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Different Healthcare Transition Models

Cecily L. Betz

Introduction

Beginning nearly three decades ago, the changing survival rates of children diagnosed with special healthcare needs (CSHCN) and disabilities were forecasted to bring about significant changes in the care models to meet their service needs [1]. In response, experimental models of care were developed to support this new generation of CSHCN who were growing into adulthood [2]. Since then, the tentative stages of early service development have progressed at an accelerated pace with the development, implementation, and testing of HCT service models [3–7]. Currently, limited evidence exists regarding interventions to effect successful HCT outcomes; however, a growing body of research and consensus opinion are available to guide the development of models considered to exemplify best practices [8–14].

This chapter will begin with an examination of the recommended structural components to include in the development of healthcare transition service models. Service components of HCT models of care that have been described in the literature will be presented. A discussion of the processes involved with HCT, which are based upon the frameworks of HCT care reported in the literature, will follow. Depending on the service model, the process of service delivery differs in terms of the selection and integration of structural components. A discussion of the expected and proposed outcomes of HCT care will be presented, and the chapter will conclude with an analysis of the current state of model development.

Key Structural Components of Different Models

To date, position statements authored by the major pediatric professional organizations have provided the guidance for the early development of HCT service models [8–11, 13, 14]. Although there is widespread recognition of the limitations of the HCT models given their preliminary stages of development, there is an emerging body of evidence to support the inclusion of structural components as integral to this service model evolvement. The key HCT structural components that will be discussed are the Adoption of HCT Guidelines/Protocol of Care, Period of Preparation, Transfer/Transition Readiness Assessment, Care Coordination, Healthcare Transition Coordinator, Medical Summary, Healthcare Transition Plan, Ongoing Instructional and Self-Management Support, and Evaluation of Outcomes. These structural components often require adaptation to

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C. L. Betz, Ph.D., R.N.
Department of Pediatrics, University of Southern California (USC), Keck School of Medicine,
Los Angeles, CA, USA

USC University Center for Excellence in Developmental Disabilities, Children's Hospital Los Angeles, Los Angeles, CA, USA
e-mail: cbetz@chla.usc.edu

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appropriately meet the needs of specific diagnostic groups of adolescents and young adults with special healthcare needs (AYASHCN) [6, 15].

Adoption of HCT Guidelines/Protocol of Care. Ideally, the guidelines or protocol of HCT services to be delivered over the program preparation period serves as the template for implementation. Position statements authored by specialty organizations (i.e., American Academy of Pediatrics, Society of Pediatric Nurses) are available for guidance in the development of a program-specific service for a diagnostic group of AYASHCN or for institutional-wide policies and procedures as presented in Table 36.1 [9, 10]. Other resources for HCT pro-

Table 36.1 Resources to consult for the development of HCT protocols/clinical guidelines

Resource	Description	Key structural elements
Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (AAP, 2012)	Depicts an algorithm to assist pediatricians with the development of guidelines/protocol that can be adapted to their programmatic needs	• Initiate HCT plan at age 12 years • Start HCT planning at age 14 years • HCT is individualized and written based upon identified needs beginning at age 14 and expanded as needed • Plan is reviewed regularly and updated • Readiness assessments are conducted • Transfer of care occurs when pediatric eligibility terminates
2016 Society of Pediatric Nurses Transition Position Statement	Provides a framework for the development of a HCT protocol, which is nursing-focused based upon an interdisciplinary model of care	• *Extended HCT preparation (age 12)*: This preparation involves nurses and interdisciplinary colleagues with the expertise in the comprehensive biopsychosocial needs of all adolescents as they move from pediatric-focused care to emerging adult and adult provider systems • *Transfer of care period*: The process of execution will begin prior to the transition to adult care, and the intensity of the execution process will increase as plans progress • *Post healthcare transition/transfer of care*: Although pediatric nurses do not generally provide direct care for young adults following the transfer of care, there are several important considerations to be addressed following the transfer to adult care to ensure successful outcomes
Six Core Elements of Health Care Transition 2.0	Provides a framework for guidance to assist with the development of a HCT service program	• Transition policy • Transition tracking and monitoring • Transition readiness • Transition planning • Transfer of care • Transfer completion
6 Key elements and 1 Indicator (Suris & Are, 2015)	Provide guidance with the development of HCT service models in terms of conceptualizing the components of the service model to foster the successful HCT	• Patient not lost to follow-up (indicator) • Assuring a good coordination between pediatric and adult professionals (key element) • Starting planning transition at an early age (key element) • Discussing with patient and family about self-management (key element) • Including young person's views and preferences to the planning of transition (key element) • If developmentally appropriate, seeing the adolescent alone at least for part of the consultation (key element) • Identifying an adult provider willing to take on the young patient before transfer (key element)

