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Pediatric Nurses' Role in Health Care Transition Planning: National Survey Findings and Practice Implications

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ABSTRACT

Purpose: Youth and young adults (YYA) with chronic illness and/or disability (CID) face numerous challenges in transition from pediatric to adult health care. Established evidence supports interdisciplinary team approaches to preparing youth and families for transition and transfer. The purpose of this national survey was to address a gap in current knowledge specific to pediatric nursing professionals' roles and responsibilities in health care transition planning (HCTP).

Methodology: A quantitative descriptive study using a survey questionnaire validated by experts in the field investigated respondents' role in HCTP, inclusion of HCTP in job description, levels of HCTP knowledge, and ratings of importance of HCTP elements. A volunteer sample of 1814 respondents was drawn from two professional organizations.

Results: Over 64% of respondents performed HCTP activities related to complex chronic illness management. Only 18% reported specialized training in HCTP. The highest-ranking items in regard to perceived importance were educating and supporting disease self-management and speaking with families about complex needs. Predictors of perceived importance were role, inclusion of transition planning in a job description, percentage of time in direct care, caring for those aged 14 years and older, and level of knowledge about HCTP.

Conclusions: The findings highlight key aspects of the pediatric nurse role in HCTP and identify specific elements that can be addressed to support future HCTP role development.

Practice implications: Pediatric nurses perform a vital role in HCTP for YYA with CID that may be enhanced with the inclusion of HCTP activities in job descriptions and specialized interdisciplinary HCTP training related to this emerging and growing population.

Introduction

Advances in health care and unfolding technological developments have contributed to dramatically changing the life trajectory of children diagnosed with many childhood onset chronic illnesses. Over the last decade, the literature has supported the finding that >90% of those diagnosed during childhood will survive into adulthood (Mahan, Betz, Okumura, & Ferris, 2017; Mannino, 2015; Perrin, Anderson, & Van Cleave, 2014; Pinzon & Harvey, 2006). Specific examples of childhood onset chronic illness survival rates include cystic fibrosis (37 years; MacKenzie et al., 2014); sickle cell disease (40s; National Heart, Lung, and Blood Institute, 2018); congenital heart defects according to type of lesion: mild (comparable to typical population), moderate (75.4 years), and severe (53.4 years; van der Bom et al., 2015); and childhood acquired type 1 diabetes estimated to be approximately 12 years less than for the general population (mid 60s; Huo, Harding, Peeters, Shaw, & Magliano, 2016). These evolving and ever-changing developments with the lived experiences of youth and young adults (YYA) and their concomitant needs for health services have created unrelenting and growing pressures on the pediatric and adult systems of health care.

Both the pediatric and adult systems of health care face challenges of creating models of service linkages to effect uninterrupted and coordinated transfer of care processes for this vulnerable emerging adult population. The most recent recommendations from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians highlight the evolution of healthcare transition practice to be more interdisciplinary and especially inclusive of nurses and social workers (White & Cooley, 2018). It is essential to increase awareness among YYA and their families of the need for pediatric and adult clinicians to share responsibilities. Continuity of care between pediatric and adult settings is impacted by a myriad of factors. They include a lack of early, well-planned preparation that

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engages the adolescent and family on the differences between pediatric and adult systems of care, deficits with condition-related self-management knowledge and skills, and changes in health care following the transfer. Other factors include limited resources for Health Care Transition (HCT) programmatic development and sustainability and interdisciplinary colleagues with limited training to provide HCT services (Benson et al., 2018; McManus & White, 2017).

In addition, the complexity and varied eligibility criteria of health care institutions, along with the type of care provided for transitioning YYA, contribute to the difficulties in accessing not only health care but also other services that are adult oriented (i.e., postsecondary education and employment). A recent study surveying youth in subspecialty pediatric care reported that less than half possessed the health care knowledge, attitudes, and skills to successfully transition to adult services (Benson et al., 2018). Many health care professionals consider the tsunami of YYA with chronic illness and/or disability (CID) reaching adulthood, combined with health care system complexity and unprepared young adults and health care workforce as a "perfect storm" (Betz, 2017a; Everitt, Gerardin, Rodriguez, & Book, 2017; Tanner et al., 2017).

