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Importance and feasibility of transitional care for children with medical complexity: results of a multi-stakeholder Delphi process

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Abstract

Background—Children with medical complexity (CMC) account for disproportionate hospital utilization and adverse outcomes following discharge, and several gaps exist regarding the quality of hospital-to-home transitional care for this population. We conducted an expert elicitation process to identify important and feasible hospital-to-home transitional care interventions for CMC from the perspectives of parents and healthcare professionals.

Methods—We conducted a two-round electronic Delphi process to identify important and feasible transitional care interventions. Panelists included parents of CMC and multidisciplinary

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healthcare professionals. In the first round, panelists rated the importance and feasibility of 39 transitional care interventions on a 9-point Likert scale; agreement between panelists was defined according to RAND/UCLA Appropriateness Methods. The second round of data collection evaluated 16 interventions that panelists did not agree on in the first round and 8 new or revised interventions, accompanied by quantitative and qualitative data summaries.

Results—A total of 29 parents of CMC and 37 healthcare professionals participated in the Delphi process (response rate 75%). Both stakeholder panels endorsed the majority of interventions as important; healthcare professionals were less likely to rate several interventions as feasible compared with the parent panel. Over two rounds of data collection, the two stakeholder panels endorsed 25 interventions as both important and feasible. These interventions related to family engagement during the hospitalization, care coordination and social support assessment, pre-discharge education, and written materials.

Conclusions—Parents and healthcare professionals considered several transitional care interventions both important and feasible. This research may inform hospitals' transitional care programs and policies.

Keywords

transitions; hospital discharge; pediatrics; children with medical complexity

Introduction

The importance and significance of hospital-to-home transitions following hospitalization have been the focus of considerable research and healthcare policy.^{1–5} Ineffective transitions of care are associated with adverse events in up to one fifth of patients, including medication errors, communication failures, and procedure-related injuries.^{3,6} Recognizing the central role that patients and their families play in hospital-to-home transitions, the importance of patient and family engagement in transitional care has been emphasized at a national level.^{1,7}

Although the majority of research about hospital-to-home transitions has been conducted in adult populations, pediatric-focused work has characterized several gaps in care coordination and communication that occur at the time of hospital discharge.^{8–14} Among adults, a number of studies have demonstrated how transitions of care can be improved with interventions such as transitional care needs assessments, transitional care coaching, and direct communication between hospital-based and primary care physicians.^{15–18} Similar studies in pediatric populations are warranted, and multi-stakeholder engagement to prioritize pediatric-specific transitional care interventions is an important precursor to this work.

Children with medical complexity (CMC), defined as those with chronic medical conditions coupled with severe functional limitations and significant healthcare needs, comprise a pediatric population at particular risk of difficult transitions and adverse experiences following hospital discharge.^{19–22} This population accounts for 10% of hospital admissions, 25% of pediatric hospital days, one third of hospital charges, and greater than 60% of readmissions following hospital discharge.^{22,23} Because many CMC experience multiple

hospitalizations and transitions, their parents have unique and valuable perspectives about how to optimize transitional care.

Similarly, healthcare professionals who provide care for CMC in inpatient and outpatient settings can provide important guidance regarding pediatric-specific transitional care interventions. Therefore, we conducted an expert elicitation process using established Delphi methods to identify important and feasible transitional care interventions for CMC from the perspectives of their parents and healthcare professionals.

Methods

Study overview

We implemented a two-round electronic Delphi process with two groups of panelists in the fall of 2015 to prioritize transitional care interventions for CMC (Figure 1). The first panel included parents of CMC who received care at four hospitals (one freestanding children's hospital, one general hospital, and two children's hospitals nested within larger hospitals). The second panel included a diverse group of healthcare professionals who provided care for CMC at these hospitals. We used an electronic Delphi process because it allowed participants to submit responses anonymously and independently without being biased by other participants' identities and responses, to respond at a time that was convenient for them, and to revise their responses based on feedback about how their responses compared with others.^{24–26} The Tufts Medical Center Institutional Review Board provided study approval.

