

Perceptions of Health Care Transition Care Coordination in Patients With Chronic Illness

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abstract

OBJECTIVES: Expert consensus jointly authored in 2011 by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians supports the use of health care transition (HCT) care coordination (CC). Although gaps in care are addressed in these practice-based implementation recommendations, such recommendations have never undergone rigorous assessment. We assessed the effectiveness of implementation on quality of chronic illness care and CC during HCT for adolescents and young adults.

METHODS: Adolescents and young adults with special health care needs were enrolled in a randomized HCT CC intervention. Intervention participants received HCT CC as outlined in the 2011 clinical report. Perceptions of chronic illness care quality and CC were assessed at 0, 6, and 12 months.

RESULTS: Intervention participants had a Patient Assessment of Chronic Illness Care score at 12 months of 3.6 vs 3.3 compared with participants in the control group ($P = .01$). Intervention participants had higher average scores for patient activation (3.7 vs 3.4; $P = .01$), problem solving (3.8 vs 3.4; $P = .02$), and coordination/follow-up (3.0 vs 2.5; $P < .01$). The Client Perceptions of Coordination Questionnaire revealed that intervention participants had 2.5 times increased odds to endorse mostly or always receiving the services they thought they needed and had 2.4 times increased odds to have talked to their provider about future care ($P < .01$).

CONCLUSIONS: Implementing recommended HCT CC practices improved patient or patient caregiver perception of quality of chronic illness care and CC especially among the most complex patients.



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WHAT'S KNOWN ON THIS SUBJECT: An unsuccessful transition from pediatric to adult primary care can have negative effects on health and life outcomes. Care coordination has been shown to be effective in facilitating many care transitions, but not specifically in health care transition.

WHAT THIS STUDY ADDS: With this study, we used randomized methodology to determine the efficacy of health care transition care coordination best practices and their effects on the perception of chronic illness care among a vulnerable sample of adolescents with special health care needs.

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The need for better health care transition (HCT) practices for adolescents and young adults (AYAs) with special health care needs has received well-deserved attention over the past 30 years. AYAs with special health care needs have ≥ 1 chronic physical, developmental, behavioral, or emotional condition and require services beyond those normally required.¹ These individuals may have trouble navigating the health care system and experience adverse health outcomes as a result.² More than 90% of children with special health care needs are living well into adulthood, often requiring specialized support to transfer care from the pediatric to adult health care system.³ However, nationally, less than half (41%) of these children with special health care needs and their caregivers reported receiving recommended HCT guidance.⁴

With the lack of seamless transfer from the pediatric to adult health care system, risk for discontinuity of care, foregone care, and an overall dissatisfaction with the health care system is presented.^{5–7} Similar to other disparities in the US health system, racial and ethnic minority children, as well as those living in poverty, are at a significantly greater risk for discontinuities in care.⁸ Ultimately, unsuccessful HCT is associated with poorer quality of health care, poorer quality of health, and increased morbidity and mortality.³ These potentially avoidable outcomes are costly to the patient and health care system.²

To address the need for practical guidance on implementing HCT programs and practices, in 2002, and again in 2011, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)–American Society of Internal Medicine jointly authored consensus statements. With these statements, the organizations emphasize the importance of

supporting and facilitating the transition of all children, including those with special health care needs, into adult care and outlining specific recommendations.^{9,10} The 2011 AAP–AAFP–ACP clinical report included an algorithm and a corresponding set of materials for practice-based implementation of coordination around transition services. The framework includes 6 core elements used to set a standard for providing high-quality, developmentally appropriate health care services.¹⁰ These elements include a transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer connection.¹⁰

Previous studies have revealed care coordination (CC) in other settings associated with favorable family–provider relations, improved health outcomes, and decreased cost.^{11,12}

In no study have authors yet conducted a rigorous and focused evaluation of implementation of the recommended 6 core elements as a transition service for a population of transition-aged youth with varying special health care needs. To address these gaps in current knowledge, we use this study to evaluate HCT CC effectiveness by measuring patient-level perception of CC and perceived quality of chronic illness care.

