

1 **Hospital Discharge for Children with Medical Complexity and Adverse Events**

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8 **Short title:** Adverse Events and the Child with Medical Complexity

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11 Phoenix Children’s Hospital as a nurse.

12
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14
15 **Abbreviations:** Case Mix Index (CMI); Child(ren) with Medical Complexity (CMC); Children and
16 Youth with Special Health Care Needs (CYSHCN); Care Transition Measurement Tool - 15 (CTM-
17 15); Institutional Review Board (IRB); legally authorized representative (LAR); Length of Stay
18 (LOS)

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20 **Article Summary**

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23 **What is Known on This Subject**

24 There is limited data on identifying and understanding adverse events related to hospital
25 discharge transition for children with medical complexity. The last large landmark retrospective
26 study to investigate adult post-discharge adverse event prevalence occurred in 2003.
27 Retrospective chart studies do not capture any uncharted data.

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29 **What This Study Adds**

30 This study adds to the emerging data on challenges faced by families who have a child with
31 medical complexity. This interactive study is unique in how it identifies and addresses issues
32 before, during, and after discharge using measurement tools, interview questions, and chart
33 reviews. Implications could translate into potential cost savings, focus areas for adverse event
34 reduction, and prevent harm.

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45 **Contributors' Statement Page**

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85 **Abstract**

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87 **Objective**

88 To understand and prevent adverse discharge events, the project assesses the needs and gaps
89 of discharge care coordination for child(ren) with medical complexities (CMC). The National
90 Survey of Children’s Health show 87.4% of CMC does not receive care in a well-functioning
91 system, and 47.4% did not receive adequate care coordination ¹. Therefore, does initiating
92 measurement tools and communication before and after discharge identify and prevent
93 discharge related adverse events?
94

95 **Methods**

96 After IRB approval, a mixed-methods approach project occurred at southwestern pediatric free-
97 standing hospital. Through eight weeks of convenience sampling, CMC caregivers were
98 recruited in the inpatient setting (n=5). Qualitative and quantitative data were obtained
99 through: [Pediatric] Care Transitions Measurement Tool – 15 (CTM- 15), with a Cronbach’s
100 alpha of .93²; a demographics survey; a post-discharge survey; and electronic health records.
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102 **Results**

103 The CTM-15 post-discharge score was 83.3 ($N = 4$, $SD = 9.83$, $SE_M = 4.92$). CTM-15 qualitative
104 data included: communication issues; rushed discharge; poor discharge anticipatory guidance;
105 hospital policy concerns; follow-up appointment issues; and prescription errors. LOS average
106 for all participants was 137.8 days ($SD = 102.75$, $SE_M = 45.95$) and 40 hospital days were
107 unintended ($SD = 41.55$, $SE_M = 18.51$). Issues encountered 30 days post-discharge included:
108 prescription errors, follow-up issues, and home health issues.
109

110 **Conclusion**

111 Hospitalized CMC have an increased risk to encounter a discharge adverse event
112 because of a complex intertwining of disciplines, services, medications, and needs.
113 Communication, tools, and surveys did not capture all the problems encountered by families
114 with CMC; however, it did identify areas of notable concern.
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Main Body of Manuscript

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Introduction

Hospitalized children and families look forward to hearing the words “ready for discharge.” However, the transition from hospital to home for children with medical complexity (CMC) can be a tumultuous time full of errors, miscommunication, delays, and uncertainty. A mixed-methods approach project aims to understand and prevent adverse discharge events by assessing the needs and gaps of discharge care coordination for CMC.

CMC is a subset of children and youth with special health care needs (CYSHCN) that are medically fragile children or youth with chronic conditions that interfere with activities of daily living requiring multiple health resources and services³⁻⁶. Although estimations on population vary, there is a consensus across literature that the CMC population is increasing. Despite the rise in the population, aspects of pediatric medical care lag, including quality care coordination throughout the discharge transition.

Malfunctioning healthcare systems and poor care coordination can lead to adverse hospital discharge events. The National Survey of Children’s Health statistics show that 87.4% of caregivers with a CMC expressed their child does not receive care in a well-functioning system, and 47.4% thought they did not receive adequate care coordination¹. In other words, almost 9 million CMC struggled to obtain care in a well-functioning system, and 3.7 million CMC had suboptimal care coordination.

A pediatric hospital in the Southwestern United States has performed over 130 tracheotomies since 2019. Their airway unit has an average Case Mix Index (CMI) of 2.57 of 5.6 with an average length of stay (LOS) of 12 days⁷. The CMI and LOS can vary for children with new tracheostomies, but their LOS is notably longer. Caregivers and healthcare providers have raised safety and efficiency concerns regarding the discharge transition period. Therefore, does initiating measurement tools and communication before and after discharge identify and prevent discharge related adverse events?

Methods

Framework

The projects’ theoretical framework is the Chronic Care Model developed by Ed Wagner⁸. The IOWA Model Revised provides the implementation framework⁹.