Pivotal to the development of evidence-based HCT services is an interdisciplinary workforce of professionals with expertise to provide the ongoing services needed to facilitate youth and family preparation for the transition to emerging adulthood, with the eventual transfer of care and integration into adult society. Historically, pediatric HCT literature has been published by physicians, with fewer generated by nurses or focused on the unique pediatric nursing role. Until recently, standards of practice, instructional models, and position statements have been generated by the American Academy of Pediatrics (2002), which has joined with other medical specialty organizations to release subsequent updates (American Academy of Pediatrics, 2002; Cooley et al., 2011). Despite pediatric nurses' presence in the provision of health care services to this population in primary care and specialty clinics, the literature is just beginning to reflect the scope of the registered and advanced practice nursing role. In addition to the provision of care, leadership in quality improvement team initiatives, and guidance in system processes and program design, the implementation and evaluation of team-based care strategies have become more prevalent in the literature over the past decade (Disabato, Cook, Hutton, Dinkel, & Levisohn, 2015; Jurasek, Ray, & Quigley, 2010).

Nursing and other professional disciplines in health care are now moving forward with the development of HCT practice standards and position statements (Betz, 2017b). A recent systematic review conducted to explore the roles, views, and perspectives of HCT professions provided insights and understanding about nursing's involvement (Nehring, Betz, & Lobo, 2015). The individuals most surveyed in these studies were physicians. None of the studies had surveyed nurses exclusively. When nurses were surveyed, their responses were integrated with the responses of other interdisciplinary respondents (Fair, Sullivan, & Gatto, 2010; Flume, Taylor, Anderson, Gray, & Turner, 2004; Gilliam et al., 2011; Iles & Lowton, 2010; Ishizaki et al., 2012; Lundin, Danielson, & Ohrn, 2007; McLaughlin et al., 2008; Price, Corbett, & Dovey-Pearce, 2011). Findings from a focus group of pediatric nurse practitioners is serving as a foundation for developing a position statement from the National Association of Pediatric Nurse Practitioners, expected to be published in 2020 (Lestishock, Daley, & White, 2018).

Purpose

The purpose of the study was to explore nurses' role and responsibilities in health care transition planning (HCTP) for YYA with CID. The following research questions guided this study: (1) To what extent are nurses involved in HCTP for YYA with CID? (2) What HCTP activities are nurses providing to YYA with CID? and (3) What are the associations between selected professional demographic characteristics of nurses and provision of HCTP services?

Nurses, specifically pediatric nursing professionals, are ideally suited to participate in, initiate, and lead evidence-based transition planning for YYA with CID. Long-standing relationships with families, significant time spent coordinating care with educational and social agencies, and knowledge of unique disease-specific care and self-management requirements have already led pediatric-registered and advanced practice nurses to take on the task of guiding the transition and transfer of these vulnerable youths (Betz, 2013; Jurasek et al., 2010; Lestishock et al., 2018). Yet generally, the nurses' role is often "behind the scenes" or not described in the literature, despite mention of the need for patient and family education and leadership in care coordination, which are responsibilities often assumed by pediatric nursing professionals (Betz, 2017b; Mannino, Disabato, & Betz, 2018).

Method

This study utilized a quantitative descriptive methodology to gather information via an online survey using Survey Monkey™. The theoretical framework chosen was the model proposed by the international and interdisciplinary Health Care Transition Research Consortium. The model represents a comprehensive approach that includes four domains with specific processes, variables, and potential mediators that impact healthcare transition outcomes. The four domains are individual, family/social support, environment, and the health care system. Although nurses have an indirect impact on the individual and family/social support domains, the health care system domain outlines the important contextual elements related to the pediatric system of care that are encompassed in the care delivered to this population. Elements included in this domain are the availability of care coordination; self-management assessment; and instruction, reinforcement, and the relationships between patients, families, and the health care team (Betz et al., 2014). This model, along with national best practice publications and state/national agencies reflecting six core elements of HCT, served as the framework for the development of the survey items.