gram development found in Table 36.1 include the Six Core Elements of Health Care Transition 2.0 [16] and the HCT framework developed by Suris and Akre that identifies six key elements and indicators considered essential for a HCT program and demonstrative of its success [12].

Period of Preparation. All HCT service models incorporate a period of preparation. The service interval for HCT preparation depends on the structural components and the process of the model design. Some models concentrate on the transfer of care with a short-term focus compared to those whose focus is more divergent, that is, directed toward other facets of healthcare transition planning. Examples of the latter include the *Movin On Up*, *Center for Youth and Adults with Conditions of Childhood* model, and a transitional program for youth with juvenile idiopathic arthritis [17–21]. Pediatric professional organizations recommend that the preparation period be initiated in early adolescence, between the ages of 12 and 14 years [9, 10]. One model suggests initiation of HCT planning at nearly 10 years of age [17]. Programs with longer preparation periods incorporate a life span approach extending from early adolescence to emerging adulthood. Preparation programs that emphasize the transfer of care are less focused on other developmental considerations and are generally 2 years or less in duration [3–7, 22, 23].

Transfer/Transition Readiness Assessment. For many AYASHCN who receive specialty care in a pediatric medical center, there is an inevitable future date wherein interdisciplinary services are terminated as insurance coverage ends. Termination of insurance plan eligibility varies, with public insurance coverage ending between 18 and 21 years of age and private insurance coverage ending at age 26 (see Chaps. 8, 23, 24, and 25). Hospital policies concerning the termination of the provision of care for AYASHCN who lose insurance may differ among selected specialty care departments within the same institution.

Some programs use age as the determining factor for transfer timing, typically between 18 and 21 years; other programs transfer care based upon significant life events, such as marriage or pregnancy, that legally enable younger adolescents who have not yet reached the state's age of majority to become the decision-maker [3–5, 11]. Other programs recommend the transfer to adult care based on a more comprehensive approach that involves formalized assessment of readiness and/or determination of the AYASHCN's maturity [14, 24–26]. Various readiness assessment tools available are described in Chap. 13. These measures are generally used to evaluate areas in which greater transition preparation is needed. Some experts have advocated for HCT planning to begin early in adolescence for those with complex medical needs such as AYASHCN with severe seizures or spina bifida, wherein the meaning of readiness does not infer an immediacy or soon-to-be-anticipated transfer of care [3, 17, 27] but rather a long-term process of knowledge and skill attainment [3, 17, 27]. The ultimate goal of all HCT preparation programs, whatever the model, is to facilitate the AYASHCN's adaptation to a new system of care and transition into a stage of development with higher-order competencies to function as independently and productively as possible [24].

Transition readiness refers to a defined set of generic and fundamental skills/knowledge that AYASHCN should possess prior to transferring to adult care such as making physician appointments, knowing the names of medications, and communicating with their healthcare providers. An important element of the transfer of care is the identification of self-management skills and knowledge that the AYA may still need to learn to be as self-sufficient and self-reliant as possible [8–10].

Self-management, which is the ability to manage the tasks associated with the daily care needs of the AYASHCN, is an essential self-care competency that must be achieved. The self-management skills and knowledge needed to be as feasibly independent as possible will be dependent on the level of involvement of the SHCN, the type of SHCN, and the functional capacity of the AYA, which includes cognitive level of functioning and gross and fine motor skills. Healthcare self-management not only involves the most fundamental tasks associated with daily management of the condition but also the array of competencies needed to be a health-literate and health-competent consumer [17].

A number of condition-specific self-management tools to assess self-management knowledge and skills exist (see Chap. 13 for a more thorough description of available measures). For example, the Epilepsy Self-Management Scale (ESMS), with established psychometric properties, measures epilepsy self-management [28, 29]. The Adolescent/Young Adult Self-Management and Independence Scale II with demonstrated reliability and validity has been used with adolescents and emerging adults (ages 12–25 years) with spina bifida to measure self-management as it pertains to their condition and independent living [30, 31]. Tools measuring self-management knowledge and skills of AYA with type 1 diabetes, HIV, and arthritis have been reported [32–34].