Setting

A free-standing 430-bed pediatric hospital in the Southwestern United States with a 24-bed airway unit is the project setting.

Population

The identified population of CMC for this project is pediatric patients less than 18 years old with a new tracheostomy who had a legally authorized representative (LAR) with English proficiency. Other inclusion criteria for the participants includes: an inpatient bed on the airway unit, one or more pieces of durable medical equipment, and greater than one medical diagnosis. These inclusion criteria help narrow the population to pediatric patients with complexities.

Recruitment

The project lead recruited participants through convenience sampling on the airway unit for eight weeks with the help of the unit’s tracheostomy educator. The lead approached the prospective participant’s LAR to introduce and provide information about the project. The LAR

171 had 24 hours to contemplate participation in the project. The 24-hour timeframe respects the
172 family's autonomy and decision-making during a vulnerable time. However, if the LAR
173 expressed interest sooner, they could participate.

174 **Design**

175 After Institutional Review Board (IRB) expedited review approval, a mixed-methods
176 approach project recruited caregivers with children with new tracheostomies through
177 convenience sampling in the inpatient setting to gain insight into the problems surrounding
178 discharge for CMC. The [Pediatric] Care Transitions Measurement Tool – 15 (CTM- 15), with a
179 Cronbach's alpha of .93, gathered pre- and post-discharge hospital transition data using a Likert
180 scale ². A demographics survey, a post-discharge survey, and chart reviews also collected
181 quantitative and qualitative data to identify possible correlations or specific issues not
182 addressed by the CTM-15.

183 The post-discharge survey created for the project was composed of seven questions: (1)
184 Was your transition from hospital to your home smooth?; (2) Do you have any concerns right
185 now?; (3) Do you have all the equipment, medication, formula, etc. you need?; (4) Have you
186 had any problems with your equipment, medication, formula, etc.?; (5) Do you feel safe to care
187 for your child?; (6) Do you anticipate you will need additional help or resources before your
188 child's next follow-up appointment?; and (7) Do you think the number of days at the hospital
189 could have been reduced?.

190 The project lead met the caregiver while inpatient greater than one week before
191 discharge to administer the demographics survey and CTM-15 to gather baseline data. After 24
192 – 72 hours post-discharge, a phone interview collected data for the CTM-15, followed by the
193 post-discharge surveys. When actionable items arose, the lead contacted the corresponding
194 person related to the issue to provide clarity or resolution for the family.

195 **Results**

196 **Demographics**

197 Five LARs with children with new tracheostomies were identified to participate in the
198 project. The LARs were primarily Hispanic or Latina single mothers with a high school degree or
199 some college. The children were male, mainly Hispanic or Latino, and predominantly less than
200 two years old. Each child had more than two medical conditions requiring care from several
201 specialties. The average number of specialties involved in each child's care is 10 ($SD = 2.92$, SE_M
202 $= 1.30$). Each child had two or more pieces of durable medical equipment at discharge.

203 **CTM-15 & Post-discharge survey**

204 The average pre-discharge score for CTM-15 was 32.4 and post-discharge score
205 increased to 83.3 ($N = 4$, $SD = 9.83$, $SE_M = 4.92$). Verbally administering the CTM-15 after
206 discharge provided additional qualitative data. The LAR expressed concerns or questions after
207 providing the Likert scale answer.

208 Qualitative data gathered through the CTM-15 included: communication issues between
209 families and providers; rushed discharge process; lack of anticipatory guidance after discharge;
210 concerns about hospital policy; follow-up appointment issues; and prescription errors. The
211 post-discharge questions revealed parental worries, errors, communication issues, and follow-
212 up concerns. Of note, two participants had medication prescription errors. One error was found
213 at discharge and was corrected; however, the other medication error was found after discharge
214 during the post-discharge survey questions.

215 **Electronic health records**

216 Average LOS for all participants was 137.8 days ($SD = 102.75$, $SE_M = 45.95$). After
217 reviewing the electronic health records, prolonged stays averaged an additional 40 days ($SD =$
218 41.55 , $SE_M = 18.51$). Additional LOS increased because incomplete tracheostomy education and
219 home health services or supplies were unavailable. Two of the five participants had prolonged
220 LOS because of preventable hospital-acquired conditions. The average of three participants
221 who received a CMI score was 9.78 ($SD = 4.27$, $SE_M = 2.14$). Two participants' CMI scores were
222 unable to be calculated by the end of the project. Issues encountered at or up to 30 days post-
223 discharge included: two formula prescription errors, four follow-up concerns, and one home
224 health service issue.

225 **Discussion**

226 Although the project has a small sample size, each participant encountered issues
227 before and 30 days after discharge. All but one patient had unintended extended LOS.
228 Influencing factors that could contribute to extended LOS include the COVID-19 pandemic. The
229 pandemic led to alterations in medical staffing, higher rates of professionals leaving the field of
230 medicine, and increased the turnover rate across many hospitals. The pandemic has also
231 altered home healthcare services availability, access to medical supplies, shortages of medical
232 equipment, and other resources.