Using these elements, 13 HCTP activities were identified and aligned with the scope of practice for pediatric nursing. The survey items developed for Nurses' Role in Health Care Transition Planning (NR-HCTP) were validated using the multi-stage process of development, judgment quantification, and refinement (Lynn, 1986). Relevant domains identified in the development phase included four constructs adapted from the current literature, best practices, and national resources: nurses' role, HCT planning, YYA, and CID. Each of these constructs was represented in survey items and sub-item statements.

These 13 HCTP activities are reported in the literature and based on recommendations and/or position papers from professional organizations (American Nurses Association, National Association of Pediatric Nurse Practitioners, Society of Pediatric Nurses, 2015; Betz, 2017b; Cooley et al., 2011; Deanfield et al., 2003; Sable et al., 2011) and government-funded agencies such as the National Alliance to Advance Adolescent Health's Got Transition program (Got Transition, 2019). A full description of the development and content validation process of the instrument was published in 2018 (Mannino et al., 2018).

Sample

Nurses from two professional pediatric nursing organizations, Pediatric Nursing Certification Board (PNCB) and the Society of Pediatric Nurses (SPN), were recruited voluntarily after investigators received permission from the respective organizations for this study. PNCB members who had previously agreed to third-party emails were invited to participate through an emailed invitation with an explanation of the study purpose, a statement that participation in the survey implied consent, and a link to the survey. An announcement was sent to the SPN membership containing an invitation to participate in the survey together with a survey link, which was made available on the SPN website.

Data were collected between June and December of 2016. A total of 1814 responses were received. From PNCB, there were 1647 responses representing 15.2% of the members who opened the survey, with 9% of the members on the email addresses list participating in the study. There were 167 responses from SPN, although the actual rate of response could not be determined as the number of members who accessed the website and/or saw the survey announcement and link during the survey period was not available. This study was approved by the Institutional Review Board.

Statistical analysis

Descriptive statistics were computed for sample characteristics: professional role, certification, level of education, work setting, percentage of time involved in direct patient care, and caring for patients aged 14 years and older. NR-HCTP items were calculated with frequencies and percentages, means, and standard deviations. The measure of self-reported knowledge pertaining to 13 HCTP activities was assessed on a Likert-type scale ranging from 1 (*low knowledge of a given activity*) to 5 (*high knowledge of a given activity*). The measure of self-reported perceived importance those HCTP activities had to the nurses' professional role was assessed on a Likert-type scale of 1 (*low importance*) to 3 (*high importance*); zero was assigned to activities that were not in the nurses' professional role. Pearson product-moment correlation coefficients were computed across three measures: "job skills" (HCTP activities that were included in the nurses' job description); "total knowledge" (self-reported knowledge that nurses had pertaining to all HCTP activities); and "total importance" (self-reported perceived importance nurses placed on all HCTP activities). "Job skills" was computed as a dichotomous variable: 0 was assigned to activities not included in the nurses' job description and 1 was assigned to activities that are included. The mean of all 13 HCTP activities were used to calculate "total knowledge" and "total importance." Multiple linear regression analyses were calculated to explore which sample characteristics may predict the nurses' self-reported level of knowledge pertaining to 13 HCTP activities and the importance that nurses perceived those same activities held within their professional role.

