

UCLA

UCLA Previously Published Works

Title

Priorities and Outcomes for Youth-Adult Transitions in Hospital Care: Perspectives of Inpatient Clinical Leaders at US Children's Hospitals

Permalink

<https://escholarship.org/uc/item/9802j4wp>

Journal

Hospital Pediatrics, 10(9)

ISSN

2154-1663

Authors

Coller, Ryan J
Ahrens, Sarah
Ehlenbach, Mary L
et al.

Publication Date

2020-09-01

DOI

10.1542/hpeds.2020-0016

Peer reviewed

RESEARCH ARTICLE

Priorities and Outcomes for Youth-Adult Transitions in Hospital Care: Perspectives of Inpatient Clinical Leaders at US Children's Hospitals

Ryan J. Coller, MD, MPH,^a Sarah Ahrens, MD,^b Mary L. Ehlenbach, MD,^a Kristin A. Shadman, MD,^a Mala Mathur, MD, MPH,^a Kristin Caldera, DO,^c Paul J. Chung, MD, MS,^{d,e,f,g} Andrew LaRocque, BA,^b Heather Peto, MD, MPH,^{a,b} Kole Binger, BA,^a Windy Smith, RN,^h Ann Sheehy, MD, MS^b

OBJECTIVES: Adults with chronic conditions originating in childhood experience ongoing hospitalizations; however, efforts to guide youth-adult transitions rarely address transitioning to adult-oriented inpatient care. Our objectives were to identify perceptions of clinical leaders on important and feasible inpatient transition activities and outcomes, including when, how, and for whom inpatient transition processes are needed.

METHODS: Clinical leaders at US children's hospitals were surveyed between January and July 2016. Questionnaires were used to assess 21 inpatient transition activities and 13 outcomes. Perceptions about feasible and important outcome measures and appropriate patients and settings for activities were summarized. Each transition activity was categorized into one of the Six Core Elements (policy, tracking, readiness, planning, transfer, or completion). Associations between perceived transition activity importance or feasibility, hospital characteristics, and transition activity performance were evaluated.

RESULTS: In total, 96 of 195 (49.2%) children's hospital leaders responded. The most important and feasible activities were identifying patients needing or overdue for transition, discussing transition timing with youth and/or families, and informing youth and/or families that future stays would be at an adult facility. Feasibility, but not importance, ratings were associated with current performance of transition activities. Inpatient transition activities were perceived to be important for children with medical and/or social complexity or high hospital use. Emergency department visits and patient experience during transition were top outcome measurement priorities.

CONCLUSIONS: Children's hospital clinical leaders rated inpatient youth-adult transition activities and outcome measures as important and feasible; however, feasibility may ultimately drive implementation. This work should be used to inform initial research and quality improvement priorities, although additional stakeholder perspectives are needed.

ABSTRACT



^aDepartments of Pediatrics, ^bMedicine, and ^cOrthopedics and Rehabilitation, School of Medicine and Public Health, University of Wisconsin-Madison, Madison, Wisconsin; ^dDepartment of Pediatrics, David Geffen School of Medicine and ^eDepartment of Health Policy and Management, Fielding School of Public Health, University of California, Los Angeles, Los Angeles, California; ^fRAND Health Care, RAND Corporation, Santa Monica, California; ^gChildren's Discovery and Innovation Institute, Mattel Children's Hospital, Los Angeles, California; and ^hAmerican Family Children's Hospital, Madison, Wisconsin

www.hospitalpediatrics.org

DOI: <https://doi.org/10.1542/hpeds.2020-0016>

Copyright © 2020 by the American Academy of Pediatrics

Address correspondence to Ryan J. Coller, MD, MPH, Department of Pediatrics, University of Wisconsin-Madison, 600 Highland Ave, Madison, WI 53792. E-mail: rcoller@pediatrics.wisc.edu

HOSPITAL PEDIATRICS (ISSN Numbers: Print, 2154-1663; Online, 2154-1671).

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported in part by the Clinical and Translational Science Awards Program, through the National Institutes of Health National Center for Advancing Translational Sciences, grant UL1TR000427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The project was also supported by the University of Wisconsin-Madison's departments of pediatrics and medicine. Funded by the National Institutes of Health (NIH).