METHODS

Study Participants

A convenience sample was recruited from an urban, academic adolescent medicine practice within a pediatric tertiary referral health system between July 2012 and July 2014. This setting is the largest provider of adolescent medicine in the region. Eligible participants were between 16 and 22 years old and insured by a single Medicaid-managed care organization for supplemental security income eligible youth with chronic conditions.¹³ It is expected that, by age 22, patients will transfer

care to an adult provider. To be eligible for Medicaid in the District of Columbia, AYAs have to have a disability and meet financial criteria based on the federal poverty level.¹⁴ Patients with insufficient knowledge of English to participate in the phone interviews were not eligible.

Study Design

This randomized trial was approved by and conducted in compliance with the hospital's institutional review board. Written informed assent and/or consent was obtained from participants aged 16 to 17 years and from their guardian; consent was obtained from participants aged ≥ 18 years and their guardian when appropriate. Participants were interviewed at baseline, 6, and 12 months postenrollment and received compensation for their participation in the study.

At baseline, demographic information was collected and patient perception of quality of chronic illness care and CC was assessed by using the Patient Assessment of Chronic Illness Care (PACIC)¹⁵ and the Client Perceptions of Coordination Questionnaire (CPCQ).¹⁶ If the participant was significantly functionally impaired by their special health care need(s), interviews were conducted with the appropriate caregiver by proxy. The timing and procedures for data collection were the same for intervention and control groups.

Complexity Stratification

After baseline data collection, participants were stratified by age (16–18 years and 19–22 years) to account for differences in participant responses based on proximity to age of transfer. Participants were also stratified into complexity tiers (low, moderate, or high) by using the Care Coordination Assignment Tool, version 1.0, developed by the Health Care Home Initiative.¹⁷ This tool assigns a complexity score taking into account the patient's

diagnoses, presence of chronic or severe conditions, and whether the conditions require a care team. After stratification, participants were assigned to either the control or intervention group by using a predesigned, computerized, stratified randomization scheme designed to balance participants within strata. Half of the participants received enhanced usual care (control group), whereas the other half received the AAP-AAFP-ACP 6 core elements (intervention group) implemented by a dedicated nurse care coordinator.

Description of Intervention

Both the control and intervention groups received enhanced usual care. All participants received a care notebook that included the clinic's transition policy, a blank transition readiness assessment form, a local adult doctor referral list vetted by the study team, and information on insurance, guardianship, and advance directives. At enrollment, all participants were entered into the clinic's HCT transition registry to facilitate tracking and communication.¹⁸ (Supplemental Table 5).

The intervention group received all aspects of enhanced usual care but was also assigned a HCT nurse who coordinated the delivery of specific intervention services. These services included (1) a face-to-face systematic review of the readiness assessment with the participant and/or caregiver, (2) a status assessment of ongoing HCT planning and preparation, and (3) monthly phone calls with the participant and/or caregiver to update and fill gaps in the HCT action plan. Focusing on practice-based and patient-level components of the 2011 AAP-AAFP-ACP 6 core elements allowed transition planning that was individualized for each patient. The HCT nurse care coordinator provided participants in the intervention group with a transition

checklist and action plan, as well as a comprehensive portable medical summary. Close communication with the nurse care coordinator facilitated the identification and solution of problems as issues arose. For intervention participants nearing the required age of HCT (22 years), the nurse care coordinator assisted with the process of selecting an adult primary care practice facilitating contacts and individualized introductions. The transition process included direct communication between the nurse care coordinator and adult medical practice, including the transfer of the most recent readiness assessments, portable medical summary, and if applicable, disease-specific information, such as recommended treatment guidelines for specific conditions. Finally, transition completion included direct communication among the patient, nurse care coordinator, adult provider, and pediatric provider with all parties remaining available as needed until the patient had been seen by and established care with the adult provider. Only participants that met age criteria (age 22 years) transferred their care during the study period.

All intervention materials were adapted directly from publicly available materials from the Maternal and Child Health Bureau-funded National Center for Health Care Transition Improvement.¹⁸

Instruments

Patient assessment of quality of care for chronic conditions was assessed with the PACIC questionnaire.¹⁵ The PACIC is a validated (Cronbach's $\alpha = 0.93$), 20 question, self-report that asks the patient about the past 6 months and assesses 5 domains, including patient activation (ie, "Given choices about treatment to think about"), delivery system design and/or decision support (ie, "Given a written list of things I should do to improve my health"), goal setting

(ie, "Asked to talk about my goals in caring for my condition"), problem solving (ie, "Helped to plan ahead so I could take care of my condition even in hard times"), and follow-up and/or coordination (ie, "Contacted after a visit to see how things were going").¹⁵ A Likert scale is used in the questionnaire, in which patients are asked how frequently, on a scale of 1 to 5 from none to always, over the past 6 months when receiving care for their chronic conditions had they specific interactions and/or discussions with their health care providers. Each subscale is scored by averaging the number of items completed within that scale, and the overall PACIC score is the average of all subscales. Patient and health care team interactions, patient centeredness, and, in particular, aspects of patient self-management support are emphasized by the PACIC questions.