Participants

For purposes of this study, complex chronic medical conditions were defined according to the Pediatric Medical Complexity Algorithm consensus definition for medical complexity (examples include muscular dystrophy, cystic fibrosis, and leukemia).²⁷ Eligibility criteria for participation in the parent panel included: (i) parent of a child with a complex chronic medical condition; (ii) age ≥ 18 years of age; (iii) English-language proficiency; (iv) access to the internet and an email account; and (v) hospitalization of their child in the previous year.

Parent participants were recruited with a goal of representing children with diverse types of complex chronic conditions who received care in different types of hospital systems. Similarly, we aimed to represent healthcare professional participants with diverse professional roles working in different healthcare systems. Consistent with Delphi processes, both parent and healthcare professional panelists were recruited based on nominations; we sought nominations of healthcare providers as well as parents from inpatient- and outpatient-based physicians and nurses via email requests to division leaders, hospitals' listservs/email distribution systems, and via Massachusetts Family Voices, a community-based listserv that includes parents and other advocates for children and youth with special healthcare needs.^{28,29} Previous research suggests that panel sizes of 10 to 40 participants are feasible to engage in Delphi processes; we aimed to recruit two panels of 40 participants each to allow

for comparison of responses between the groups, and to allow for attrition between the two rounds of data collection.^{25,30}

Data collection

Panelists were requested to participate in two rounds of data collection. In the first round, panelists rated the importance and feasibility of 39 transitional care interventions, developed based on a review of the literature and semi-structured interviews with parents of CMC and healthcare professionals.¹⁰ The list of interventions included items related to family engagement to identify hospitalization goals, interdisciplinary care coordination, pre-discharge teaching and education, written materials, and post-discharge communication and follow-up activities. Prior to survey distribution, cognitive interviews with four parents of CMC and three healthcare professionals, not included in these Delphi panels, were conducted to ensure that the intervention statements and response options were clear and comprehensive.³¹ Minor modifications were made to the Round 1 instrument based on feedback received during the cognitive interviews. The revised survey was then pilot tested with three additional parents of CMC and five healthcare professionals, not included in the final sample, to ensure feasibility of data collection with respect to survey length and utilization of the web-based interface.

The data collection instruments were distributed via a web-based survey platform. Panelists were asked to rate the importance and the feasibility of each intervention on a 9-point Likert scale, with higher ratings indicating greater perceived importance/feasibility, and were encouraged to use the full range of this scale.²⁸ In rating importance, panelists were asked to consider the relative importance of each intervention for CMC and their families as they prepared for discharge home from the hospital. In rating feasibility, panelists were asked to consider how easy or difficult it would be to implement each action/intervention. They were also asked to provide free-text comments to justify their responses. Up to three email reminders over a 6-week period were sent to encourage responses.

Following receipt of all first round data, personalized reports were provided to each panelist illustrating the distribution of responses on the first round for each intervention via histograms, a reminder of their own first-round responses, and a thematic summary of free-text responses and representative quotations providing parents' and healthcare professionals' perspectives regarding the specified intervention. In the second round of data collection, panelists were asked to re-rate the importance and feasibility of interventions in the context of these reports. Second-round items included interventions that were categorized as having uncertain importance or uncertain feasibility by either panel in the first round, and new interventions suggested by panelists in the first round of free-text responses. Up to three email reminders were sent to request completion. To incentivize participation, gift cards were provided to panelists for each round of data collection they completed.

Analysis

Following receipt of responses from both the first and second rounds of data collection, we calculated the following statistics for each panel and overall: (i) median importance and feasibility rating for each intervention, (ii) interpercentile range, a measure of response

dispersion (IPR, defined as the 70th percentile minus the 30th percentile), (iii) interpercentile range central point (IPRCP), the center point of the IPR ($IPRCP = IPR/2$), (iv) asymmetry index (AI), the distance between the IPRCP and the central point of the 9-point Likert scale, ($AI = Abs[5 - IPRCP]$), and (v) interpercentile range adjusted for symmetry (IPRAS, equal to $2.35 + [AI * 1.5]$, developed based on the recognition that when ratings are symmetric, the IPR needed to define disagreement among panelists is smaller than when they are asymmetric). Further details regarding these statistical methods are provided in the RAND/UCLA Appropriateness Manual.²⁸ We used conventional qualitative content analysis to analyze the free-text responses and summarize the emergent themes.³² Two research team members reviewed all free text responses and developed a coding framework; coding was performed by one research team member with coding audits performed by the principal investigator. Thematic summaries and representative quotes from parent and healthcare professional participants were provided with the quantitative data summaries.