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

Dr Coller conceptualized and designed the study, conducted primary data analysis, and drafted the initial manuscript and revisions; Drs Ahrens, Ehlenbach, and Shadman assisted with project conceptualization and data interpretation and reviewed and revised the manuscript; Drs Mathur, Caldera, and Peto assisted with data interpretation and revised the manuscript; Dr Chung assisted with data analysis and critically reviewed and revised the manuscript; Ms Binger, Ms Smith, and Mr LaRocque assisted with data collection and interpretation of data analyses and reviewed the manuscript; Dr Sheehy assisted with project conceptualization, data collection, and data interpretation and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

Children's hospital discharges for 18- to 21 year-old patients with chronic conditions appear to be increasing at faster rates than discharges for other age groups.¹ The magnitude of this reality is sizable, with spending on adult patients admitted to children's hospitals surpassing \$1 billion per year² and a potentially negative influence on outcomes including length of stay and charges.³⁻⁵ Nevertheless, decisions to admit adults with chronic conditions originating in childhood (CCOCs) to children's or adult-oriented hospitals are complicated. Adult-oriented hospitals may not be equipped to care for adult manifestations of CCOCs,^{6,7} whereas children's hospitals may lack the resources and expertise to provide comprehensive care to adults.¹

To date, youth-adult transition recommendations have been focused largely on ambulatory care, with less guidance for optimizing transitions of future hospital care to adult-oriented inpatient settings.⁸⁻¹² Noting that hospitalizations are a commonly proposed outcome measure of transition work,¹³⁻¹⁵ it is clear hospital care has relevance to youth-adult transition initiatives. Hospitalized adolescents and young adults have demonstrated substantial lack of preparedness to transition to adult-oriented care.¹⁶ The current state of inpatient transition practices at US children's hospitals was recently reported,¹⁷ revealing a relative absence of formal or comprehensive processes to guide a transition to the adult inpatient setting. Because >90% of children with chronic illnesses survive to become adults^{13,18} and many have conditions with increased hospitalization risk in early adulthood, health systems need to determine if, when, and how to facilitate transitions from child-oriented to adult-oriented inpatient care.

In this study, our objective was to identify perspectives of inpatient general pediatric service leaders from US children's hospitals about important and feasible inpatient transition activities and outcomes. Our secondary objective was to describe their perspectives about when, how, and for whom inpatient transition processes are needed. To help guide subsequent hospital

transition research and quality improvement, we also explored whether perceptions of feasibility were associated with current performance of inpatient transition activities.

METHODS

Study Design, Setting, and Participants

We surveyed inpatient general pediatric service leaders from US children's hospitals between January and July of 2016. The detailed survey development and distribution methods have been described previously.¹⁷ Briefly, hospitals were identified by using the online Children's Hospital Association directory. We sought a single respondent from each hospital. To identify the leader of inpatient care with the most knowledge of his or her institution's practices related to the transition to adult inpatient care, we used a structured protocol. This included the following steps: before sending the survey, study team members contacted each hospital's inpatient general pediatric service leaders to describe the purpose of the study, confirm contact information, and when relevant, receive contact information for a designee having more expertise to receive the survey. We excluded hospitals without inpatient general pediatrics services (eg, rehabilitation or subspecialty-only facilities). The study was approved by the University of Wisconsin-Madison's Institutional Review Board.

Survey Design

A novel survey instrument was developed from consensus-based recommendations of a multidisciplinary team of internal medicine and pediatric physicians, nurses, case managers and social workers, child life specialists, and patient and family advisors at our institution. Together, members of the team had experience working in >10 other health systems. The survey was refined after pilot testing with 5 pediatricians not involved in the study at 3 different institutions. Specific inpatient youth-adult transition activities and potential outcomes of this transition were developed from ideal-state process mapping and creation of a previously published

conceptual framework of determinants for implementing a formal inpatient transition initiative.¹⁷ In total, 21 specific transition activities and 13 inpatient transition outcomes were included. The 21 transition activities were also grouped in categories by using the Six Core Elements framework¹²: policy, tracking and monitoring, readiness, planning, transfer of care, or transfer completion.

TABLE 1 Youth-Adult Transition in Hospital Care Survey Respondent Characteristics From US Children's Hospitals

	Overall n (%)
Respondent role	
Division director	36 (41)
Medical director	22 (25)
Department chair	6 (7)
Delegate	15 (17)
Other	8 (9)
Children's hospital administrative structure	
Freestanding	31 (36)
Hospital within hospital (separate building)	19 (22)
Hospital within hospital (same building)	37 (43)
Medical center	
Community (versus university based)	68 (78)
Urban versus rural	
Urban	76 (88)
Estimated weekly discharges	
<25	20 (23)
25-50	38 (44)
51 or more	28 (33)
Inpatient provider scope	
Inpatient only	61 (71)
Mixed (inpatient and outpatient) only	3 (4)
Combination inpatient and mixed	22 (26)
Providers with adult-oriented training	
Dual training in internal medicine and pediatrics	35 (40)
Family medicine	3 (4)
Specific adult-oriented hospital for transition	
Yes	36 (42)
Ambulatory transition process	
Yes	41 (45)

Respondents rated perceived importance and feasibility of performing each of the 21 transition activities and measuring each of the 13 transition outcomes using 5-point Likert scales (1 = "not at all," 2 = "a little," 3 = "somewhat," 4 = "very," or 5 = "extremely"). Respondents subsequently indicated whether these same activities were performed at their institution at least 50% of the time.

