicated postoperative recoveries at home.

Methods: An exploratory qualitative study at an academic pediatric hospital in Eastern Canada was performed. Participants included 12 parents of children aged 3–6 years who underwent adenoid/tonsillectomy and experienced unexpected outcomes or complications during the postoperative recovery period. Participants participated in semi-structured interviews within 6 months of their child's surgery. Interviews were transcribed verbatim and thematic analysis was used to identify themes in the parents' experiences.

Results: Parents described struggling to make the decision to come back to hospital, that adequate information does not prevent emotional difficulties, and feeling somewhat responsible for the unexpected outcome or complicated course of recovery. Communication with healthcare providers was considered very important in helping with the recovery process.

Conclusion: This research helps to inform healthcare professionals about how they might better support families during complicated recovery processes. Areas of action may include clear communication, setting expectations, and psychosocial support.

1. Introduction

Pediatric adenotonsillectomy is commonly performed as a day-surgery procedure because studies have shown the possibility of improved postoperative recovery, reduced risk of hospital-borne infection, and better cost-effectiveness when children recover at home [1–4]. However, early transition to the home environment places the majority of postoperative responsibilities on parents.

Caring for children by parents at home can present unique challenges after medical encounters. Studies have documented both physical and emotional stressors for parents when managing care for their children post-surgery/hospitalization. For instance, mothers reported feeling unsure about their ability to manage pain and symptoms, knowing how to balance activity and safety, and which symptoms to report to healthcare providers following their child's hospitalization [5]. Parents of children who underwent invasive spinal surgery reported key stresses including fear and distress about treatment, difficulty seeing their child in pain and frustration that they could not take away the pain, and frequent feelings of uncertainty and responsibility [6]. Parents have also reported heightened levels of worry, anxiety, guilt, and fear; at the same time parents acknowledge lacking the psychosocial strategies to alleviate these negative emotions [7].

Most research to date on parents' experiences caring for their children postoperatively have been in situations in which the recovery went smoothly [5,6,8–10]. Managing postoperative care at home may become even more challenging for parents if their child experiences a complication or unexpected outcome. Previous research focusing on suboptimal medical outcomes has largely been conducted with adult patients [11–13]. In pediatrics, parents act as decision makers and caregivers, and therefore it is important to focus on parents' experiences of managing their child's complex postoperative recovery, so healthcare providers can better understand and attend to unique patient/parent needs.

The aim of this study was to provide an in-depth description of
parent's experiences of managing their child's postoperative recovery when complications or unexpected events occur. Understanding the parental experience in this context may support the development of more effective family-informed interventions to aid future practice.

2. Methods

2.1. Study design

This exploratory qualitative study used a semi-structured interview guide (Appendix) to examine parents’ experiences of managing their child’s complicated postoperative recovery at home. The use of qualitative research provides an opportunity for an in-depth understanding of stakeholder perspectives about the research question and using them to directly guide the development of recommendations and interventions.

Ethical approval was obtained (IWK Health Centre).

2.2. Participants

Participants included 12 parents of typically-developing children aged 3–6 years who underwent tonsillectomy with or without adenoidectomy at a pediatric hospital in Eastern Canada. All children were discharged from the hospital on the day of surgery and subsequently experienced an unexpected outcome or complication during the recovery process requiring direct assessment by a healthcare provider. The semi-structured interviews occurred within 6 months from the surgery date.

2.3. Sample size

The 12 interviews provided a thorough description of parents’ experiences of managing their child’s recovery at home and provided a diverse range of postoperative complications. Data analysis was initiated after several interviews and interviews were conducted until data saturation was reached when no novel themes or insights emerged from subsequent interview transcripts.

2.4. Procedure

Parents were informed of the study via posters displayed in the pediatric otolaryngology clinic, or via a recruitment letter. Interested parents were contacted by a member of the research team (M.P. or J.L.) and screened to ensure that they met the inclusion criteria (i.e., they experienced a complication or an unexpected event during the recovery period at home). After obtaining consent, eligible participants were interviewed using a semi-structured interview guide, which lasted approximately 60 min. The interviews were conducted by two researchers (M.P. or J.L.) who had no previous connection to the families.