On the basis of these calculations we evaluated each intervention to determine its: (i) perceived importance (categorized as important, unimportant, or uncertain importance); (ii) perceived feasibility (categorized as feasible, unfeasible, or uncertain feasibility); and (iii) agreement in responses among the panelists (categorized as agreement or disagreement). Disagreement was defined as an IPR greater than the IPRAS, indicating response dispersion.²⁸ An intervention was considered important or feasible when its median score on the 9-point Likert scale was between 7 and 9 and there was agreement among panelists. An intervention was considered unimportant or unfeasible when the median score was between 1 and 3 with agreement among panelists. An intervention was considered to have uncertain importance or feasibility when the median score was between 4 and 6, or when there was disagreement among panelists, regardless of the median.²⁸ These determinations were made for each panel separately and overall. For items rated in both the first and second rounds of data collection, the second round of responses was used to determine importance and feasibility categorizations. Items were considered important and/or feasible if both stakeholder panels rated them as such.

Results

Participants & response rates

Of the 48 parents of CMC who were nominated to participate, 29 agreed and completed the first round of data collection (60.4% response rate). Of the 40 healthcare providers nominated to participate, 37 agreed and completed the first round (92.5% response rate; combined response rate of 75%). Table 1 illustrates participants' sociodemographic characteristics. The majority of panelists on the parent panel were mothers who had completed high school; most of their CMC were assisted by technology and less than half received home nursing support. Healthcare professional panelists included case managers, family navigators, nurses, nurse practitioners, physicians, and social workers. The majority were female with an average of 16 years of clinical experience. In the second round of data collection, 29 family members and 33 healthcare professionals participated, representing 75.9% and 89.2% of those who completed the first round. There were no significant

differences in the demographic characteristics of participants who completed the first and second rounds of data collection (data not shown).

First round data collection

In the first round of data collection, parent panelists rated 38 interventions as important. The only item they rated as having uncertain importance related to evaluating families' priorities for their child's hospitalization on the first day of his/her hospitalization. The healthcare professional panel also rated 38 interventions as important; the only item rated as having uncertain importance by this panel was the intervention to discharge CMC by noon on their day of discharge.

In rating feasibility of interventions, the parent panel rated 33 interventions as feasible and 6 as having uncertain feasibility. Healthcare provider panelists rated 22 items as feasible, 14 as uncertain feasibility, and three as unfeasible. Areas of discrepancy between the two panels included seven items related to resource availability for counseling and care for CMC in their homes, three items regarding discharge timing and the timing of follow-up appointments, two items regarding education for non-English proficient families in their native languages, and one item related to the timing of identifying families priorities for their child's hospitalization. While healthcare professions were uncertain about the feasibility of these interventions, parents considered them to be feasible.

In aggregate, 21 transitional care interventions were rated as both important and feasible by both stakeholder panels in the first round. These interventions related to: (i) family engagement to identify hospitalization goals; (ii) interdisciplinary care coordination and social supports; (iii) teaching and verbal communication focused on hospital-to-home transitions; and (iv) written materials provided before hospital discharge.

Second round data collection

The second round of data collection contained 24 items, including 16 interventions rated by parents or healthcare professionals as having uncertain importance and/or feasibility in the first round, 2 revised items, and 6 new items based on feedback from respondents in the first round. Panelists were asked to rate the importance of 9 items (the 8 new or revised items and 1 item that was rated on the first round as having uncertain importance) and feasibility for all 24 items.