In addition, respondents were asked a series of questions about when, how, and for whom inpatient transition processes should take place. Using 5-point Likert scales, respondents rated the appropriateness of patient characteristics and other contextual triggers to identify the need for inpatient transition activities, as well as the best timing, age, and settings to initiate planning. The survey also contained questions on the respondents' hospital characteristics, including administrative structure (freestanding or hospital within hospital), university-based or community, urban or rural, estimated number of discharges per week, scope of practice (inpatient only, combination inpatient and outpatient), presence or absence of specific hospital to receive adult patients, and whether ambulatory pediatric-adult transition processes existed.

Data Collection

The University of Wisconsin-Madison Survey Center conducted this survey using the Qualtrics Internet-based platform. An invitation with a printed URL to the survey was first sent to potential respondents by US mail. Up to 2 e-mail reminders containing the URL at 5 and 10 days after the initial mailing were then sent. One reminder phone call followed by a mailed paper copy of the survey questionnaire 2 weeks after the last emailed request was sent to nonresponders. Participants received \$20 as an incentive.

Statistical Analysis

Mean importance and feasibility ratings for each of the 21 transition activities were calculated. We also calculated a mean rating for the transition activities grouped by each of the Six Core Elements categories (eg,

TABLE 2 Perceptions of Youth-Adult Transition in Hospital Care Activities at US Children's Hospitals

Core Element	Specific Inpatient Transition Activity	Importance, Mean (SD)	Feasibility, Mean (SD)
Policy	Transition policy that includes the inpatient transition	4.0 (0.8)	3.6 (0.9)
	Tracking and monitoring		
	Proactive identification of patients anticipated to need transition	4.5 (0.7)	3.8 (0.8)
	Proactive identification of patients overdue for inpatient transition	4.5 (0.7)	3.8 (0.8)
Readiness	Formal assessment of transition readiness	4.0 (0.8)	3.4 (0.8)
	Transition timing discussed with youth or family	4.5 (0.7)	3.7 (0.7)
	Transition education provided to family	3.9 (0.9)	3.3 (1.0)
	Communication differences between pediatric and internal medicine providers reviewed with families	4.1 (0.9)	3.4 (0.9)
Planning	Transition care plan created with needs and long-term therapeutic goals created	4.2 (0.7)	3.4 (1.0)
	Transition care plan provided to the patient and/or family	4.3 (0.7)	3.6 (1.0)
	Care conference between pediatric and internal medicine providers	3.6 (1.0)	2.8 (1.1)
	Agreement on inpatient transition timing achieved between primary care and subspecialists	4.2 (0.7)	3.1 (1.0)
	Agreement on inpatient transition timing achieved among subspecialists	4.3 (0.8)	3.1 (1.0)
	Ability for medical decision-making established	3.8 (1.1)	3.4 (0.9)
	Insurance problems addressed	4.2 (0.8)	3.5 (1.0)
	Patient and/or family informed subsequent stays will be at adult inpatient facility	4.5 (0.7)	3.9 (0.8)
	Adult inpatient facility toured	3.3 (1.0)	3.1 (1.1)
	Transfer of care	Standardized handoff communicated between pediatric and internal medicine providers	4.2 (0.7)
Transition checklist used to complete tasks		3.9 (0.8)	3.6 (0.9)
Patient and/or family meet inpatient adult care team		3.5 (1.1)	2.8 (1.1)
Transfer completion	Pediatric provider and patient and/or family interaction during first nonpediatric stay	3.1 (1.1)	3.1 (1.0)
	Child life consult during first nonpediatric stay	2.8 (1.2)	3.0 (1.3)

As part of a larger quality improvement initiative at our institution, a multidisciplinary team developed an ideal-state inpatient transition experience within a children's hospital for adults' CCOCs. To facilitate description, these were categorized by using labels from the Six Core Elements Framework. Ratings were as follows: 1 = not at all, 2 = a little, 3 = somewhat, 4 = very, and 5 = extremely.

policy, tracking and monitoring, etc). After confirming ratings were normally distributed, linear regression was used to identify statistically significant associations

between feasibility ratings and children's hospital characteristics. Next, logistic regression was used to identify associations between current performance (or lack

thereof) of each transition activity and importance or feasibility ratings. Lastly, inpatient transition outcomes were summarized with descriptive statistics, and importance and feasibility ratings were plotted on a 2-by-2 matrix to identify the outcomes perceived to be most important and feasible to measure. We considered the highest-priority outcomes to have both mean ratings above the median of all outcomes and to have the majority (>50%) of respondents rate them very or extremely important and feasible to measure. All analyses were completed in Stata SE version 14.0 (Stata Corp, College Station, TX), and $P < .05$ was considered statistically significant.