Instruction enables AYA with SHCN to become more informed and competent as healthcare consumers, which is pivotal to functioning as independently and productively as possible as adults [35]. For parents, preparatory instruction not only provides them with the HCT knowledge and skill building they may need to be effective advocates but also to be a navigator for their son or daughter [36].

Care Coordination. As the Agency for Healthcare Research and Quality states: “Care coordination involves deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient’s care to achieve safer and more effective care” [37]. Care coordination, which can be provided by any discipline, is essential to the provision of comprehensive HCT services. Community-based pediatric care based upon a medical home model provides care coordination services (Table 36.1; see also Chap. 26). Beginning with their diagnosis, most AYASHCN require services from an interdisciplinary team. This requires care coordination, which intensifies during HCT planning and transfer. A HCT coordinator is pivotal to ensure the uninterrupted transfer of care and referrals to community-based systems of care for AYASHCN [7, 9, 10, 19, 20, 27, 38–41] (see Table 36.2). Care coordination activities include (a) continuous assessment of needs, (b) reevaluation of services provided based on emerging needs, (c) facilitating communication among team members and among team members and AYASHCN and their parents/guardians, (d) ensuring referrals are completed, (e) providing ongoing instructional and self-management support, and (f) serving as an informational resource.

Healthcare Transition Coordinator. The HCT coordinator [3, 5, 10, 17, 20, 25, 38–40, 42, 43] is

Table 36.2 Role responsibilities of healthcare transition coordinator

- Serves as the lead for the development of the HCT policy
- Ensures team members are cognizant and supportive of HCT policy
- Identifies the needs for HCT program materials/resources
- Designates (when possible) individuals responsible for creating resources; assists with the development of resources
- Coordinates the assessment of transition readiness
- Coordinates the ongoing assessment of self-management knowledge and skills
- Serves as the lead for healthcare transition planning
- Facilitates the development of the written healthcare transition plan
- Formulates with team members realistic timeframe for goal achievement
- Continuously monitors needs for HCT services and supports
- Serves as the liaison/contact person for the AYA with SHCN and family pertaining to HCT
- Updates the HCT Plan as needed
- Implements a plan to evaluate the outcomes of care
- Serves as the liaison among HCT team members to facilitate communication pertaining to changes in AYA status; scheduling
- Facilitates care coordination that involves clinical, biopsychosocial, and educational needs
- Facilitates service referrals to transition and adult agencies; systems of care
- Facilitates the transfer of care procedure
- Ensures that each AYA whose care is transferred has medical summary
- Works with financial administrator to obtain reimbursement for services
- Develops and implements quality improvement projects to assess outcomes of services [6, 8, 15, 36]

responsible for coordinating the clinical evaluations and recommendations of HCT team members into a HCT plan of care that integrates diverse perspectives and input based upon the needs of the AYASHCN and family. The HCT coordinator is typically responsible for ensuring that referrals for services and supports are made, identified needs for instruction are provided, and benchmarks achieved or to be achieved are noted [17, 26, 43]. To illustrate, in a patient with spina bifida who is also obese, the physical therapist recommends increasing physical activities and exercise and offers a listing of community-based adaptive sports and exercise programs. The dietician's recommendations pertain to workable weight management strategies the AYA and family have discussed. The HCT coordinator will ensure that (a) PT has provided the AYA and parent with the list of available community-based programs and has reviewed the offerings listed with them, (b) the AYA and parent are encouraged to contact the clinic office if obstacles are encountered with contacting these programs, (c) PT follows up with the AYA and parent as to the recommendation made during the previous clinic visit, adjustments are made as needed, (d) the dietician provides contact information should questions/issues arise, and (e) dietician is scheduled to follow up with the status of weight management goals. The HCT coordinator serves as the primary team member responsible for monitoring and updating the plan, as needed.