2.5. Data analysis

Interviews were transcribed verbatim and interpreted using thematic analysis methodology [14]. The primary coder (M.P.) used NVivo version 11 for Macintosh (Victoria, Australia) to inductively code the transcripts line-by-line and assemble codes into themes and subthemes as they emerged from the data. The lead interviewer (J.L.) also reviewed the three randomly selected transcripts using codes identified by the primary coder to ensure researcher bias was minimized. The transcripts were found to be fully represented by the pre-existing codes and the emergent themes reflected the transcripts on review by the lead interviewer. Several meetings with all authors were held to refine categorization of the themes. All authors agreed that the themes represented the parental experiences described.

Table 1

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex of parent</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10 (83.3%)</td>
</tr>
<tr>
<td>Male</td>
<td>2 (16.7%)</td>
</tr>
<tr>
<td>Sex of child</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (66.7%)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (33.3%)</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Two parents at home</td>
<td>9 (75%)</td>
</tr>
<tr>
<td>One parent at home</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>Maternal age in years</td>
<td>M = 38.5, SD = 5.5</td>
</tr>
<tr>
<td>Paternal age in years</td>
<td>M = 38.5, SD = 5.5</td>
</tr>
<tr>
<td>Child age at surgery in years</td>
<td>M = 4.8, SD = 1.1</td>
</tr>
<tr>
<td>Child surgery</td>
<td></td>
</tr>
<tr>
<td>Adenotonsillectomy</td>
<td>11 (91.7%)</td>
</tr>
<tr>
<td>Tonsillectomy</td>
<td>1 (8.3%)</td>
</tr>
</tbody>
</table>

M, mean; SD, standard deviation.

3. Results

None of the 12 children had significant medical problems or had undergone major previous surgeries (three children had tympanostomy tubes placed in the past). All parent participants were fluent in English. Demographic information is summarized in Table 1.

Overall, three key themes emerged from parent interviews: 1) struggling to make the decision to come back to hospital, 2) adequate information does not prevent emotional difficulties, and 3) some parents felt responsible for the complicated recovery. These themes will be discussed in detail below.

Unexpected events that complicated the normal postoperative recovery process are described in Table 2. All participants sought medical attention for these events, which were diverse with varying levels of medical acuity. Some children had a complication that was strictly related to the surgical procedure (e.g., postoperative hemorrhage), while others experienced events unrelated to the surgery (e.g., upper respiratory infection).

3.1. Theme 1: struggling to make the decision to come back to hospital

Many parents thoroughly described various challenges that made it difficult to decide if they should bring their child back to hospital for reassessment. Some parents described communication with healthcare providers as being important in this process.

3.1.1. Subtheme: communication with healthcare providers affected decision-making

Nine parents called the otolaryngology clinic nurse or resident for advice about their child’s symptoms; the three parents who did not contact the clinic or resident had children with postoperative hemorrhage and sought healthcare attention without calling for advice. The

Table 2

<table>
<thead>
<tr>
<th>Description of events complicating postoperative recovery.</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Event description</td>
<td>Bleeding (n = 4), dehydration and poor pain management (n = 2), vomiting (n = 2), fever (n = 1), respiratory infection (n = 3)</td>
</tr>
<tr>
<td>Postoperative day brought to hospital</td>
<td>M = 3.75, SD = 2.0</td>
</tr>
<tr>
<td>Was hospitalization required?</td>
<td>Yes 8 (66.7%)</td>
</tr>
<tr>
<td></td>
<td>No 4 (33.3%)</td>
</tr>
<tr>
<td>Number of days in hospital</td>
<td>M = 1.3, SD = 1.2</td>
</tr>
</tbody>
</table>

M, mean; SD, standard deviation.
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