In this round, parent panelists categorized 8 of 9 items as important, and 13 of 24 items as feasible. Healthcare providers categorized 8 of 9 items as important, and 8 of 24 items as feasible. A total of 6 items were rated as both important and feasible by both stakeholder panels. These 6 interventions included 3 items from the first round for which there had been uncertain feasibility among the healthcare professional panel, re-rated as feasible in the second round: (i) teaching about post-discharge care in the family's native language, (ii), assessment of how the child's feeding plan/schedule aligns with the family's routine, and (iii) troubleshooting potential problems about home medical equipment and supplies. Three additional interventions were rated as both important and feasible by both panels in the second round: (i) social work consults for all children with CMC during their hospital stay, (ii) written materials for families providing contact names and phone numbers for post-

discharge questions about medications, supplies, and equipment, and (iii) formal assessment of and response to families' greatest worries about their transitions prior to hospital discharge.

In total, 23 interventions were categorized as both important and feasible by both stakeholder panels, while 18 interventions were rated as important but not feasible. These are summarized in Table 2, with numeric data provided in Supplementary Table 1. Most often, parents considered items to be feasible while healthcare professionals did not; several of these items related to in-hospital resources to prepare for discharge, and one related to post-discharge telephone calls to families. The two items considered feasible by healthcare providers and of uncertain feasibility by the family panelists included phone calls to primary care providers to discuss discharge plans, and consideration of families' priorities for their child in treatment and discharge planning. Several interventions considered important by both stakeholder panels were not rated as feasible by either group (Supplementary Table 1).

Discussion

In this study, we engaged diverse stakeholders from four structurally diverse hospitals to prioritize transitional care interventions for CMC. We found high levels of agreement between parents and healthcare providers regarding the importance of a variety of interventions ranging from social work consultation for all hospitalized CMC to formal assessments of families' discharge readiness. Although healthcare professionals rated fewer of the transitional care interventions as feasible, several interventions were endorsed as important and feasible by both parents and healthcare professionals, including efforts to optimize care coordination, written materials, discharge education, and family engagement to identify hospitalization goals.

Stakeholder engagement has been shown to improve research quality and transparency, and to enhance the relevance of interventions to patients and communities.^{26,33} Although Delphi methods are well suited to multi-stakeholder engagement, patients and families are infrequent participants in Delphi processes.^{24,25} Multi-stakeholder engagement to prioritize transitional care programs and interventions for CMC and their families may be particularly relevant, both because transition processes span care settings and involve patients, families and many healthcare professionals, and because prior qualitative studies suggest that transitional care needs and priorities for CMC differ from those identified in adult populations.

To our knowledge, this work represents the first study to evaluate parents' and healthcare professionals' perspectives about the importance and feasibility of hospital-to-home transitional care interventions. However, several of the interventions endorsed in this research are consistent with past research focused on optimizing healthcare outcomes for CMC. For example, ensuring discharge readiness prior to hospital discharge and follow-up phone calls following discharge were prioritized by an expert panel as potential mechanisms to reduce hospitalizations for CMC.³⁴ Parental endorsement of discharge readiness has also been associated with decreased hospital readmission risk.¹³ Unmet needs for respite care have been identified in a national sample of children with special healthcare needs as well as

among CMC cared for in structured complex care programs;^{35,36} discussing options for respite care with parents prior to hospital discharge may address this unmet healthcare need.

A recent systematic review of the effectiveness of hospital-to-home transitional care to improve health outcomes and reduce resource utilization identified several promising interventions, but all of the studies of hospital-to-home transitions were conducted in adult populations.³⁷ Interventions associated with improved outcomes in these studies included tailored discharge education, formal assessments of patients' needs prior to hospital discharge, development of individualized transition records, and post-discharge telephone calls or home visits.^{15,18,37,38} Given the effectiveness of these interventions, the results of the present Delphi process may be used to inform the development of analogous pediatric-specific transitions tools. For example, interventions related to family engagement (Table 2) could be operationalized in a pediatric-specific transitions needs assessment, while the written materials could be included in individualized transition records. Tools such as these may be bundled with additional interventions endorsed in our research, including social work consults for all hospitalized CMC, and evaluations of transportation needs, informed by hospital- and population-specific resource availability and existing gaps. A pilot report from a recent multisite collaborative to improve hospital-to-home transitions for children found that use of a transition readiness checklist, pre-discharge teach-back education, timely and complete written handoff to the primary care provider, and a post-discharge phone call were associated with improved caregiver knowledge following hospital discharge, providing early evidence of effectiveness of these interventions.³⁹