Importantly, the HCT coordinator serves as the liaison to the AYA and family for issues encountered during the planning process, informational needs, and requests for additional service referrals. The HCT coordinator is viewed as the designated resource for the transfer of care, access to transition, and adult-related services as well as the conduit for questions pertaining to interdisciplinary and interagency services and supports. Updates on AYA and family issues and benchmarks of achievement are noted by the HCT coordinator and transmitted to other team members for updates and possible informational input to relay back to the AYA and family. A listing of HCT coordinator positional responsibilities is presented in Table 36.2.

Medical Summary. A transition medical summary is a concise synopsis of the AYA's medical history and current plan of care for the receiving adult provider/team members [5, 9–11, 14, 25]. An informative medical summary contains the following content: (a) diagnosis and its date of confirmation; (b) condition severity and level of involvement based upon provider's estimate/predetermined criteria; (c) comorbidities; (d) previous surgeries including type(s) and date(s); (e) previous ED visits including reasons and dates; (f) previous hospitalizations including reason (s) and date (s); (g) history of complication(s)/relapse(s); (h) medications, dosage, frequency, and administration mode; (i) daily treatments required for management (i.e., catheterization, postural drainage); (j) use of assistive devices (i.e., braces); (k) special diets, use of formulas, and total parental nutrition; (l) allergies; (m) measurements (i.e., BMI); (n) vital signs; and (o) contact information of HCT coordinator and members of pediatric team. A number of medical summary formats are available (see Table 36.3).

Healthcare Transition Plan. The HCT plan serves as a road map during preparation for HCT (described below). The plan begins with an assessment of needs and future plans, which then guides the development of the plan [9, 10, 17, 26]. Depending on the scope of services provided in the HCT program, those that focus on the transfer of care will formulate plans with AYA and, as appropriate, other family members. Identification of the adult primary and specialty providers who have the expertise and experience to provide the necessary services to the AYASHCN is a priority. Depending on the transfer structure arrangements, such as a joint HCT service clinic, the HCT plan may include details as to the coordination of joint care management (see *Pediatric-Adult Provider Transfer Models of Care*, below).

The plan should include maintaining or acquiring access to a health insurance plan that meets the AYASHCN's needs. Prior to the transfer of care, arrangements for supplies and durable medical equipment vendors should be made. Requisitions for durable medical equipment, i.e., wheelchairs, assistive devices (i.e., walkers,

Table 36.3 Examples of medical summaries

Medical summaries	
American College of Rheumatology	Medical Summary and Emergency Care Plan: Juvenile Idiopathic Arthritis https://www.rheumatology.org/Portals/0/Files/Medical-Summary-JIA.pdf
American College of Rheumatology	Medical Summary and Emergency Care Plan: Systemic Lupus Erythematosus (SLE) https://www.rheumatology.org/Portals/0/Files/Medical-Summary-SLE.pdf
Carolina Health and Transition (CHAT)	Alliance of Disability Advocates, Center for Independent Living, Raleigh, North Carolina http://sys.mahec.net/media/brochures/youth_guide.pdf
Got Transition?	Sample Medical Summary and Emergency Care Plan Six Core Elements of Health Care Transition 2.0 http://www.gottransition.org/resourceGet.cfm?id=227
Healthcare Information and Management Systems Society (HIMSS). Type I and Type II diabetes ©2012	Clinical Summary for New Health Care Team http://s3.amazonaws.com/rdcms-himss/files/production/public/HIMSSorg/Content/files/SampleFormClinicalSummaryTransitionNewHealthCareTeam.pdf
MyHealth Passport	SickKids Hospital website https://www.sickkids.ca/myhealthpassport/

crutches), and braces, may be needed to avert unnecessary delays in obtaining replacements if the equipment is no longer usable.

HCT programs that are more comprehensive incorporate other transitions to future planning, including postsecondary education/training; job development and placement; community living planning such as housing, civic responsibilities, public transportation, and recreational programs; and social relationships and programs. Additional content on the process involved with comprehensive models of care is presented in the section entitled *Comprehensive Model of Care*.

Ongoing Instruction, Self-management, and Support. The discussion begins with instructional needs for parents and AYASHCN and then self-management as it intensifies during HCT planning and concludes with the use of transition readiness assessments.

Parental support can be provided to caregivers as they undergo the process of role and responsibility changes [9, 10, 36]. The parent's role as the person responsible for the care and/or oversight of their children's care evolves to a role of relinquishing some or all of their parental caregiving responsibilities [44–48]. Surveys have identified parent learning needs pertaining to transition and adult-related services and programs that their children will eventually access in order to be better informed and helpful to their children [36, 49]. Although reaching out to parents has been identified as a component of care, scant efforts to provide programmatic support during the HCT process have been identified [36, 50, 51].