Patient assessment of CC was assessed by using the CPCQ.¹⁶ CC is measured by the CPCQ through the assessment of patient perception of patient-centered care and CC. In this validated questionnaire (Cronbach's $\alpha = 0.92$), 31 questions are used to ask about how often aspects of care were experienced, the participants' perceptions of care, and preferences for care.¹⁶ A Likert scale of 1 to 5, from never to always is used in the CPCQ. Responses were grouped into 2 levels of "Never," "Rarely," and "Sometimes," and "Mostly" and "Always" for analyses.

Statistical Analyses

An intent-to-treat design was used requiring that participants remain in their randomly assigned group for analysis regardless of how much or little of the study intervention the participant received. With the data collected at baseline, 6, and 12 months after enrollment, we assessed HCT CC intervention effectiveness by using repeated measures analysis to compare changes in the 2 groups over time.

TABLE 1 Participant Characteristics at Time of Enrollment

Variable	HCT Intervention, <i>n</i> = 105; <i>N</i> (%)	Control, <i>n</i> = 104; <i>N</i> (%)	<i>P</i> ^a
Age, mean (SD)	18.8 (1.8)	18.8 (1.6)	NS
Age group, y			NS
16–18	54 (51)	54 (52)	
19–22	51 (49)	50 (48)	
Sex			NS
Male	55 (52)	55 (53)	
Female	50 (48)	49 (47)	
Complexity tier			NS
Low	53 (50)	53 (51)	
Medium	28 (27)	27 (26)	
High	24 (23)	24 (23)	

NS, not significant.

^a *t*-test comparisons.

All study variables were assessed for normality and homogeneity. Summary statistics of demographic characteristics were reported and compared by using χ^2 tests to assess whether demographic variables differed between the control and intervention groups. To identify significant differences in mean scores of perspectives on CC (CPCQ questionnaire) and experiences of care (PACIC questionnaire) between intervention and control groups stratified by complexity tier independent *t*-test unadjusted analyses were used. To analyze the total PACIC score and subscale scores, we used a longitudinal linear regression, including random effects for subject and adjusted for baseline levels of each score. To analyze the dichotomous CPCQ data, we used logistic regression controlling for each respective baseline assessment and included an interaction between group and time of assessment. Whenever the interaction term failed to achieve statistical significance it was removed. All tests were assessed on the basis of a 2-tailed .05 significance level, and analyses were performed by using SAS (Version 9.4; SAS Institute, Inc, Cary, NC).

RESULTS

Participant Characteristics

A total of 209 participants were enrolled with a mean age of 19 ± 1.7

years and an almost equal distribution of male and female participants (Table 1). All but 1 participant self-identified as African American. Just less than half ($n = 101$) were 19 to 22 years old with the remainder ($n = 108$) between the ages of 16 and 18 years at the time of study enrollment. Study groups were nearly identically distributed by age and complexity tier. Approximately half (51%; $n = 106$) of participants were diagnosed with learning disabilities and/or attention-deficit/hyperactivity disorder, and well-controlled chronic conditions such as high functioning autism, mild cerebral palsy, or well-controlled anxiety and/or depression were categorized as being low complexity with minimal CC needs. A quarter (26%; $n = 55$) of participants that had moderate CC needs with chronic diagnoses related to prematurity or prenatal or perinatal insults, more severe manifestations of autism spectrum disorders, and other genetic conditions such as Down syndrome, were categorized as medium complexity. Lastly, 23% ($n = 48$) of participants were considered of high complexity with severe intellectual and physical disabilities, many with technologic dependence and most with multiple medical problems relying on others for a majority, if not all, of their self-care and care navigation.

Chronic Illness Care Results

At baseline, there were no significant differences in PACIC domain

scores between the intervention and control group (Table 2). The total PACIC score was higher for intervention participants compared with participants in the control group beginning at 6 months follow-up and remained elevated at 12 months follow-up ($P = .01$). Controlling for any differences at baseline, we observed that intervention participants endorsed higher scores at 6 and 12 months follow-up in the patient activation ($P = .01$), problem solving ($P = .02$), and CC and follow-up ($P < .01$) domains compared with participants in the control group (Table 2).