Our results should be interpreted in light of this study's strengths and limitations. First, the feasibility of these interventions may be hospital- and system-dependent, although we tried to mitigate this limitation by including panelists from four structurally diverse hospitals. Second, consistent with Delphi methods, parent participants were nominated to participate in this study based on their perceived expertise and were not purposefully sampled for sociodemographic diversity. The majority of our parent panel reported white race and completion of some college education; while these characteristics are representative of the general population of Massachusetts,⁴⁰ our results may not be generalizable to all families with CMC and may under-represent families with concurrent social complexity, which is increasingly recognized as a risk factor for hospitalization and hospital readmission.⁴¹ Similarly, our exclusion of non-English speaking parents may have resulted in the exclusion of interventions that are particularly relevant to these families. Of note, both panels endorsed the importance of providing written materials to non-English speaking families in their native language but rated this as having uncertain feasibility, suggesting a need for resource investment in this area. Third, despite encouraging panelists to use the full range of the Likert scale and our representation of diverse stakeholders, we observed ceiling effects with little variation in panelists ratings about the importance of interventions. This may make it difficult to prioritize interventions based on importance ratings, but does provide a large number of interventions that hospitals can select from when developing transitional care programs for CMC. For example, hospitals could use our list of interventions as the basis for a needs assessment, and implement interventions that would address their needs and align with their available resources. The strengths of this work include the diversity of special health care needs reflected in our population, as well as the diversity of healthcare

professionals and care settings represented. We applied robust methods to engage multiple stakeholders, using a process that allowed participants to submit their responses anonymously and independently without being biased by other participants' identities.^{24–26} Our demonstration of the feasibility of this method may inform future stakeholder-engaged research in other pediatric and non-pediatric disciplines.

Conclusion

We engaged diverse stakeholders in transitional care for CMC, including their parents, inpatient- and outpatient-based physicians and nurses, as well as social workers and family navigators, to identify important and feasible transitional care interventions for this population of children. These results can inform hospitals' efforts to improve transitional care for CMC, and may increase the relevance and quality of future transitional care research.^{26,33}

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

AI	asymmetry index
CMC	children with medical complexity
IRP	interpercentile range
IPRAS	interpercentile range adjusted for symmetry
IPRCP	interpercentile range central point

References

1. Snow V, Beck D, Budnitz T, et al. Transitions of Care Consensus policy statement: American College of Physicians, Society of General Internal Medicine, Society of Hospital Medicine, American Geriatrics Society, American College Of Emergency Physicians, and Society for Academic Emergency M. J Hosp Med. 2009; 4(6):364–370. [PubMed: 19479781]
2. [Accessed July 10, 2017] Centers for Medicare and Medicaid Services Readmissions Reductions Program. Available at: <https://www.cms.gov/medicare/medicare-fee-for-servicepayment/acuteinpatientpps/readmissions-reduction-program.html>
3. Kripalani S, Jackson AT, Schnipper JL, Coleman Ea. Promoting effective transitions of care at hospital discharge: A review of key issues for hospitalists. J Hosp Med. 2007; 2(5):314–323. [PubMed: 17935242]
4. Robert Wood Johnson Foundation. Health Policy Brief: Improving Care Transitions. Health Aff. 2012 Sep.:1–6.