In studies exploring AYA's instructional needs, issues pertaining to information about the transition process, the availability of adult services, and the additional information about their condition have been identified by AYA [35]. Although, HCT programs report instructional assistance provided to AYASHCN, it is unclear as to the type, scope, and effectiveness of instruction provided. Preparatory instruction for AYA has been identified as an area of need to be addressed in HCT programs. Although recommendations have been suggested in terms of peer support programs to assist AYA during this period of HCT, few have been implemented and validated [35, 44, 52, 53].

Key Processes that Define Different Models

There are two predominant HCT delivery models: the transfer vs. transition models. The transfer model has a narrow focus: the transfer of care from pediatric to adult healthcare systems, including primary and specialty care. The transition model is broader in scope. Its aim is to not only facilitate the transfer of care to the adult healthcare system but to address the other domains of emerging adulthood. Recently published systematic reviews have noted that most studies examining HCT models of care have focused primarily on the transfer of care to adult providers [1, 3, 12, 21, 22, 27, 56].

Comprehensive Model of Care. A framework of several HCT service models reported is based upon a comprehensive model of care [4–7, 54]. These models incorporate a broader perspective: facilitating the transfer of care and transition to adulthood. The HCT preparation period of comprehensive models of care is usually longer; it may extend from early adolescence to emerging adulthood, distinguishing the transfer of care as an event in contrast to the process of healthcare transition planning [3, 5, 6].

Comprehensive models of care are based upon a life span approach that addresses the biopsychosocial and developmental needs of AYASHCN. A comprehensive HCT model acknowledges that AYASHCN needs permeate all aspects of living and, therefore, require attention to other domains including educational, employment, social, and community living [15, 54].

The scope and breadth of comprehensive service models are dependent upon the resources and support within the healthcare setting and in the community of choice of the AYASHCN and their family. For example, the scope of interdisciplinary (ID) services in a tertiary level pediatric healthcare setting will differ from services in a rural setting. There may be limited job training and employment opportunities for AYASHCN in rural compared to urban settings. Other alternatives can be considered such as local volunteer experiences, informal networking with family and friends, as well as online training programs.

Initiation of a comprehensive HCT program takes time and can be done incrementally. The development of the capacity to provide comprehensive services is a process requiring ongoing time and effort. The development of a HCT program plan that includes the framework for implementation with benchmarks to be achieved as identified in the tables of this chapter will ultimately facilitate the achievement of its mission and goal.

Based upon a comprehensive HCT approach, self-management instruction is not solely focused on the fundamental tasks and knowledge required for daily SHCN care. Self-management instruction attends to other lived experiences that the AYASHCN encounter that are affected by the chronic condition. For example, instruction on acquiring the health-related accommodations needed in the educational settings is provided to ensure the student receives the support needed to perform academically [11].

Instruction about the provision of health-related accommodations in schools includes advocacy training for parents/guardians and AYASHCN about obtaining needed health-related accommodations. The HCT coordinator would review the adolescent's current IEP or 504 plan in terms of what is currently being provided and what may be needed. Also, the HCT coordinator would be expected to provide instruction to the AYASHCN and parents/guardians about the student's legal rights and protections pertaining to receiving additional services and supports at school as illustrated in the case example at the end of the chapter.

Comprehensive models of care continuously explore AYASHCN needs for advocacy, service and support referrals, and instruction as it pertains to their lived experiences and future planning. For example, youth employment could be explored at age 16 years. Participation in youth employment programs is associated with positive psychosocial outcomes [55, 56]. Additionally youth employment programs provide AYASHCN with preparatory job training and experiences in a supportive and supervised environment as the students will be trained by job coaches who, in many instances, will be coordinating these efforts with school personnel. HCT coordinators are in an ideal position given their understanding of the health-related services and supports needed for employment purposes to make referrals to youth employment programs that include these job training and placement experiences.

Other activities related to employment options include counseling AYA on their rights and protections as an interview applicant to address issues of disclosure concerning their condition. Anticipatory guidance can be provided about employment issues concerning provision of workplace accommodations, workplace resources, and dealing with coworkers and supervisors. These long-term recommendations enhance AYA efforts to obtain employment.