In stratified analyses by complexity tier, there existed differences at baseline between intervention and control groups (Table 3). Among the highest complexity tier, the total PACIC score was higher in the intervention group 6 and 12 months postenrollment ($P = .01$). At 6 months follow-up, intervention participants in the high complexity tier had higher scores in patient activation ($P = .01$), goal setting ($P = .03$), and CC and follow-up domains ($P < .01$). These trends were not true for the other 2 complexity tiers, and differences were not seen between intervention and control groups (Table 3).

Care Coordination Results

At baseline, there were differences in CPCQ questions when comparing the intervention with the control

TABLE 2 Mean of PACIC Score at Baseline, 6, and 12 Months Postenrollment, Unadjusted and Adjusted for Baseline

	Time	Unadjusted ^a Mean (95% CI)			Adjusted ^b Mean (SE)		
		Intervention, <i>n</i> = 105	Control, <i>n</i> = 104	<i>P</i>	Intervention, <i>n</i> = 105	Control, <i>n</i> = 104	<i>P</i> ^c
Total score	Baseline	3.1 (2.9–3.3)	3.0 (2.8–3.2)	.27			
	6 mo	3.4 (3.2–3.6)	3.0 (2.8–3.3)	.02	3.4 (0.09)	3.1 (0.09)	.01
	12 mo	3.6 (3.4–3.8)	3.2 (2.9–3.4)	.01	3.6 (0.08)	3.3 (0.10)	
Subdomain							
Patient activation	Baseline	3.0 (2.8–3.2)	2.7 (2.5–3.0)	.16			
	6 mo	3.4 (3.1–3.7)	3.1 (2.8–3.3)	.09	3.4 (0.11)	3.0 (0.12)	.01
	12 mo	3.8 (3.6–4.0)	3.3 (3.0–3.6)	.01	3.7 (0.10)	3.4 (0.12)	
Delivery system design and/or decision support	Baseline	3.6 (3.4–3.8)	3.6 (3.3–3.8)	.86			
	6 mo	3.9 (3.7–4.1)	3.7 (3.5–3.9)	.19	4.0 (0.08)	3.7 (0.10)	.10
	12 mo	4.0 (3.8–4.1)	3.7 (3.5–4.0)	.13	3.9 (0.08)	3.7 (0.10)	
Goal setting	Baseline	3.1 (2.9–3.4)	3.0 (2.8–3.2)	.46			
	6 mo	3.4 (3.1–3.6)	3.1 (3.0–3.3)	.13	3.4 (0.10)	3.1 (0.10)	.06
	12 mo	3.6 (3.4–3.8)	3.2 (3.0–3.4)	.02	3.5 (0.10)	3.2 (0.11)	
Problem solving	Baseline	3.3 (3.1–3.6)	3.2 (2.9–3.4)	.30			
	6 mo	3.5 (3.2–3.8)	3.2 (3.0–3.5)	.14	3.5 (0.11)	3.2 (0.11)	.02
	12 mo	3.9 (3.7–4.1)	3.4 (3.1–3.7)	.01	3.8 (0.11)	3.4 (0.13)	
Coordination and/or follow-up	Baseline	2.7 (2.4–2.9)	2.4 (2.2–2.6)	.12			
	6 mo	2.9 (2.6–3.2)	2.5 (2.3–2.7)	.01	2.9 (0.12)	2.5 (0.11)	<.01
	12 mo	3.0 (2.8–3.3)	2.5 (2.2–2.7)	<.01	3.0 (0.12)	2.5 (0.11)	

CI, confidence interval.