Results

Sample characteristics

All the survey respondents ($n = 1814$) were registered nurses (100%), with the majority (93%) holding a professional practice certification. Professional roles mostly reflected those in advanced practice nursing roles ($n = 781$, 43%) and staff nurse roles ($n = 640$, 35%). Nearly 60% of nurse respondents possessed graduate degrees. The primary work setting for a majority of respondents ($n = 1095$, 61%) was in pediatrics. This included either in-patient or ambulatory clinic positions in a pediatric hospital ($n = 923$, 51%) and positions in in-patient pediatrics within a general hospital ($n = 172$, 10%). Almost three-quarters ($n = 1317$, 72.5%) of the respondents reported over half of their time at work involves direct patient care, and almost all ($n = 1700$, *93.7%*) reported caring for patients aged 14 years and older (Table 1).

Table 1
Sample characteristics ($N = 1814$).

	n	%
Professional practice certification		
Yes	1687	93
No	127	7
Professional role		
NP, CNS, APRN	781	43
Staff nurse	640	35
Leadership/administration	197	11
Nursing faculty/academia	82	5
Clinical education/staff development	69	4
Researcher	45	3
Level of education (degree earned)		
MSN	870	48
BSN	545	30
AND	121	7
DNP	103	6
PhD	56	3
Diploma	37	2
Work setting		
Inpatient pediatric hospital	514	28
Outpatient/ambulatory pediatric hospital	409	23
Other outpatient/ambulatory setting	283	16
In-patient pediatric unit within general hospital	172	9.5
Community-based (clinic/school/vocational/residential/disability)	170	9.4
College/university	102	6
Other	164	9
Percentage of work time involving direct patient care		
0–9%	136	7.5
10–25%	147	8.1
26–50%	112	6.2
51–75%	235	12.9
76–100%	1082	59.6
Not involved in direct patient care	102	5.6
Percentage of weekly time caring for YYA ≥14 years		
0–25%	457	25.2
26–50%	741	40.8
51–75%	385	21.2
76–100%	117	6.4
No patient care of YYA ≥14 years	114	6.3

Note: NP = nurse practitioner; CNS = clinical nurse specialist; APRN = advanced practice registered nurse; AND = associate nursing degree; DNP = doctor of nursing practice; YYA = youth and young adults.
Missing data: education (83/1814); Percentages may not equal 100% due to statistical rounding.

Transition planning skills in the job description

Although 85% of the respondents ($n = 1539$) reported that their job description does not include or imply "transition planning" as part of their role, and none of the respondents indicated the word "transition" was included in their job title, most reported performing HCTP activities regardless. Of the 13 HCTP activities, "speaking with families about complex health needs" ranked first as the activity performed by the most respondents ($n = 1150$) and "collaborating with vocational agencies" ranked 13th as the activity performed by the least ($n = 485$). Table 2 identifies the ranking of all 13 HCTP activities performed by nurses and notes whether or not the activity was included in the nurses' job description. The ranking was determined by adding the number of those who indicated the activity was part of their job to the number of those who indicated the activity was not part of their job but they were performing it regardless. As these findings reveal, the first seven activities that were performed by at least 50% of the respondents align with current standards of nursing practice pertaining to the care of YYA with CID (American Nursing Association et al., 2015; Blake, 2018; Betz et al., 2016; Craft-Rosenberg & Krajicek, 2006; Nehring, Natvig, & Betz, 2013). These activities were focused on education, advocacy, and support—all skills associated with the provision of services for YYA with complex health needs of all ages. Within the Health Care Transition Research Consortium model for HCT used as the framework for this study, education, advocacy, and support align with the environment, health care system, and family/social support domains, respectively (Betz et al., 2014).

Training and level of knowledge of HCT activities

Although only 18% ($n = 332$) reported having specialized training in HCTP, the respondents reported being knowledgeable ($M = 41.6$, $SD = 12.2$, Range = 13–65) about all 13 HCTP activities. Nurses reported being most knowledgeable about "acting as a health advocate for youth" ($M = 3.9$, $SD = 1.0$, Range = 1–5) and least knowledgeable

Table 2
HCTP activities performed by nurses.