These selected examples of services provided illustrate the scope and depth of HCT planning offered in comprehensive models of care. The extent to which comprehensive services can be provided will depend on the resources available not only within the healthcare setting but also within the community itself.

Pediatric-Adult Provider Transfer Models of Care. There are differences between the pediatric and adult systems of healthcare, including the family-centered model in pediatrics compared to patient-centered model in adult care [26, 57]. For additional content on the service delivery differences between these two systems of care, refer to Chap. 15.

Training and clinical practice concerns pertaining to the provision of care during HCT have been identified in studies of pediatric and adult providers. Pediatricians and adult providers identify the limitations of their training for AYASHCN and hence their hesitancy to provide services to this growing population [57]. Pediatricians identify gaps in their training and clinical practice pertaining to HCT planning best practices.

The competencies and comfort level of adult providers to provide care to AYASHCN have been described [58]. Furthermore, adult providers have AYASHCN referred to them as ill-prepared healthcare consumers [59].

The limitations of knowledge and clinical acumen of providers of both systems of care are not confined to provision of primary and specialty care services. It also involves knowledge of community resources and other health-related services such as therapy, durable equipment and medical supply vendors, and disability advocacy organizations. It also involves knowledge of when to confer with interdisciplinary colleagues to initiate referrals for services and adult community-based agencies that can provide assistance for psychosocial development and the competencies associated with the emerging adult [26, 60, 61]. Capacity building of providers on both ends of the bridge of two very different service models is needed to improve care [26].

The goal of the transfer of care process is to eliminate the potential for discontinuity with the provision of care and to ensure the receiving primary care and specialty adult providers are receptive, professionally competent, and well informed about the AYA's past medical history and treatment needs [4, 11, 15]. The importance of the transfer of care has been emphasized in position statements of pediatric, pediatric and adult consensus, and interdisciplinary organizations. The transfer of care to an adult system of healthcare is the centerpiece of the healthcare transition model. The methodology of implementing the transfer event has been operationalized differently in various models reported. Table 36.4 displays different models for the transfer of care.

These transfers of care models include shared service with both the pediatric and adult providers for a time-limited interval [11, 25], occurring in the pediatric setting pre-transfer or post-transfer in the adult setting [62]. A variation of the formal joint service model is combined meetings with pediatric and adult providers including AYA with SHCN and parents present [28]. Some programs have shared services pre- and post-transfer in both settings [23, 63]. A comparable model has been developed involving nurses from the pediatric and adult teams who provide joint services to AYA with epilepsy [64]. An expansion of the medically-oriented shared services is the "joint working" collaboration involving pediatric and adult care providers from various service systems of care-interagency colleagues with whom one is not accustomed to working (i.e., job developers and rehabilitation specialists) [64].

Another model is the intermediate transfer from pediatrics to an adolescent/young adult clinic prior to final transfer to adult services [32, 65, 66]. Other models locate adult providers on a

Table 36.4 Transfer of care models

Program	Providers involved	Transfer protocol
Cadario et al. (2009)	HCT coordinator; pediatric and adult endocrinologists	1. Joint pediatric and adult endocrinologist last visit in pediatric care 2. Summary report given to AYA and adult MD 3. Joint pediatric and adult endocrinologist first visit in adult care
Hankins et al. (2012)	Pediatric hematology nurse case manager	1. Tour of adult clinic and meet members of adult hematology team 2. Lunch with pediatric team to discuss issues pertaining to transfer of care and transition 3. RN case manager schedules appointment with hematology adult services
Hazel et al. (2010)	Nursing	1. Transfer letter sent to adult rheumatologist 2. Youth (between 17 and 19 years of age) are responsible for making appointment 3. Nursing monitors until transfer is complete
Holmes-Walker et al. (2007)	HCT coordinator (diabetes educator)	1. Transfer of care from pediatric to young adult clinic (YAC) prior to final transfer to adult services 2. YAC based in adult hospital 3. Telephone reminders 4. Missed appointments rebooked 5. After hours telephonic support
Pyatak et al. (2017)	Pediatric and young adult case managers (public health background)	1. Transfer from pediatric clinic to young adult diabetes clinic (up to 30 years of age) 2. Received reminder calls for clinic visits and follow-ups pertaining to clinic attendance
Steinbeck et al. (2015)	HCT coordinator	1. Provided hard copy and flash drive of transfer information including adult providers, diabetes resources; letter of referral 2. Scheduled appointment with adult provider 3. Structured series of calls to follow up on adult appointment
Vanelli et al. (2004)	Pediatric and adult MDs	1. Information about the forthcoming transfer of care provided at 18 years and older 2. 1st joint peds/adult visit in pediatric care 3. 2nd joint peds/adult visit in adult care