RESULTS

In total, 96 of 195 (49.2%) individuals responded (Table 1), with the most common respondent roles including division director (41%) or medical director (25%). Respondents were primarily from university-based centers (78%) in urban settings (88%). Children's hospitals were freestanding (36%) or hospitals within hospitals (same building [43%]; separate building [22%]). Additional respondent and hospital characteristics are described elsewhere.¹⁷

Transition Activity Importance and Feasibility Perceptions

Importance was rated higher than feasibility across the transition activities (Table 2). The most important activities (mean of 4.5 for each) were identifying patients needing or overdue for transition, discussing timing with youth and/or

families, and informing youth and/or families that future stays would be at an adult facility. These same items had the highest feasibility ratings (means of 3.7–3.9).

When grouped by the Six Core Elements categories, the activities within tracking and monitoring had the highest importance (mean 4.5) and feasibility (mean 3.8) ratings (Table 3). Transfer completion activities, which included interactions during the first nonpediatric stay between pediatric providers and youth and/or family as well as child life, had the lowest perceived importance (mean 3.0) and feasibility (mean 3.1).

Hospital Characteristics Associated With Perceived Feasibility

Certain hospital characteristics were associated with transition activity feasibility ratings (Table 4). Having a youth-adult transition policy that includes inpatient care had higher perceived feasibility for respondents from freestanding, university-based, and higher-volume children's hospitals. Tracking and monitoring and transfer of care activities had higher perceived feasibility for respondents from higher-volume children's hospitals. Transfer completion activities had higher perceived feasibility for respondents from hospitals within hospitals and those having a specific hospital to receive adult patients. Of note, however, having an ambulatory youth-adult transition process was not associated with perceptions of feasibility. Readiness and planning activity feasibility ratings were not associated with any hospital characteristics.

Feasibility Perceptions and Transition Activity Performance

Relationships between current transition activity performance and importance or feasibility ratings are shown in Supplemental Figs 1 and 2. Importance ratings were inconsistent and weakly associated with performing any transition activities (Supplemental Fig 2). Higher feasibility ratings, on the other hand, were frequently associated with both performance of activities within that core element and also activities in other core elements (Supplemental Fig 3). For example, whereas higher feasibility ratings for planning were associated with providing a transition care plan to the patient and/or family (a specific planning activity), higher feasibility ratings for planning were also significantly associated with performing activities in each of the other core elements.

Inpatient Transition Activities: When, How, and for Whom

More than 80% of respondents reported that at least some of their patients need this type of transition process (Table 5), with nearly one-third (30%) estimating that most or all need it. Each of the queried patient characteristics (ie, medical or social complexity, past hospital use, or likelihood for future hospital use) was felt to be a very or extremely appropriate signal for the need for inpatient transition process by >75% of respondents. Initiating inpatient transition when general transition planning began was reported as very or extremely appropriate by 81% of respondents.

Inpatient Transition Outcome Measurement

The mean ratings for 5 outcomes were above the median for both importance and feasibility to measure (Fig 1): (1) number of emergency department (ED) visits in early adulthood, (2) ambulatory provider satisfaction with transition, (3) patient and family satisfaction with overall transition, (4) provider confidence in patient and family managing their health and health care, and (5) patient and family confidence managing their health and health care. Among these 5 items, 2 (ED

TABLE 3 Youth-Adult Transition in Hospital Care Importance and Feasibility by the Six Core Elements

Activities Grouped by Core Element	Importance, Mean (SD)	Feasibility, Mean (SD)
Policy	4.0 (0.8)	3.6 (0.9)
Tracking and monitoring	4.5 (0.7)	3.8 (0.8)
Readiness	4.1 (0.7)	3.4 (0.7)
Planning	4.1 (0.5)	3.3 (0.7)
Transfer of care	3.9 (0.7)	3.2 (0.8)
Transfer completion	3.0 (1.0)	3.1 (1.0)

Ratings were as follows: 1 = not at all, 2 = a little, 3 = somewhat, 4 = very, and 5 = extremely. Mean ratings of items grouped within each youth-adult transition core element were calculated by summing the total scores for each 5-point Likert question and dividing by the number of items.