5. Coleman EA, Mahoney EPC. Assessing the quality of preparation for post hospital care from the patient's perspective: the care transitions measure. *Med Care*. 2005; 433:246–255.
6. Kripalani S, Lefevre F, Phillips CO, Williams MV, Baker DW. Deficits in Communication and Information Transfer Between Hospital-Based and Primary Care Physicians. *JAMA*. 2007; 297(8): 831–841. [PubMed: 17327525]
7. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press; 2001.
8. Solan LG, Beck AF, Brunswick SA, Sauers HS. The Family Perspective on Hospital to Home Transitions : A Qualitative Study. *Pediatrics*. 2015; 136(6):e1539–e1549. [PubMed: 26620060]
9. Desai AD, Durkin LK, Jacob-files EA, Mangione-smith R. Caregiver Perceptions of Hospital to Home Transitions According to Medical Complexity : A Qualitative Study. *Acad Pediatr*. 2016; 16(2):136–144. [PubMed: 26703883]
10. Leyenaar J, O'Brien E, Leslie L, Lindenauer P, Mangione-Smith R. Families' priorities regarding hospital-to-home transitions for children with medical complexity. *Pediatrics*. 2016
11. Coghlin DT, Leyenaar JK, Shen M, et al. Pediatric discharge content: a multisite assessment of physician preferences and experiences. *Hosp Pediatr*. 2014; 4(1):9–15. [PubMed: 24435595]
12. Harlan GA, Nkoy FL, Srivastava R, et al. Improving transitions of care at hospital discharge—implications for pediatric hospitalists and primary care providers. *J Healthc Qual*. 2010; 32(5):51–60. 2010;32(5)51–60.
13. Berry JG, Ziniel SI, Freeman L, et al. Hospital readmission and parent perceptions of their child's hospital discharge. *Int J Qual Heal Care*. 2013; 25(5):573–581.
14. Leyenaar JK, Desai AD, Burkhart Q, Parast L, Roth CP. Quality Measures to Assess Care Transitions for Hospitalized Children. *Pediatrics*. 2016; 138(2):1–9.
15. Jack BW, Chetty VK, Anthony D, Greenwald JL, Sanchez GM. A Reengineered Hospital Discharge Program to Decrease Rehospitalization: a randomized trial. *Ann Intern Med*. 2009; 150:178–187. [PubMed: 19189907]
16. Coleman, Ea, Parry, C., Chalmers, S., Min, S. The Care Transitions Intervention. *Arch Intern Med*. 2006; 166(17):1822–1828. [PubMed: 17000937]
17. Koehler BE, Richter KM, Youngblood L, et al. Reduction of 30-day postdischarge hospital readmission or emergency department (ED) visit rates in high-risk elderly medical patients through delivery of a targeted care bundle. *J Hosp Med*. 2009; 4(4):211–218. [PubMed: 19388074]
18. Balaban RB, Weissman JS, Samuel PA, Woolhandler S. Redefining and redesigning hospital discharge to enhance patient care: A randomized controlled study. *J Gen Intern Med*. 2008; 23(8): 1228–1233. [PubMed: 18452048]
19. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011; 127(3):529–538. [PubMed: 21339266]
20. Simon T, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics*. 2010; 126(4):1–10. [PubMed: 20566603]
21. Walsh KE, Roblin DW, Weingart SN, et al. Medication errors in the home: a multisite study of children with cancer. *Pediatrics*. 2013; 131(5):e1405–14. [PubMed: 23629608]
22. Berry JG, Hall DE, Kuo DZ, Hall M, Kueser J, Kaplan W. Hospital Utilization and Characteristics of Patients Experiencing Recurrent Readmissions Within Children's Hospitals. *JAMA*. 2011; 305(7):682–690. [PubMed: 21325184]
23. Leyenaar JK, Ralston SL, Shieh M, Pekow PS, Mangione-Smith R, Lindenauer PK. Epidemiology of Pediatric Hospitalizations at General Hospitals and Freestanding Children's Hospitals in the United States. *J Hosp Med*. 2016; 0(0):1–7.
24. Boulkedid R, Abdoul H, Loustau M, Sibony O, Alverti C. Using and reporting the Delphi method for selecting healthcare quality indicators: a systematic review. *PLoS One*. 2011; 6(6):e20476. [PubMed: 21694759]
25. Sinha IP, Smyth RL, Williamson PR. Using the Delphi technique to determine which outcomes to measure in clinical trials: recommendations for the future based on a systematic review of existing studies. *PLoS Med*. 2011; 8(1):e1000393. [PubMed: 21283604]
26. Khodyakov D, Savitsky TD, Dalal S. Collaborative learning framework for online stakeholder engagement. *Heal Expect*. 2015; 19:868–882.

