

# Topical Review: Advancing Research on the Transition to Adult Care for Type 1 Diabetes

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## Abstract

**Objective** To acknowledge and address the gaps in health care transition (HCT) in type 1 diabetes (T1D) literature by proposing an expanded model that could guide future research. **Method** Topical literature review. **Results** Empirical research examining the outcomes of HCT in T1D is limited by methodological and interpretive problems. The relevant evidence indicates that HCT outcomes are both multi-systemic and multidimensional; the authors propose an expanded model that incorporates multiple stakeholder perspectives of HCT outcomes. **Conclusions** The development and validation of a standard index of HCT outcomes based on the expanded model of HCT outcomes could provide a means for assessing relations between HCT readiness and outcomes, facilitate the design of longitudinal studies to determine the predictive validity of HCT readiness assessment and the efficacy of HCT interventions, and inform the design and evaluation of appropriate interventions targeting those mechanisms.

**Key words:** emerging adulthood; health care transition; transition outcomes; type 1 diabetes.

The health care transition (HCT) from pediatric to adult care is a critical developmental stage in the lives of emerging adults with type 1 diabetes (T1D) who are expected to deal with the complex demands of T1D care in addition to the normative challenges faced by this age-group (Arnett, 2012; Weissberg-Benchell, Wolpert, & Anderson, 2007). Not surprisingly, the process and outcomes of the transfer from pediatric to adult care are inadequate, including poor continuity of care, out-of-range glycemic control, and suboptimal self-care behaviors (Hendricks, Monaghan, Soutor, Chen, & Holmes, 2013; Lyons, Becker & Helgeson, 2014). Yet, relative to the extensive psychological and behavioral research on T1D and the public health significance of health outcomes in this growing population, research on HCT in T1D has not impacted T1D health care policy, practices, or outcomes appreciably.

There is consensus in the HCT in T1D literature that health outcomes of the HCT are generally poor (Lyons et al., 2014). However, existing T1D research tends to be methodologically weak (Lyons et al., 2014) without consensus on the specific components or operational criteria defining successful HCT, which impedes comparison across studies and advancement of this research. Therefore, this line of research could have a greater impact on outcomes of care for

emerging adults with T1D if it is both more rigorous and more clearly focused (Lyons et al., 2014; Peters et al., 2011).

In this topical review, we present an integrative framework that could lead to more actionable research on these problems through an expansion of the (Schwartz, Tuchman, Hobbie, and Ginsberg 2011; Schwartz et al., 2013) Social-Ecological Model of Adolescents and Young Adult Readiness for Transition (SMART). SMART is an empirically derived and validated model of HCT readiness. SMART offers a valuable framework for understanding HCT readiness and the variables influencing it, but the model stops short of addressing the question: "What outcomes should patients be prepared to achieve?" In this paper, we put forth an expansion of SMART adapted for the T1D population that adds a conceptualization of variables that may influence how HCT readiness affects youths' biomedical, behavioral, and emotional outcomes.

We review literature on outcomes of HCT in T1D and justify incorporating the multidimensional nature of HCT outcomes in our expanded model. We outline an agenda for stakeholder-guided research for understanding the multidimensional outcomes of HCT in T1D. Finally, we argue that development and validation of a standard, multidimensional profile of HCT outcomes could

facilitate longitudinal studies of mechanisms affecting HCT outcomes and inform future intervention trials (Table I).

### SMART Overview and HCT-Related Constructs

SMART was developed to address the complexity of HCT and to establish evidence-based programs and assessment tools (Schwartz et al., 2011; Schwartz et al., 2013). SMART applies a social-ecological framework to HCT readiness, emphasizing multiple factors and stakeholders (i.e., patients, parents, and providers) as influences on HCT readiness. SMART purports that objective factors (e.g., access/insurance, demographics, cognitive status) influence subjective factors (e.g., knowledge, beliefs, motivations, self-efficacy, relationships, and psychosocial functioning), which are potentially modifiable through intervention. Although validated with pediatric cancer survivors, SMART was developed and designed to be generalizable to any health condition by incorporating literature on HCT in people with special health care needs in general and in specific chronic illnesses other than pediatric cancer (Schwartz et al., 2011). Indeed, the SMART components are applicable to T1D, as most are addressed in the pertinent American Diabetes Association (ADA) recommendations (Peters et al., 2011).

In proposing SMART, the authors differentiated several important constructs (Schwartz et al., 2011). The HCT process is the

purposeful, planned movement of emerging adults with chronic health conditions from pediatric to adult health care systems (Blum et al., 1993). An ADA expert panel proposed recommendations for navigating the HCT process in youth with diabetes (Peters et al., 2011), although they were derived from expert opinion rather than a strong evidence base. *Transfer*, a discrete event, is the movement to a new health care setting, provider, or both (Betz & Telfair, 2007). *HCT readiness* is the affective, behavioral, and cognitive capacity of the adolescent and his or her primary support system (family and medical providers) to prepare for, begin, continue, and finish the HCT process (Betz & Telfair, 2007; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004).

SMART does not address *HCT outcome* as a model construct (Schwartz et al., 2011), although multiple outcomes of the HCT process are commonly assessed in the HCT literature. In this paper, we define HCT outcomes as the end result of the HCT process whether or not the patient completes the transfer to adult care (i.e., initiates care and follows up with an adult health care provider or becomes lost to follow-up). As described in detail below, we propose that HCT outcomes are multidimensional (i.e., include biomedical, behavioral, and emotional components) and multi-systemic (i.e., influence and are influenced by multiple stakeholders and systems). The objective of the HCT process is for the patient to demonstrate *successful HCT outcomes* (a multidimensional construct).