TABLE 4 Associations Between Children's Hospital Characteristics and Perceived Feasibility of Youth-Adult Transition in Hospital Care

	Policy β (95% CI)	Tracking and Monitoring β (95% CI)	Readiness β (95% CI)	Planning β (95% CI)	Transfer of Care β (95% CI)	Transfer Completion β (95% CI)
Children's hospital administrative structure						
Freestanding	Reference	Reference	Reference	Reference	Reference	Reference
Hospital within hospital (separate building)	-.46 (-0.95 to 0.03)	-.43 (-0.87 to 0.02)	.05 (-0.35 to 0.45)	-.47 (-0.58 to 0.25)	-.36 to (-0.83 to 0.10)	.36 (-0.22 to 0.94)
Hospital within hospital (same building)	-.46 (-0.88 to -0.05)*	-.16 (-0.54 to 0.22)	-.10 (-0.44 to 0.23)	.03 (-0.32 to 0.37)	-.18 (-0.56 to 0.20)	.53 (0.05 to 1.01)*
Medical center						
Community (versus university based)	-.46 (-0.91 to -0.01)*	.09 (-0.32 to 0.50)	-.19 (-0.55 to 0.16)	-.10 (-0.46 to 0.27)	.13 (-0.28 to 0.55)	-.29 (-0.81 to 0.24)
Estimated weekly discharges						
<25	Reference	Reference	Reference	Reference	Reference	Reference
25-50	.34 (-0.06 to 0.85)	.01 (-0.41 to 0.44)	-.07 (-0.45 to 0.32)	.11 (-0.29 to 0.51)	.23 (-0.21 to 0.66)	.15 (-0.40 to 0.70)
51 or more	.91 (0.43 to 1.39)*	.46 (0.01 to 0.91)*	-.02 (-0.42 to 0.39)	.11 (-0.32 to 0.53)	.48 (0.03 to 0.94)*	.13 (-0.44 to 0.71)
Inpatient provider scope						
Inpatient only	Reference	Reference	Reference	Reference	Reference	Reference
Mixed (inpatient and outpatient) only	-.05 (-1.08 to 0.98)	-.33 (-1.26 to 0.61)	-.48 (-1.29 to 0.33)	-.45 (-1.28 to 0.38)	-.61 (-1.52 to 0.31)	-.68 (-1.85 to 0.49)
Combination inpatient and mixed	-.26 (-0.70 to 0.17)	-.10 (-0.49 to 0.29)	-.13 (-0.47 to 0.21)	-.31 (-0.66 to 0.03)	-.17 (-0.55 to 0.22)	-.38 (-0.88 to 0.11)
Specific adult-oriented hospital to receive patients						
No	-.10 (-0.49 to 0.29)	.10 (-0.24 to 0.44)	-.13 (-0.43 to 0.16)	-.29 (-0.59 to 0.00)	-.28 (-0.62 to 0.05)	-.44 (-0.86 to -0.03)*
Ambulatory transition process						
No	-.32 (-0.72 to 0.08)	-.13 (-0.50 to 0.23)	-.19 (-0.51 to 0.13)	-.21 (-0.55 to 0.12)	-.23 (-0.61 to 0.16)	-.03 (-0.51 to 0.46)

β corresponds to the average unit difference in feasibility rating between the tested category and the reference. For example, the average feasibility for policy transition activities was 0.46 lower for respondents from a hospital within hospital (same building) than for those from a freestanding children's hospitals.

* $P < .05$.

visits and patient and family satisfaction) were also rated very or extremely important and very or extremely feasible to measure by >50% of respondents (Table 6). More than 50% of respondents also rated inpatient provider satisfaction, number of hospitalizations, and average length of stay per visit as both very or extremely important and very or extremely feasible to measure outcomes of inpatient transition processes.

DISCUSSION

In this national survey, we characterized perceptions of inpatient general pediatric service leaders at US children's hospitals about important and feasible youth-adult transition activities and outcomes relevant to general inpatient care. We sought to inform research and improvement priorities by highlighting activities perceived to be important and feasible. Initial priorities

suggested in this study (to develop systems to proactively identify and communicate with youth and families needing inpatient youth-adult transition processes) parallel those from national youth-adult health care transition guidelines.^{8,12} Inpatient provider opinions that these activities may be most appropriately accomplished during ambulatory care is consistent with research in which authors suggest

TABLE 5 Respondent Perceptions About Needs for Youth-Adult Transition in Hospital Care

	Appropriateness, Mean	%
Relatively how many adolescent patients need an inpatient transition process?		
All	—	11
Most	—	19
Some	—	51
A few	—	17
None	—	1
Patients needing inpatient transition process		
Medical complexity	4.5	95 ^a
Social complexity	4.2	86 ^a
Likelihood for future hospitalization	4.2	83 ^a
High past hospital use	4.1	79 ^a
Triggers to initiate inpatient transition process		
Ambulatory transition begun	4.0	81 ^a
Readiness assessment score	3.7	63 ^a
No. hospitalizations per y	3.4	53 ^a
No. ED visits per y	3.1	33 ^a
Settings to initiate inpatient transition process		
At hospital (during a hospitalization)	3.1	35 ^a
At home (in between visits)	3.6	56 ^a
At clinic (during a visit)	4.3	91 ^a

Appropriateness ratings were as follows: 1 = not at all, 2 = a little, 3 = somewhat, 4 = very, and 5 = extremely.