^a Unadjusted estimate provided using *t*-test comparisons.^b Adjusted estimates provided by using mixed linear regression controlling for baseline.^c *P* value for both 6 and 12 mo.**TABLE 3** Mean of PACIC Score at Baseline, 6, and 12 Months Postenrollment Among Complexity Tier (High Participants), Unadjusted and Adjusted for Baseline

	Time	Unadjusted ^a Mean (95% CI)			Adjusted ^b Mean (SE)		
		Intervention, <i>n</i> = 24	Control, <i>n</i> = 24	<i>P</i>	Intervention, <i>n</i> = 24	Control, <i>n</i> = 24	<i>P</i> ^c
Total score	Baseline	3.7 (3.3–4.0)	3.1 (2.5–3.6)	.05			
	6 mo	3.8 (3.4–4.2)	2.9 (2.5–3.4)	<.01	3.8 (0.17)	3.1 (0.19)	.01
	12 mo	3.8 (3.4–4.2)	3.1 (2.6–3.6)	.05	3.8 (0.15)	3.2 (0.22)	
Subdomain							
Patient activation	Baseline	3.7 (3.3–4.1)	2.9 (2.3–3.5)	.02			
	6 mo	3.9 (3.4–4.4)	3.0 (2.6–3.5)	.01	3.8 (0.21)	3.1 (0.21)	.01
	12 mo	4.1 (3.8–4.5)	3.6 (3.0–4.2)	.10	4.2 (0.17)	3.5 (0.24)	
Delivery system design and/or decision support	Baseline	4.2 (3.8–4.5)	3.5 (3.0–4.0)	.04			
	6 mo	4.2 (3.8–4.6)	3.8 (3.3–4.2)	.17	4.2 (0.16)	3.8 (0.19)	.12
	12 mo	3.9 (3.5–4.3)	3.4 (3.0–4.0)	.11	3.8 (0.16)	3.5 (0.20)	
Goal setting	Baseline	3.8 (3.4–4.2)	2.9 (2.4–3.45)	.01			
	6 mo	3.7 (3.3–4.2)	3.0 (2.5–3.5)	.03	3.7 (0.19)	3.1 (0.22)	.03
	12 mo	3.7 (3.3–4.2)	3.1 (2.5–3.6)	.05	3.7 (0.18)	3.1 (0.23)	
Problem solving	Baseline	3.9 (3.4–4.3)	3.2 (2.7–3.9)	.13			
	6 mo	3.7 (3.2–4.3)	3.2 (2.7–3.7)	.17	3.8 (0.23)	3.2 (0.24)	.07
	12 mo	4.0 (3.5–4.4)	3.3 (2.6–4.0)	.08	3.9 (0.20)	3.3 (0.28)	
Coordination and/or follow-up	Baseline	3.2 (2.7–3.6)	2.6 (2.2–3.1)	.08			
	6 mo	3.4 (2.9–4.0)	2.4 (1.9–2.9)	<.01	3.3 (0.23)	2.4 (0.22)	<.01
	12 mo	3.5 (2.9–4.0)	2.5 (2.0–3.0)	.01	3.4 (0.21)	2.5 (0.24)	

CI, confidence interval.

^a Unadjusted estimate provided by using *t*-test comparisons.^b Adjusted estimates provided by using mixed linear regression controlling for baseline.^c *P* value for both 6 and 12 mo.

group (Table 4). Controlling for these differences, we observed that, at 6 months postenrollment, intervention participants reported receiving less conflicting advice from providers ($P < .01$) and were less confused about

the role of providers ($P = .03$) than participants in the control group. At 12 months, intervention participants reported more often receiving the services they thought they needed ($P = .03$), were less confused about

the role of providers ($P = .03$), and reported more frequent discussions with providers about future care ($P < .01$) than their counterparts in the control group (Table 4). Stratified analyses of complexity tier paralleled

TABLE 4 CPCQ at Baseline, 6, and 12 Months

Question	Time	Mostly or Always Responses, %		Odds Ratio ^a (Intervention Versus Control)		P
		Intervention, n = 105	Control, n = 104	Estimate	95% CI	
“How often did you get the services you thought you needed?” (question 1)	Baseline	74	70			.51 ^b
	6 mo	75	81	0.67	0.32–1.37	.27
“In the past 3 months, how often did you feel the care you received was well coordinated?” (question 7)	12 mo	87	73	2.50	1.08–5.72	.03
	Baseline	66	72			.29 ^b
“How often were you happy with the quality of care you received?” (question 8)	6 and 12 mo	81	78	1.20	0.65–2.20	.56
	Baseline	73	85			.03 ^b
“How often were you confused about the roles of different services providers?” (question 9) ^c	6 and 12 mo	88	79	2.02	1.00–4.06	.05
	Baseline	16	24			.16 ^b
“How often did you seem to get conflicting advice from service providers?” (question 11) ^c	6 and 12 mo	12	21	0.48	0.25–0.94	.03
	Baseline	19	23			.48 ^b
“Overall, how satisfied are you with the care you have received in the past 3 months?” (question 15) ^d	6 mo	17	37	0.35	0.17–0.70	<.01
	12 mo	31	24	1.51	0.75–3.05	.24
“How often does your GP talk with you about your future care?” (question 19)	Baseline	76	81			.36 ^b
	6 and 12 mo	91	85	1.98	0.92–4.25	.08
	Baseline	59	57			.72 ^b
	6 mo	56	52	1.19	0.65–2.18	.57
	12 mo	66	46	2.43	1.27–4.63	<.01

GP, general practitioner.