HCTP activity, in rank of performance by nurses	Listed in job description		Not listed in job description but doing it anyway		Total	
	n	%	*n*	%	*n*	%
1. Speaking with families about complex health needs	885	48.8	265	14.6	1150	63.4
2. Speaking with other health professionals about complex health needs	905	49.9	229	12.6	1134	62.5
3. Acting as a health advocate for youth	869	47.9	226	12.6	1095	60.5
4. Educating youth about self-management abilities	808	44.5	281	15.5	1089	60.0
5. Acting as a health advocate for a family or caregiver	836	46.1	249	13.7	1085	59.8
6. Supporting youth in self-management	794	43.7	286	15.8	1080	59.5
7. Supporting a family or caregiver throughout the transition	550	30.3	363	20.0	913	50.3
8. Collaborating with educational agencies	510	28.1	232	12.8	742	40.9
9. Collaborating with community agencies	460	25.3	217	12.0	677	37.3
10. Facilitating the transfer of care to adult practice	304	16.7	358	19.7	662	36.4
11. Mentoring other health care professionals on transition guidelines	341	18.8	268	14.8	609	33.6
12. Sharing health care transition program knowledge	303	16.7	251	13.8	554	30.5
13. Collaborating with vocational agencies	292	16.1	193	10.6	485	26.7

Note: HCTP Activities: Health Care Transition Planning Activities that nurses perform to facilitate the movement from pediatric to adult health care; "Total" reflects the number and percentage of nurses performing the activity.

about "collaborating with vocational agencies" ($M = 2.5$, $SD = 1.3$, Range = 1–5). Table 3 identifies the rank order of all 13 HCTP activities. The rank was determined by the number of nurses that self-reported having high knowledge of a given activity.

Level of importance of HCTP activities

Overall, respondents reported the 13 HCTP activities as having a high perceived importance ($M = 29.7$, $SD = 9.3$, Range = 0–39). Individually, the activity of "educating youth about self-management abilities" was reported as having the highest perceived importance ($M = 2.56$, $SD = 0.79$, Range = 0–3) by most nurses ($n = 899$, 69%). Table 4 identifies the rank order of all 13 HCTP activities according to respondents' perceived level of importance.

Exploration of associations with selected variables

Correlation analyses suggest moderate to strong positive associations between the number of "job skills" (number of HCTP activities out of the possible 13 that are included as skills in the nurse's job description) and the "total importance" those skills are to the nurse's current role ($r = 0.448$, $n = 1184$, $p < .01$) and the "total knowledge" pertaining to those activities ($r = 0.506$, $n = 1186$, $p < .01$). The analyses also suggest moderate to strong positive associations between "total knowledge" pertaining to the 13 HCTP activities and "total importance" ($r = 0.466$, $n = 1206$, $p < .01$).

Multiple linear regression analyses were calculated to explore the associations among "total knowledge" and "total importance" with sample characteristics. All sample characteristics were included in the regression models that predicted knowledge and importance. Of these, analyses suggest professional role, practice certification, having "transition planning" in the job description, having specialized training in HCTP, and the time spent caring for patients aged 14 years and older are statistically significant predictors of nurses' self-reported "total knowledge" related to HCTP activities. Education level, work setting, having the word "transition" in job title, and the percentage of time involved in direct patient care were not statistically significant predictors.

Regression analyses also suggest that statistically significant predictors of the "total importance" nurses perceive HCTP activities to have, include professional role, having "transition planning" in the job description, the percentage of time involved in direct patient care, the time spent caring for patients aged 14 years and older, and self-reported knowledge of HCTP activities. The predictors that were not statistically significant were education level, work setting, practice certification, and having the word "transition" in the job title. Table 5 presents the significant predictors in both analyses.

Discussion

This study sought to explore several questions about the extent to which the study's respondents—pediatric nurses and advanced practice registered nurses (APRNs)—are involved in providing HCTP services.

Table 3
Nurses' level of knowledge of HCTP activities.