^a Percent of respondents who considered it very or extremely appropriate.

view these aspects of transition in relatively similar ways. Nevertheless, the success of implementation efforts will likely have strong contextual influences, and understanding unique barriers and facilitators to transition activity performance is important. For example, respondents from lower-volume hospitals did perceive less feasibility for policy, tracking and monitoring, and transfer activities. Implementation initiatives for these activities may require different strategies and resources on the basis of hospital size, structure, and scope.

Current performance of the surveyed transition activities was associated with perceived feasibility; however, the direction of the relationships remains unclear. These activities could be rated feasible because they were already being performed rather than being performed because they were perceived to be feasible. If participants only rated items as feasible when they were already being performed, one might have expected the relationships between feasibility and activity performance to be more limited to the core element being rated. However, importance perceptions were notably weak predictors of transition activity performance. Additional research should be used to clarify and address the barriers to performing transition activities that stakeholders consider to be “important.”

The outcomes of inpatient youth-adult transition rated most important and feasible to measure correspond to trends in the youth-adult transition field. For example, ED visits, hospital use, and patient experience have been relatively common outcomes in transition research and quality improvement.^{13–15,22,23} Provider and patient confidence to manage health and health care (the second and third most important perceived outcomes overall in our study) are reminiscent of the transition field’s focus on readiness and self-management.^{12,24–26} These measures allude to notions of general patient activation, which has been linked to a number of important health outcomes.^{27,28} Understanding how youth-adult transitional

that transfers to adult care are best conducted when the youth’s health is stable (ie, not hospitalized).¹⁹ According to the surveyed stakeholders, ED visits during early adulthood and patient and/or family experience with overall transition may be particularly useful outcomes because the majority considered them important and feasible to measure.

Although broad concepts (eg, assessing readiness) are considered important from both hospital-focused and comprehensive youth-adult transition perspectives,^{9,16} with our research, we extend these concepts by suggesting a set of inpatient-specific activities that could theoretically be incorporated into existing transitional care strategies. For example, assessment of transition readiness may need to cover aspects of inpatient care for youth with high risk for future hospitalization. The Transition Readiness Assessment Questionnaire,^{20,21} a tool commonly used

to assess readiness, has a section on appointment keeping. For high-risk youth, one might conceive of a complementary set of questions that are focused on navigating hospital structures or managing postdischarge questions.

We were surprised to not find more relationships between institutional characteristics and perceptions of feasibility. It was striking that the feasibility of these inpatient transition activities was perceived similarly whether a respondent’s institution had an ambulatory youth-adult transition process. We speculate this is because many existing youth-adult transition processes may not have a connection to inpatient care. Moreover, readiness and planning, the 2 core elements with the largest numbers of transition activities had no associations between perceived feasibility and hospital characteristics. This may imply that hospitals different from each other could