^a Logistic regression analyses.

^b Cochran–Mantel–Haenszel P value.

^c This question is reverse coded; lower percentages are associated with better results.

^d The scale for this question is slightly different: very dissatisfied, moderately dissatisfied, neutral, moderately satisfied, very satisfied.

results from the entire study population.

DISCUSSION

AYA populations with complex medical and psychosocial needs are highly vulnerable during times of care transition.³ AYAs with special health care needs are a relatively small population, yet are significant users of the health care system and account for a large proportion of health care expenses.⁴ Impacting care transitions by improving coordination, engagement, and perception of quality are likely important first steps toward improved clinical outcomes. Unsuccessful or poorly coordinated HCT can lead to increased confusion, dissatisfaction, foregone care, decreased adherence to recommended care, and preventable hospitalizations.¹⁹ On the other hand, successful HCT is associated with higher health care quality, reduced medical complications, improved outcomes, greater adherence, lower costs, improved education and vocational outcomes, higher levels of satisfaction, and more independence.¹⁹

Authors of most studies in which transition interventions are evaluated have been limited by studying cohorts with a single condition (eg, type 1 diabetes, cystic fibrosis). With this study, we are the first, as we know, to look at a population of youth with a variety of special health care needs implementing an intervention with a comparison group. Unfortunately, there is still a need for more rigorous research in which authors evaluate models of HCT for AYA, because outcome data are limited.²

CC in other populations has been shown to reduce inpatient hospital admission costs, specifically among high risk patients, improve medical outcomes, reduce inappropriate use, and improve satisfaction.^{20,21} By implementing HCT CC, modeled on

the AAP–AAFP–ACP 6 core elements as standard of care, improved patient health outcomes and overall cost savings may be possible. With this study, we suggest that investing in HCT CC, especially for AYAs with multiple and complex chronic conditions, may impact quality of chronic illness care. Six months after the start of the intervention, intervention participants reported less confusion and higher satisfaction with their care compared with their counterparts. This perception of improved quality of care was most significant at the 1-year milestone. Especially compelling is that the highest complexity participants appear to have experienced the most benefit. Given this finding, the health care system and providers may choose to focus limited resources on this complex population. With our findings, we support that CC has the potential to improve HCT outcomes for patients, providers, and overall health care system effectiveness by anticipating and responding to the needs of AYA.²²

With this study, we relied on convenience sampling, which is prone to selection bias and sampling error. Although this sample is representative of an urban environment and was chosen because of its vulnerability, a limitation of this study is a potential lack of generalizability due to demographic homogeneity. Previous research has revealed this population to be appropriate because young adults from racial, ethnic, and low socioeconomic minorities are at increased risk for gaps in care as they transition into adulthood.⁸ In light of focusing this intervention on a high risk vulnerable population, our finding that quality

of chronic illness care is improved is significant. Authors of future research may evaluate the HCT CC framework within other racially and ethnically diverse populations to ensure the generalizability of these recommendations.

With the intent-to-treat study design, we account for varying intervention “dose” depending on multiple factors such as patient engagement and availability and potential exposure of the control group to some elements of the intervention. In addition, given the range of ages (16–22), not all participants transferred care during the study period. Both the PACIC and CPCQ instruments are validated and included in the Agency for Healthcare Research and Quality Care Coordination Measures Atlas; however, clinically meaningful differences in outcome scores have not yet been established. Authors of future research should aim to identify clinically meaningful differences and associations with improved patient outcomes. For AYAs who were not able to complete the surveys, parents or caregivers completed as proxy. A limitation of this study is that we do not treat these scenarios any differently. However, we aimed to account for these differences in our randomized study design by balancing assignments within strata, assuming the proportion who had parents respond as a proxy should be the same in each group.