HCTP activity, in rank of self-reported high knowledge	1 Low		2		3		4		5 High	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
1. Acting as a health advocate for youth	68	3.7	125	6.9	279	15.4	433	23.9	390	21.5
2. Speaking with families about complex health needs	33	1.8	90	5.0	293	16.2	501	27.6	386	21.3
3. Acting as a health advocate for a family or caregiver	77	4.2	124	6.8	284	15.7	434	23.9	375	20.7
4. Speaking with other health professionals about complex health needs	34	1.9	93	5.1	326	18.0	483	26.6	366	20.2
5. Educating youth about self-management abilities	52	2.9	126	6.9	310	17.1	484	26.7	328	18.1
6. Supporting youth in self-management	61	3.4	117	6.4	309	17.0	489	27.0	325	17.9
7. Supporting a family or caregiver throughout the transition	161	8.9	197	10.9	330	18.2	413	22.8	202	11.1
8. Mentoring other health care professionals on transition guidelines	315	17.4	260	14.3	300	16.5	260	14.3	162	8.9
9. Collaborating with educational agencies	305	16.8	229	12.6	312	17.2	287	15.8	162	8.0
10. Collaborating with community agencies	336	18.5	235	13.0	328	18.1	256	14.1	143	7.9
11. Sharing health care transition program knowledge	384	21.2	284	15.7	268	14.8	225	12.4	133	7.3
12. Facilitating the transfer of care to adult practice	337	18.6	304	16.8	327	18.0	223	12.3	108	6.0
13. Collaborating with vocational agencies	410	22.6	271	14.9	313	17.3	204	11.2	99	5.5

Note: HCTP = Health Care Transition Planning; $M = 41.6$; $SD = 12.2$; Range = 13–65; $p < .001$.

Table 4
Importance of HCTP activities in professional role.

HCTP activity, in rank of self-reported high importance	Low importance		Important		High importance		Not in current role	
	n	%	*n*	%	*n*	%	*n*	%
1. Educating youth about self-management abilities	62	3.4	261	14.4	899	69.2	78	4.3
2. Speaking with families about complex health needs	61	3.4	258	14.2	918	50.6	62	4.8
3. Supporting youth in self-management	60	3.3	253	13.9	912	50.3	76	4.2
4. Acting as a health advocate for youth	58	3.2	265	14.6	893	49.2	78	4.3
5. Acting as a health advocate for a family or caregiver	61	3.4	293	16.2	860	47.4	80	4.4
6. Speaking with other health professionals about complex health needs	71	3.9	323	17.8	856	47.2	49	2.7
7. Supporting a family or caregiver throughout the transition	98	5.4	334	18.4	755	41.6	108	6.0
8. Mentoring other health care professionals on transition guidelines	175	9.6	411	22.7	580	32.0	130	7.2
9. Sharing health care transition program knowledge	164	9.0	408	22.5	583	32.1	135	7.4
10. Facilitating the transfer of care to adult practice	190	10.5	406	22.4	551	30.4	153	8.4
11. Collaborating with educational agencies	201	11.1	436	24.0	509	28.1	149	8.2
12. Collaborating with community agencies	201	11.1	440	24.3	508	28.0	146	8.0
13. Collaborating with vocational agencies	243	13.4	441	24.3	441	24.3	175	9.6

Note: HCTP = Health Care Transition Planning; $M = 29.7$; $SD = 9.3$; Range = 0–39; $p < .001$.

The study findings revealed that the majority of respondents indicated they performed selected items of HCTP practice activities. These activities reflect the standards of practice for YYA with CID that is not specifically associated with HCTP but rather with the ongoing and chronic care needs of YYA with complex health needs (American Nurses Association et al., 2015; Betz et al., 2016; Blake, 2018). The recent SPN Position Statement on *Transition of Pediatric Patients into Adult Care* embodies these nursing activities into the framework of HCT care and reflects the scope and standards of pediatric nursing practice that have been established through research, is taught in nursing degree programs, and is made available through professional nursing organizations and nursing credentialing agencies (Betz, 2017b).