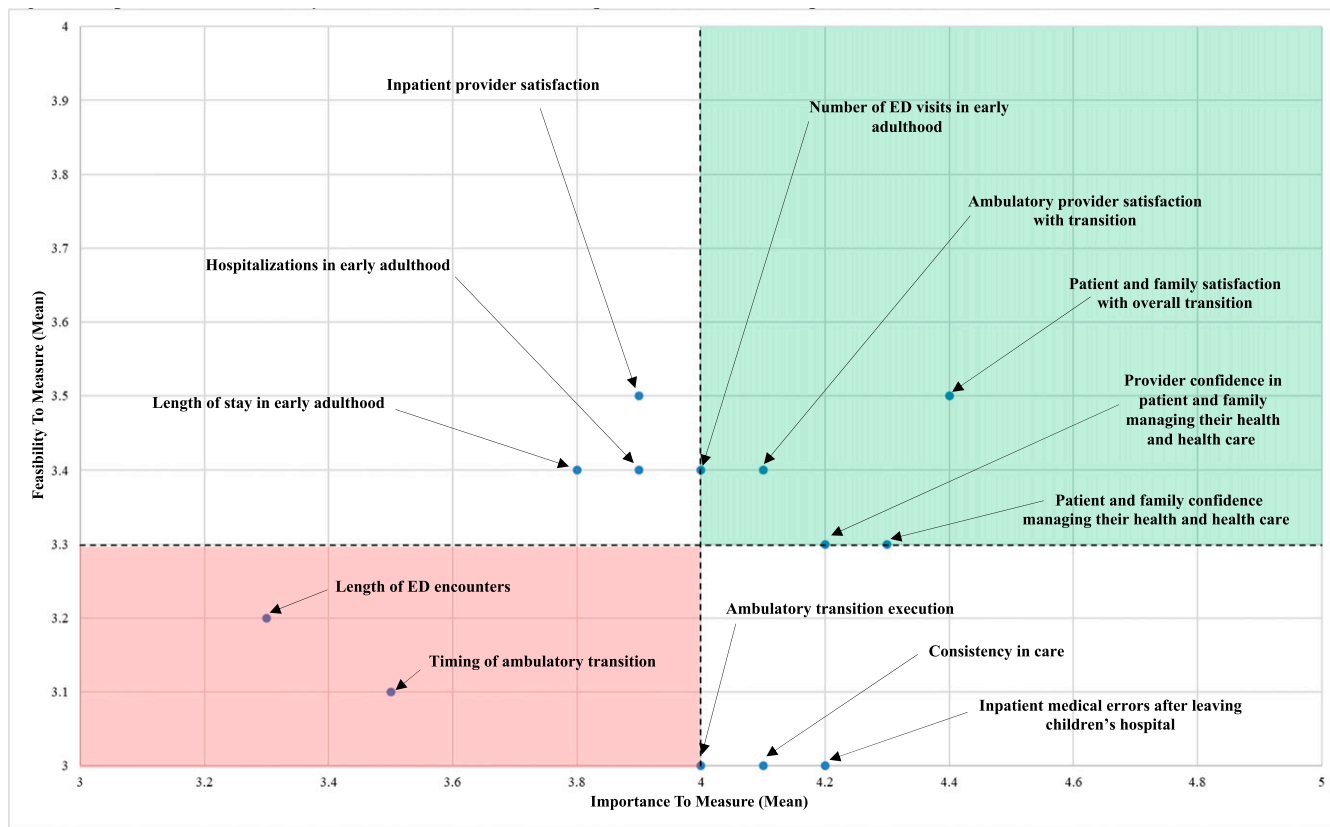


FIGURE 1 Importance and feasibility of outcomes of youth-adult inpatient transition in hospital care. Ratings are as follows: 1 = not at all, 2 = a little, 3 = somewhat, 4 = very, and 5 = extremely. Points represent each rated transition outcome. Dotted lines indicate median ratings for importance and feasibility to measure. Green quadrant represents outcomes with importance and feasibility ratings both above the median, and the red quadrant represents outcomes with importance and feasibility ratings both below median.

care acts as a determinant (or potential intervention point) to increase general activation of CCOC during early adulthood would likely be a valuable focus for subsequent study.

Our study findings need to be interpreted with several limitations in mind. The survey provides inpatient clinical leader perspectives only, and other stakeholders may have different perspectives. The novel survey instrument has unknown reliability and validity, and although it was developed with input from a multidisciplinary adult and pediatric health care team including patients and parents, important transition activities and outcomes may be missing. Although we attempted to systematically identify the best respondent at each institution, it is possible that responses may have differed if another

individual participated from each institution.

Despite these limitations, we anticipate that the relevance of this work will continue to grow as the prevalence of adults with CCOCs continues to increase. We suspect that surveyed inpatient general pediatric service leaders view these specific activities as important because they recognize that acute hospital care is distinct from other health care encounters, often having higher stakes. For example, hospitalization reflects times of crisis and can expose unique clinical, financial, and psychosocial vulnerabilities.

CONCLUSIONS

The results of this study contribute toward a roadmap for future prospective research. To sharpen the focus on inpatient youth-

adult transition care, authors of subsequent studies should collect adult inpatient provider, patient, family caregiver, subspecialist, and ambulatory provider opinions to refine these activities and outcomes. Although inpatient providers felt that only certain patients may benefit from transition planning and that ambulatory clinic is an appropriate setting to conduct these activities, both perspectives require validation with other stakeholders. If ambulatory settings prove to be a viable context to introduce planning and preparation for future adult-oriented hospital care, it will be important to understand how providers with relevant knowledge (hospital-based physicians or nurses) can efficiently collaborate with outpatient providers to achieve this goal. Results of studies in which authors adapt and implement these elements within

TABLE 6 Youth-Adult Transition in Hospital Care Outcome Importance and Feasibility

Outcomes	Importance		Feasibility	
	Rating, Mean	Very or Extremely, %	Rating, Mean	Very or Extremely, %
Patient and family satisfaction with overall transition	4.4	91	3.5	54
Patient and family confidence managing their health and health care	4.3	89	3.3	44
Provider confidence in patient and family managing their health and health care	4.2	83	3.3	41
Inpatient medical errors after leaving children's hospital	4.2	86	3.0	32
Ambulatory provider satisfaction with transition	4.1	80	3.4	44
Consistency in care	4.1	82	3.0	36
ED visits in early adulthood	4.0	78	3.4	59
Ambulatory transition execution	4.0	80	3.0	33
Inpatient provider satisfaction	3.9	70	3.5	54
Hospitalizations in early adulthood	3.9	69	3.4	57
Length of stay in early adulthood	3.8	64	3.4	57
Timing of ambulatory care transition	3.5	48	3.1	33
Length of ED encounter in early adulthood	3.3	45	3.2	47

Ratings were as follows: 1 = not at all, 2 = a little, 3 = somewhat, 4 = very, and 5 = extremely. Consistency was defined as less back and forth across internal medicine and pediatrics services or redundant testing.

existing comprehensive transition programs at children's hospitals would be informative. Researchers of subsequent work should also refine the appropriate populations, triggers, and settings for inpatient youth-adult transition care.