27. Simon TD, Cawthon ML, Stanford S, et al. Pediatric medical complexity algorithm: a new method to stratify children by medical complexity. *Pediatrics*. 2014; 133(6):e1647–54. [PubMed: 24819580]
28. Fitch K, Bernstein SJ, Mcdonnell J, Kahan JP. The RAND / UCLA Appropriateness Method User'S Manual. 2000
29. Hasson F, S K, H M. Research guidelines for the Delphi survey technique. *J Adv Nurs*. 2000; 32(4):1008–1015. [PubMed: 11095242]
30. Khodyakov D, Hempel S, Rubenstein L, et al. Conducting Online Expert panels : a feasibility and experimental replicability study. *BMC Med Res Methodol*. 2011; 11(1):174. [PubMed: 22196011]
31. Collins D. Pretesting survey instruments : An overview of cognitive methods. *Qual life Res*. 2003; 12:229–238. [PubMed: 12769135]
32. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005; 15(9):1277–1288. [PubMed: 16204405]
33. Concannon, TW PhD, Fuster, M., et al. A Systematic Review of Stakeholder Engagement in Comparative Effectiveness and Patient-Centered Outcomes Research. *J Gen Intern Med*. 2014; 29(12):1692–1701. [PubMed: 24893581]
34. Collier RJ, Nelson BB, Klitzner TS, et al. Strategies to Reduce Hospitalizations of Children With Medical Complexity Through Complex Care : Expert Perspectives. *Acad Pediatr*. 2017; 17(4): 381–388. [PubMed: 28108374]
35. Kuo DZ, Berry JG, Glader L, Morin MJ, Johaningsmeir S, Gordon J. Health Services and Health Care Needs Fulfilled by Structured Clinical Programs for Children with Medical Complexity. *J Pediatr*. 2016; 169:291–296.e1. [PubMed: 26526361]
36. Nageswaran S. Respite Care for Children With Special Health Care Needs. *Arch Pediatr Adolesc Med*. 2009; 163(1):49–54. [PubMed: 19124703]
37. Desai AD, Popalisky J, Simon TD, Mangione-Smith RM. The effectiveness of family-centered transition processes from hospital settings to home: a review of the literature. *Hosp Pediatr*. 2015; 5(4):219–231. [PubMed: 25832977]
38. Naylor M, Brooten D, Jones R, Lavizzo-Mourey R, Mezey M, Pauly M. Comprehensive discharge planning for the hospitalized elderly. A randomized clinical trial. *Ann Intern Med*. 1994; 120(12): 999–1006. [PubMed: 8185149]
39. Mallory LA, Osorio N, Prato BS, et al. Project IMPACT Pilot Report : Feasibility of Implementing a Hospital-to-Home Transition Bundle. *Pediatrics*. 2017; 139(3):e20154626. [PubMed: 28202769]
40. US Census Bureau. [Accessed May 28, 2017] American Community Survey. Available at: <https://www.census.gov/programs-surveys/acs/>
41. Sills MR, Hall M, Cutler GJ, et al. Adding Social Determinant Data Changes Children's Hospitals' Readmissions Performance. *J Pediatr*. 2017; 186:150–157.e1. [PubMed: 28476461]

What's new

This study used an expert elicitation process to identify important and feasible transitional care interventions for children with medical complexity from the perspectives of parents and multidisciplinary healthcare professionals, providing a family-centered evidence-base to focus improvements in pediatric transitional care.

Figure 1.
Overview of study design.