less formalized basis [8–10, 14, 25] wherein the AYA is referred to the adult provider without any prior contact. In one transfer program, the AYA is expected to assume the responsibility for making the appointment [67], whereas in another model, the HCT coordinator is responsible for coordinating the transfer of care [68].

There is general agreement that transfer of care should be a formalized and structured process [4, 11]. An important feature, although not always possible, is to have ongoing professional communication between the transfer teams based upon mutual commitment and collaboration [15]. Effective channels of communication are predicated on forming partnerships with providers in the community, which requires additional time and effort between service centers/providers. However, the pediatric-adult partnerships described here can be more difficult for larger medical centers that draw populations of AYASHCN from larger catchment areas. In these situations, an emerging adult may live far beyond the catchment area of the pediatric medical center, and forming professional linkages with adult providers in their community may be difficult for the pediatric specialty program. In other circumstances, the emerging adult may move to another state to attend college or for employment, economic, or social reasons, creating additional challenges to locating adult primary and specialty care providers.

HCT Program Outcomes

The measurement of HCT program outcomes has been a challenge. The majority of outcomes reported are service-oriented rather than

AYA-oriented. Additionally, examination of the outcomes associated with HCT has been predominately focused on those associated with the transfer event such as clinic attendance, avoidable emergency department visits, and hospitalizations [6, 69, 70].

HCT outcomes are categorized into two primary types: disease specific and non-disease specific [6]. As several systematic reviews of the literature demonstrate, the predominant outcome type reported to date is disease-specific [3, 66], including biomedical measures and use of clinical services, such as hospitalization rates and emergency department use. Non-disease outcomes include demographic data (i.e., race, age, gender) and psychosocial variables (patient activation, self-efficacy, employment, postsecondary enrollment) and those related to the transfer of care event (i.e., age of transfer, AYA self-report, clinic attendance, rates of retention).

Examples of biomedical indices used to measure HCT outcomes include A1C levels [32, 71], tacrolimus levels [42], and other indices of health status such as blood pressure and adverse consequences of congenital adrenal hyperplasia [72]. Transition outcomes suggested for monitoring adolescents with hemophilia are bleeding episodes, joint functioning, and adherence to factor replacement regimen [73]. Several studies reporting on the transfer of care of AYA with solid transplants have examined transplant loss and rejection as HCT outcomes [74, 75]. The biomedical indices serve as proxy measurements of adherence behaviors and uninterrupted access to adult care [3, 6, 42, 69]. Examination of disease-specific outcomes has limitations as the findings may not be generalizable.

Outcomes with generic focus have more applicability [3, 69]. The most frequently studied non-condition indices are clinic attendance [6], patient satisfaction [21, 42, 76, 77], and quality of life [6, 42, 78]. Few studies have examined outcomes associated with postsecondary education, employment, housing, or rates of marriage/partnerships with significant others [69, 79, 80] due in part to the emphasis on the transfer of care [3, 6, 80]. The paucity of research investigating psychosocial outcomes is due in part to the lack of theoretical frameworks used as the basis for the study [2, 3, 12, 16, 66, 81, 82]. There is also a lack of consistency with the time intervals selected to measure the outcomes of HCT services. A recent systematic review reported that measurement of study outcomes ranged from 3 to 24 months [4]. However, many challenges exist with tracking AYASHCN into other systems of care, and include loss to follow-up, assignment of new identifiers that prohibit tracking, and the costs associated with long-term tracking [4, 6].

Limitations of the Science

Limitations of the aforementioned research include:

- Lack of rigorous designs as few randomized control designs were cited [3–6, 70, 80, 81].
- Small convenience samples with insufficient power for analysis [4].
- A lack of consistency with the operationalization of the construct of transfer of care.
- Insufficient details provided about the interventions make it difficult to understand intervention effects [3–6, 70, 80, 81] and synthesize findings across studies [26].
- Few intervention models incorporate technology; unlike previous generations, this generation of AYASHCN is accustomed to and often prefers it [15].