There were six designated HCTP activities specifically identified by less than half of the study respondents as presented in Table 2: mentoring other healthcare professionals on transition guidelines (1 item); collaborating with educational, community, and vocational agencies (3 items); sharing healthcare transition program knowledge (1 item); and facilitating the transfer of care to adult practice (1 item). This cluster ranked lower than activities associated with chronic care for YYA with CID on measures related to those activities being currently performed (Table 2), self-reported knowledge (Table 3), and perceived importance (Table 4). All six are associated with service coordination and referral to transition- and adult-oriented agencies, having specialized HCTP knowledge and skills enabling the transfer of care, as well as the sharing of HCTP knowledge with others (American Academy of Pediatrics, 2002; Betz, 2017b).

Table 5
Summary of Regression Analyses.

Significant Predictors of Nurse's Knowledge of Thirteen HCTP Activities					
Predictor	B	SE(B)	β	*t*	*p*
Professional Role	.789	.183	.149	4.317	<.001
Practice Certification	3.362	1.305	.068	2.576	.010
"Transition Planning" in Job Description	6.685	.885	.204	7.551	<.001
Specialized HCTP Training	7.078	.829	.233	8.540	<.001
Time with Patients >14 Years Old	1.127	.367	.089	3.070	.002
$R = .423$; $R^2 = .179$; $F = 28.662$; $p<.001$					
Significant Predictors of Nurse's Rating of Perceived Importance the Thirteen HCTP Activities were to their Current Role					
Predictor	B	SE(B)	β	*t*	*p*
Professional Role	.552	.132	.137	4.199	<.001
"Transition Planning" in Job Description	1.792	.645	.072	2.781	.006
Time Involved in Direct Patient Care	.879	.182	.142	4.836	<.001
Time with Patients >14 Years Old	1.270	.021	.441	16.331	<.001
Knowledge of HCTP Activities	.336	.021	.441	166.331	<.001
$R = .556$; $R^2 = .310$; $F = 51.092$; $p<.001$					
HCTP = Health Care Transition Planning					

The analyses also revealed that if the nurses' job description included HCTP activities, there was a significantly higher level of self-reported knowledge and perceived level of importance those activities had in their practice role. As the data revealed, a minority of nurses in the total sample had HCTP stated in their job description, ranging from 30% to as low as 16%. In addition to HCTP activities being included in the nurses' job description, knowledge and perceived importance of HCTP activities was predicted by the percentage of times nurses were involved in direct patient care for youth aged 14 years and older. That is, nurses who are involved in providing HCT services reported being knowledgeable about the importance of addressing this service need for youth with CID. A recent systematic review of nursing transition care coordinator roles indicated that although overall outcomes for patients and health systems were inconsistent, models that included frequent face-to-face interactions and disease-specific monitoring and follow-up showed improved outcomes (Conway, O'Donnell, & Yates, 2017). Having transition planning specifically included in a nursing job description for those who work with YYA in transition to adult care could support increased opportunities for disease-specific monitoring and follow-up.

Identified gaps between practice and education

The study findings reveal the gaps pertaining to the specialization of HCT practice and the need for more robust education and training. Over 80% of nurse respondents indicated they had not received specialized training in HCTP. The findings of this study also align with the 2018 clinical report on supporting the transition from adolescence to adulthood in medical home recommendations for enhanced infrastructure, education, and training for all health care clinicians. Educational content for HCT training health care professionals suggested in the 2018 clinical report included young adult development, interprofessional practice paradigms, and team-based care (White & Cooley, 2018). The findings of this study are also consistent with a recent systematic review of providers from all disciplines involved in HCTP. Findings of the systematic review highlight the service and training gap that exists in the field. Interdisciplinary providers consistently reported their levels of discomfort and practice limitations with their HCT knowledge and skills (Nehring et al., 2015).