REFERENCES

- Goodman DM, Hall M, Levin A, et al. Adults with chronic health conditions originating in childhood: inpatient experience in children's hospitals. *Pediatrics*. 2011;128(1):5–13
- Goodman DM, Mendez E, Throop C, Ogata ES. Adult survivors of pediatric illness: the impact on pediatric hospitals. *Pediatrics*. 2002;110(3):583–589
- Okumura MJ, Campbell AD, Nasr SZ, Davis MM. Inpatient health care use among adult survivors of chronic childhood illnesses in the United States. *Arch Pediatr Adolesc Med*. 2006;160(10):1054–1060
- Edwards JD, Houtrow AJ, Vasilevskis EE, Dudley RA, Okumura MJ. Multi-institutional profile of adults admitted to pediatric intensive care units. *JAMA Pediatr*. 2013;167(5):436–443
- Kinnear B, O'Toole JK. Care of adults in children's hospitals: acknowledging the aging elephant in the room. *JAMA Pediatr*. 2015;169(12):1081–1082
- Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care: internists' perspectives. *Pediatrics*. 2009;123(2):417–423
- Okumura MJ, Heisler M, Davis MM, Cabana MD, Demonger S, Kerr EA. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med*. 2008;23(10):1621–1627
- Got Transition. Center for health care transition improvement 2016. Available at: <https://gottransition.org/six-core-elements/>. Accessed April 4, 2016
- Cooley WC, Sagerman PJ; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200
- American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6, pt 2):1304–1306
- McPheeters M, Davis AM, Taylor JL, Brown RF, Potter SA, Epstein RA Jr. *Transition Care for Children With Special Health Needs. Technical Brief Number 15*. Rockville, MD: Agency for Healthcare Research and Quality; 2014
- White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home [published correction appears in *Pediatrics*. 2019;143(2):e20183610]. *Pediatrics*. 2018;142(5):e20182587
- Vaks Y, Bensen R, Steidtmann D, et al. Better health, less spending: redesigning the transition from pediatric to adult

- healthcare for youth with chronic illness. *Healthc (Amst)*. 2016;4(1): 57–68
14. Bloom SR, Kuhlthau K, Van Cleave J, Knapp AA, Newacheck P, Perrin JM. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012;51(3):213–219
 15. Fair C, Cuttance J, Sharma N, et al; International and Interdisciplinary Health Care Transition Research Consortium. International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatr*. 2016;170(3):205–211
 16. Dwyer-Matzky K, Blatt A, Asselin BL, Wood DL. Lack of preparedness for pediatric to adult-oriented health care transition in hospitalized adolescents and young adults. *Acad Pediatr*. 2018;18(1):102–110
 17. Coller RJ, Ahrens S, Ehlenbach ML, et al. Transitioning from general pediatric to adult-oriented inpatient care: national survey of US children's hospitals. *J Hosp Med*. 2018;13(1):13–20
 18. Bensen R, Steidtmann D, Vaks Y. *A Triple Aim Approach to Transition from Pediatric to Adult Health Care for Youth with Special Health Care Needs*. Palo Alto, CA: Lucile Packard Foundation for Children's Health; 2014
 19. Klostermann NR, McAlpine L, Wine E, Goodman KJ, Kroeker KI. Assessing the transition intervention needs of young adults with inflammatory bowel diseases. *J Pediatr Gastroenterol Nutr*. 2018;66(2):281–285
 20. Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ–Transition Readiness Assessment Questionnaire. *J Pediatr Psychol*. 2011;36(2):160–171
 21. Wood DL, Sawicki GS, Miller MD, et al. The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity. *Acad Pediatr*. 2014;14(4):415–422
 22. Shepard CL, Doerge EJ, Eickmeyer AB, Kraft KH, Wan J, Stoffel JT. Ambulatory care use among patients with spina bifida: change in care from childhood to adulthood. *J Urol*. 2018;199(4):1050–1055
 23. Farre A, McDonagh JE. Helping health services to meet the needs of young people with chronic conditions: towards a developmental model for transition. *Healthcare (Base)*. 2017;5(4):E77
 24. Lozano P, Houtrow A. Supporting self-management in children and adolescents with complex chronic conditions. *Pediatrics*. 2018;141(suppl 3): S233–S241
 25. Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: a systematic review. *J Pediatr*. 2017;188: 263.15–269.e15
 26. Stinson J, Kohut SA, Spiegel L, et al. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *Int J Adolesc Med Health*. 2014; 26(2):159–174
 27. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2): 207–214
 28. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004;39(4, pt 1): 1005–1026