Table 1

Characteristics of panelists

Family panelists (n=29)	n %
<u>Characteristic of child</u>	
Child gender (female)	12 (41)
Child age, yrs (median [IQR])	6 [3–14]
Technology assistance	23 (79)
Receive home nursing care	12 (41)
<u>Characteristics of panelists</u>	
Relationship to child:	
Mother	25 (86)
Father	3 (10)
Other legal guardian	1 (3)
Parent age, yrs (median, [IQR])	38 [36–45]
Parent race: *	
White	19 (65)
Asian	4 (14)
Hispanic	3 (10)
Black	1 (3)
Education:	
High school completion	3 (10)
Some college education (4 years)	17 (59)
Graduate education	9 (31)
Healthcare professional panelists (n=37)	
Professional role:	
Physician	15 (41)
Nurse/nurse case manager	13 (35)
Nurse practitioner	4 (11)
Social worker	3 (8)
Family navigator	2 (5)
Gender (female)	31 (84)
Age, yrs (median [IQR])	44 [35–54]
Race:	
White	30 (81)
Asian	3 (8)

Family panelists (n=29)	n %
Black	2 (5)
Hispanic	1 (3)
Years in practice (median [IQR])	16 [10–27]
Primary work setting:	
Inpatient	18 (49)
Hospital-based outpatient	15 (41)
Community-based outpatient	4 (11)

* Missing for 2 respondents in parent group and 1 respondent in healthcare professional group

Table 2

Transitional care interventions rated as important by both parents and healthcare professionals, stratified by feasibility ratings.

Interventions rated important & feasible by parents and healthcare professionals	Interventions rated important but not feasible by parents and healthcare professionals
Family engagement	
Healthcare team identifies family's priorities for the hospitalization and develops list of family's goals for their child *	Follow-up appointments booked at times that work for the family
Healthcare team discusses family's post-discharge goals for their child regarding activities and social engagement	Attending physician speaks directly with family before discharge
Healthcare team assesses how child's feeding plan/schedule aligns with family's routine	Healthcare team has team meeting with family in preparation for hospital discharge
	Healthcare team considers families' priorities (ie. activities) in discharge recommendations
	Families' post-discharge priorities documented in medical record
Interdisciplinary care coordination & social supports	
Medications, equipment and supplies, home nursing services, and outpatient therapies (ie. physical therapy) arranged before discharge **	Healthcare team calls families at home 1–3 days after discharge
All children receive a social work consult during their hospital stay	Families reporting that they are not ready for discharge can stay in the hospital so that the healthcare team can help with any issues or problems they have
Healthcare team facilitates discussion with family about available social supports	Healthcare team contacts the child's primary care provider prior to discharge
Healthcare team formally assesses family's readiness for discharge	Healthcare team offers to contact social supports to provide information about the hospital stay
	Healthcare team talks to the child's school about the child's discharge recommendations
	Healthcare team discusses financial concerns with family prior to discharge
	Healthcare team discusses options for respite care with family prior to discharge
Teaching and verbal communication focused on hospital-to-home transition	
Teach-back about pain and symptom management provided before hospital discharge	
Specific guidance about returning to school and other activities provided before hospital discharge	
Potential post-discharge problems and contingency planning discussed before hospital discharge	
Healthcare team asks about and helps to solve problems with setting up equipment and supplies at home (when applicable)	
Healthcare team asks about families' greatest worries regarding hospital-to-home transition and discusses potential approaches/solutions	
Teaching about child's post-discharge care provided in families' native language	
Transportation and discharge planning	
Healthcare team assesses family's transportation needs for hospital discharge	Hospital discharge occurs before noon (12pm)
	Healthcare team considers length of family's commute home in deciding discharge time of day

Interventions rated important & feasible by parents and healthcare professionals	Interventions rated important but not feasible by parents and healthcare professionals
	Healthcare team provides assistance planning a ride home from the hospital if requested
	Healthcare team ask families if they have a ride to follow-up appointments prior to hospital discharge
	The healthcare team provides assistance planning a ride to follow-up appointments if requested
Written materials provided before discharge	
Dates, times, and locations for all follow-up appointments	Specific written instructions in the family's language about how to take care of their child at home
Contact names and number(s) for questions regarding medications, equipment, and supplies	
Hospital contact number for post-discharge problems	
Summary of hospital course written in plain language (without medical jargon)	
Written schedule for medications and treatments that fits with the family's routine	

* panelists endorsed these interventions when the child was improving clinically, not at the time of hospital admission; included as two separate interventions during data collection, both endorsed as important and feasible

** included as four separate interventions during data collection; all endorsed as important and feasible