Also noted was the testing of the models themselves as the interventions were complex and were not adequately tested. Each of the studies reviewed incorporated multidimensional interventions that were not sufficiently tested as to program effects [4, 70]. Most of the reviews on the transfer of care focus on specialty care; few have explored the transfer of primary care [4]. Even fewer studies have explored issues pertaining to other populations of youth such as those with mental health problems [26, 80]. Importantly, the use of measurements that are reliable and valid has not been consistently evident in the studies conducted as reported in the HCT systematic reviews [3–6, 70, 83] nor has the time frame for evaluating outcomes [6].

Future studies will need to address the issues and limitations identified to create the evidence needed for HCT intervention models. The reviews and critical analyses provide a guide to designing more rigorous and methodologically sound research needed to advance the field of practice and science.

Case Example

David and his mother come to the Spina Bifida Clinic several months after his corrective bilateral foot surgery as he has been followed postoperatively in the orthopedic clinic by the orthopedic surgeon. During his recovery period, he has been homeschooled as he was to stay off his feet. The HCT coordinator meets with David and his mother to monitor how his postoperative recovery is progressing as well as the academic and health-related accommodations he is currently receiving while being homeschooled.

Prior to his foot surgery, the HCT coordinator had conferred with David and his mother about the forthcoming accommodations he would need while recuperating at home. The HCT coordinator reminded them that the school is required to provide the academic accommodations he needs in order to keep up with his schoolwork. The HCT coordinator explained the accommodations David would need during his postoperative recovery while at home: (a) home visits by one of the high school teachers assigned to work with students who have homeschooling and (b) provision of classroom assignments and the tutoring needed from the homeschool teacher to keep up with the classwork. David and his mother are advised to consult with the 504 coordinator at his high school to formulate the plans needed. Additionally, they were advised to contact the HCT coordinator in the event they encountered any problems.

During the first Spina Bifida Clinic appointment following his surgery, David and his mother are asked how his homeschool program progressed as he recovered postoperatively at home. David replied that now that he was back at school, he was working hard to "catch up" with his course work and "bring up" his grades. When queried about these statements, his mother replied that a homeschool teacher was not available to tutor David on his academics. In turn, David said that he had problems keeping up with his classes. David indicated that he was confident that he could "pull up his grades" to his former GPA average. As the HCT coordinator heard this recounting of his current academic challenges, David and his mother were reminded of the rights and protections that were afforded to him with having a 504 plan.

A plan was devised to enable David and his mother to participate in discussions with school personnel about the accommodations that David currently needed. The accommodations included the following plans: (a) access to academic tutoring in the classes wherein his grades were not equivalent to his typical academic performance, (b) additional time to complete his makeup work for each of the classes without academic penalty, (c) extra time initially for test-taking for examinations in his classes, and (d) academic advisement pertaining to his current GPA and strategies for raising up his GPA.

As this case example illustrates, David's needs for healthcare support extend beyond the typical confines of the clinical setting. David's lived experience with spina bifida coupled with his current stage of development and lifestyle extends into the school and community setting, wherein he lives, learns, and grows.

This case example describes a prototype of an AYASHCN lifestyle situation that is often experienced as reported in national surveys and research studies. Situations as described here can have enduring effects that last a lifetime such as school failure, due in part to the inadequate and/or lack of appropriate resources and supports that AYASHCN need in the other domains of their life. A HCT coordinator and members of the HCT team, sensitive to the lived experience of AYASHCN, can do much to promote the provision of needed resources and referrals.

Conclusion

This chapter presented a detailed discussion of the HCT models currently used in practice and tested empirically. This examination included a discussion of the key structural components and the distinguishing processes of various HCT intervention models. A discussion of the HCT outcomes was provided. This chapter concluded with the limitations associated with the state of the science as it is hindered by the designs and methods that are insufficient to generate the evidence needed to identify effective models of HCT care that will serve to improve outcomes for AYASHCN. Although the science of the field is a representative of the emerging field, much progress has been made within the last decade. Many more studies, thoughtful commentaries, and systematic reviews are strong evidence of the growth of the field. Given this backdrop of growth and development, it is likely more substantive evidence will be forthcoming to foster the implementation of effective HCT models of care.

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