Study limitations

This survey utilized a purposive sample of pediatric nurses and nurse practitioners who, by the fact of pursuing national certification, are a highly motivated group of pediatric nursing professionals. As such, the study design has implications for the generalizability of the findings to pediatric nurses who were not sought out by the researchers to

complete the survey. Given that there had not been a survey of this type reported on in the literature, the authors were able to achieve the goal of reaching a significant number of pediatric nurses and APRNs through two major professional organizations in a reasonable time frame. School nurses were not included in this survey, although the authors sought to do so through the National Association of School Nurses (NASN). After review of the survey by NASN research and leadership groups, it was determined that the HCTP activities identified in the survey and validated by experts used terminology geared toward ambulatory nursing roles and may be misunderstood by school nurses who practice in educational and vocational systems. Discussions about a survey on HCTP designed specifically for this important group of nursing professionals occurred, and this may be pursued in the future.

Implications for nursing practice, education, and research

The findings of this study indicate that there is a need for HCT training for pediatric nurses at the staff and advanced practice level who provide services to YYA with CID. The nursing standards of care can provide a relevant starting point for the development of nursing evidence-based practices (Betz et al., 2016; Blake, 2018; Craft-Rosenberg & Krajicek, 2006; Nehring et al., 2013). The recent position statement and transition guideline issued by SPN can serve as a framework for HCT training initiatives and infrastructure for the development of nursing HCT competencies (Betz, 2017b).

In addition, recent focus group outcomes on this topic from the National Association of Pediatric Nurse Practitioners established a foundation from which further practice standards and a position statement are being developed. The four themes that emerged in the focus group included education for youth and providers, health care system changes, support and communication (which includes health care informatics), and the use of technology by youth (Lestishock et al., 2018). APRNs who care for YYA are likely to have more significant and sustained involvement in health care transitions in their practice as direct-care providers who provide referrals and care coordination; they are also more likely to assume leadership compared to RNs who may change employment more frequently. The 2018 clinical report highlights the importance of team-based quality initiatives that can be led by nursing, social work, or other involved disciplines (White & Cooley, 2018). In addition, the emergence of DNP-prepared APRNs has enhanced the leadership, quality improvement, and program evaluation capabilities within health care teams, which are all needed skills to advance transition outcomes from pediatric to adult care.

The focus of this study and data analysis was to broadly summarize the nurses' role, for both RNs and APRNs, in regard to HCTP for YYA with CID. In the list of 13 HCTP activities described above, educating youth about self-management ranked 4th, with nearly two thirds of respondents ($n = 1089$, 60%) identifying it as an important activity. An additional focus of this study, but not included in this paper, was to clarify the types of self-management activities assessed by nurses and APRNs in this population. One survey item queried respondents on the frequency with which they assess youth and YYA on nine specific self-management abilities. Responses to this question will undergo separate analysis and become the focus of a subsequent paper. The survey also included three questions asking about the respondent's educational needs, access to materials, and preferred format of such materials or tools. Responses to these questions will also undergo a separate analysis and findings from these focused questions will serve to guide further national nursing and interdisciplinary professional practice discussions on the development and dissemination of training materials and tools in useful formats. Formalized professional development programs focused on nursing and team leadership skills specific to caring for this vulnerable and growing population of YYA are needed.

This study clarified the elements of the pediatric nurses' role that help YYA and their families to successfully transition to adult care. Future directions for research include surveying school nurses and adult ambulatory nurses regarding their skills and experience with YYA with CID. As this specialized field of HCTP practice and research continues to develop and evolve, there are ample opportunities for pediatric nurses in ambulatory, in-patient, and advanced practice roles to develop, implement, and test nurse-led HCT models of care.

CRediT authorship contribution statement

Jennifer A. Disabato: Conceptualization, Methodology, Software, Validation, Formal analysis.**Jennifer E. Mannino:**Conceptualization, Methodology, Validation, Data curation, Formal analysis.**Cecily L. Betz:** Conceptualization, Methodology, Validation, Formal analysis, Supervision.

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