233 The airway unit is noted to have a high turnover rate with an increased rate of traveling
234 nurses during the project's implementation in the fall of 2021. The loss of core nursing staff can
235 alter the family's education for tracheostomies, lead to inconsistent continuity of care, and loss
236 of knowledge on hospital policies and procedures. Considering the reduction in core nursing
237 staff, it can contribute to some of the quantitative discharge delay findings of prolonged
238 education of tracheostomies and oversights found 30-days post-discharge. However, it cannot
239 account for all the delays, the extent of delays, or errors.

240 Every extra day a child stays in the hospital, their risk of acquiring preventable hospital-
241 acquired conditions (HACs) increases. Many of these acquired conditions extend LOS and
242 increase the risk of mortality. The project's population is at increased risk of encountering HACs
243 because of complex disease processes, multiple medications, frequent encounters with the
244 hospital, and multiple pieces of durable medical equipment. The project identified two
245 medication errors and two preventable HACs. The average cost of adverse drug events incurred
246 is \$5,746¹⁰. Ventilator-acquired pneumonia incurred a cost average of \$19,325-\$80,013¹⁰. One
247 child could have avoided the intensive care unit and a HAC if there had been improved
248 communication among disciplines. The other child could have avoided a HAC if home health
249 resources had been available. Therefore, improved communication and care coordination had
250 the potential to avoid additional LOS, associated problems with longer LOS, and financial
251 burden.

252 The CTM-15 captured some qualitative data before administering the post-discharge
253 questions, but the post-discharge questions allowed for further elaboration beyond the specific
254 questions of the CTM-15. Despite providing insightful information, the measurement tool did
255 not produce data of statistical significance the small sample size. Not all of the barriers and gaps
256 in the discharge transition were identified using the CTM-15 or post discharge survey. The 30-
257 day chart reviews helped discover additional problems that verbal communication and the
258 CTM-15 did not capture.

259 **Limitations**

260 This study has several limitations: small sample size; limiting inclusion and exclusion
261 criteria; participants were predominantly male with a mother; limited project timeframe; and
262 pandemic-related issues. One participant did not complete the post-discharge survey and CTM-
263 15 the inability to reach the participant after discharge. The limitations of the study affect its
264 generalizability to all children with medical complexities. A larger sample size could be obtained
265 with a longer allotted timeframe, more than one unit involvement, and additional LARs fluent in
266 other languages to improve results and the overall impact for this patient population.

267 There was also variation in the project's administration of the surveys of pre-discharge
268 and post-discharge. Pre-discharge surveys were conducted on paper and self-reported, whereas
269 the post-discharge survey was administered verbally over the phone. The oral administration of
270 the surveys and tools allowed more for conversation between the LAR and the project lead,
271 leading to additional qualitative data findings. The qualitative data gathered supported their
272 Likert scale rating on the CTM-15 or their YES/ NO answer from the post-discharge survey.

273 **Sustainability**

274 This project lays the initial foundation for a 2-year pilot. This study will designate a nurse
275 practitioner and clinical navigator to engage with families who have CMC in the inpatient
276 setting to oversee medical management and care coordination to improve outcomes and
277 decrease adverse events. Similar programs with patients who have oncological diagnoses or
278 who have undergone solid organ transplant have shown success when patients are followed
279 from the inpatient to the outpatient.

280 **Conclusion**

281 Hospitalized CMC have an increased risk of encountering an adverse event in the
282 discharge transition because of a complex intertwining of disciplines, medical services,
283 medications, and healthcare needs. Communication, discharge tools, and surveys did not
284 capture all the problems encountered by families with CMC; however, it did identify areas of
285 notable concern.

286 In addition, although the project has a small sample size, several actionable care coordination
287 items are identified to improve the patient care for CMC. First, increased communication before and
288 after discharge could prevent adverse events and decrease LOS. Second, a thorough review of
289 prescriptions before discharge could prevent medication and formula errors. Third, improving or
290 standardizing tracheostomy education could reduce LOS. Addressing each actionable care coordination
291 item can reduce overall LOS improving resource use, cost savings, and patient safety.

292 **Implications & Recommendations**

293 The small sample size does not capture the prevalence of discharge transition issues for
294 CMC; therefore, rates could be higher than anticipated. Continued investigation into gaps and
295 barriers will provide an understanding of associated adverse events. Further studies with longer
296 timeframes are needed to verify the prevalence of adverse events and identify trends.

297 One solution to the problem could be a designated point of contact for these families
298 for the in-between stage "after discharge/ before first follow-up". A designated point of contact
299 might improve communication and reduce adverse events for this population. However, further
300 studies are needed to evaluate the benefits.

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