CONCLUSIONS

With this study, we provide the first evidence in which the effectiveness of the AAP–AAFP–ACP recommended 6 core elements to improve HCT coordination and

patient-level perspectives of the quality of chronic illness care in this complex population is supported. These findings reveal that this subset of youth greatly benefited from individualized HCT CC. With our study and its great variation in the type of special health care needs within the study population, we support the effectiveness of this CC intervention across a wide spectrum of complex conditions. Authors of future studies may choose to look at patient outcomes more longitudinally, to see if care is sustained, care experiences remain positive, health outcomes continue to improve, and assess cost data to see if these perceptions of improved quality of care translate to better long-term HCT outcomes.

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ABBREVIATIONS

AAFP: American Academy of Family Physicians
AAP: American Academy of Pediatrics
ACP: American College of Physicians
AYA: adolescent and young adult
CC: care coordination
CPCQ: Client Perceptions of Coordination Questionnaire
HCT: health care transition
PACIC: Patient Assessment of Chronic Illness Care

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REFERENCES

1. Child and Adolescent Health Measurement Initiative. Who are children with special health care needs (CSHCN). Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services. Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). 2012. Available at: http://www.cahmi.org/wp-content/uploads/2014/06/CSHCNS-whoarechcn_revised_07b-pdf.pdf. Accessed September 18, 2017
2. 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;188:263–269.e15
3. Bloom SR, Kuhlthau K, Van Cleave J, et al. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012;51(3):213–219
4. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children With Special Health Care Needs Chartbook 2009–2010*. Rockville, MD: U.S. Department of Health and Human Services; 2013
5. Montano CB, Young J. Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. *Postgrad Med*. 2012;124(5):23–32
6. Refaeli T, Mangold K, Zeira A, Königeter S. Continuity and discontinuity in the transition from care to adulthood. *Br J Soc Work*. 2017;47(2):325–342
7. Garvey KC, Wolpert HA, Rhodes ET, et al. Health care transition in patients with type 1 diabetes: young adult experiences and relationship to glycemic control. *Diabetes Care*. 2012;35(8):1716–1722
8. Lotstein DS, Kuo AA, Strickland B, Tait F. The transition to adult health care for youth with special health care needs: do racial and ethnic disparities exist? *Pediatrics*. 2010;126(suppl 3):S129–S136
9. 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
10. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group; Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200
11. Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovitz CS. Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics*. 2009;124(suppl 4):S428–S434
12. Peikes D, Chen A, Schore J, Brown R. Effects of care coordination on hospitalization, quality of care, and health care expenditures among Medicare beneficiaries: 15 randomized trials. *JAMA*. 2009;301(6):603–618
13. The HSC Health Care System. Health plan HSCSN. HSC health care system. 2016. Available at: www.hschealth.org/health-plan. Accessed September 18, 2017
14. Norris L. District of Columbia and ACA Medicaid expansion: DC Medicaid eligibility guidelines among most generous in U.S. Available at: <https://www.healthinsurance.org/dc-medicaid/>. Accessed September 29, 2016
15. Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). *Med Care*. 2005;43(5):436–444
16. McGuinness C, Sibthorpe B. Development and initial validation of a measure of coordination of health care. *Int J Qual Health Care*. 2003;15(4):309–318
17. Minnesota Department of Health. Care coordination tier assignment tool, version 1.0. Health Care Home Initiative. 2010. Available at: www.health.state.mn.us/healthreform/homes/payment/training/complexteirtool.pdf. Accessed April 24, 2015
18. Center for Health Care Transition Improvement. Health Care Transition resources. GotTransition. 2014. Available at: www.gottransition.org/resources/index.cfm
19. Mubanga N, Baumgardner DJ, Kram JJ. Health care transitions for adolescents and young adults with special health care needs: where are we now? *J Patient Cent Res Rev*. 2017;4(2):90–95
20. Xing J, Goehring C, Mancuso D. Care coordination program for Washington State Medicaid enrollees reduced inpatient hospital costs. *Health Aff (Millwood)*. 2015;34(4):653–661
21. Klitzner TS, Rabbitt LA, Chang RK. Benefits of care coordination for children with complex disease: a pilot medical home project in a resident teaching clinic. *J Pediatr*. 2010;156(6):1006–1010
22. Agency for Healthcare Research and Quality. Care coordination. Available at: <https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/index.html>. Accessed September 18 2017

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