**Table I.** Proposed Research Strategy for Advancing Research in Health Care Transition in Type 1 Diabetes

Goals	Methods	Output
Hypothesis generation		
Engage key stakeholders through qualitative interviews to identify the components of HCT outcomes and define successful HCT outcomes.	Conduct semi-structured interviews with the following key stakeholders: Patients who recently transitioned to adult T1D care; Caregivers of patients who recently transitioned to adult T1D care;	Hypothesis generating work resulting in operational definition of an HCT outcomes construct. Using Patient Reported Outcome Measurement Information System (PROMIS) methods (Forrest et al., 2012; i.e., multiple stakeholder engagement, qualitative interviews), the themes and subthemes that are identified can be used to populate the initial content of an HCT outcomes measure.
Develop an operational definition of the successful HCT outcomes construct.	Referring providers (pediatric T1D providers); Receiving providers (adult T1D providers); Expert providers in HCT in T1D (research productivity and/or impressive clinical experience in HCT in T1D).	
Measure development		
Develop and validate a multidimensional HCT outcomes index.	Continued use of PROMIS methods: Cognitive interviewing Translatability review Reading level analysis Item analysis Factor analysis Item-response theory calibration Differential item functioning assessment Concurrent validation.	An HCT outcomes measure will provide a multidimensional profile of a patient's HCT outcomes along biomedical, emotional, and behavioral dimensions. It remains to be seen whether these various outcome components are inter-correlated or independent, as no single study has explored that question.
Facilitate generalizable conclusions from cross-sectional and longitudinal studies and randomized controlled trials by relying on a standard index of HCT outcomes.		
Longitudinal studies		
Establish predictive validity of HCT readiness assessment and construct validity of HCT outcomes measure.	Test whether a previously validated HCT readiness measure predicts scores on a new measure of HCT outcomes in T1D.	Validation of HCT readiness and outcome measures could lead to a clearer understanding of the mechanisms affecting HCT outcomes and of the independence or associations among the various dimensions of HCT outcomes.
Provides measurement across the temporal spectrum of the HCT process.		
Intervention trials		
Design and development of HCT interventions for testing in randomized controlled trials.	Validated HCT readiness and outcomes measures can be used to inform interventions designed to facilitate a successful transition (Schwartz et al., 2011), which would likely target various stages of the HCT process and the multiple components and systems involved.	This work could contribute the first rigorous RCT of an HCT intervention in the T1D population. The proposed HCT outcomes measure would enable direct comparisons of results across future HCT studies in the T1D population.

Continued research that targets limited dimensions of HCT outcomes is unlikely to clarify which aspects of HCT readiness and of the HCT process influence each dimension of HCT outcomes.

### Multidimensional Nature of T1D Outcomes of HCT

The development of SMART represents significant progress in the literature on HCT; however, it does not account for the full spectrum of the HCT process including HCT outcomes. Indeed, the authors acknowledged that specification and measurement of HCT outcomes is fundamental in advancing this research in HCT (Schwartz et al., 2011). In the T1D literature, measures of HCT outcomes vary among studies and there is inconsistency about which measures to obtain, when to obtain them, and the criteria indicating a successful HCT. A systematic review of HCT interventions in T1D identified eight different HCT outcomes used inconsistently across studies: (1) hemoglobin A1c (HbA1c) (83%), (2) acute complications (67%), (3) continuity of post-HCT care (50%), (4) chronic complications (33%), (5) self-management skills (17%), (6) disease-specific knowledge (17%), (7) rate of screening for complications (33%), and (8) diabetes-related quality of life (17%) (Crowley, Wolfe, Lock, & McKee, 2011). Studies reporting T1D outcomes before and after HCT also vary in the types of data reported, including timelines for measurement of pre- and post-transfer HbA1c, rate of loss to follow-up, and number of hospitalizations (Daneman & Nakhla, 2011; Lyons et al., 2014). In an investigation of the association between HCT characteristics and HbA1c, Garvey and colleagues (2012) identified three measures of “unsuccessful transition,” including inadequate preparation for HCT, prolonged gap between pediatric and adult care, and patient dissatisfaction with the transition process. This varied specification of HCT outcomes creates multiple problems with interpreting results from existing HCT in T1D research:

- The methods and theoretical rationale for targeting specific HCT outcomes are rarely described. Although researchers frequently choose HbA1c as their HCT outcome measure because it reflects glycemic control (Lyons et al., 2014; Schwartz et al., 2014), the conclusions that can be made from this research are limited by the concern of emerging adults dropping out of health care and a consequential inability to obtain and compare results (Lyons et al., 2014) and de-emphasis of other important dimensions such as health care utilization, HCT satisfaction, emotional well-being, and quality of life (Schwartz et al., 2014).
- Expected changes in HCT outcomes are rarely hypothesized. For example, HbA1c continues to worsen in the early years of emerging adulthood (Bryden et al., 2001; Insabella, Grey, Knafel, & Tamborlane, 2007). Thus, for an HCT to be considered successful, should HbA1c decrease or remain stable?
- The heterogeneity of HCT outcomes limits the ability to draw generalizable conclusions about the effects of the HCT process on physical and psychological health, as well as the efficacy of interventions to improve HCT readiness.
- Few studies utilized patient-reported outcomes and none engaged stakeholders (e.g., emerging adults, family members, referring and receiving physicians) to specify research questions or develop measures of HCT outcomes that are valued by these groups (Institute of Medicine, 2011; Patient-Centered Outcomes Research Institute, 2014).
- Longitudinal studies demonstrating that HCT readiness predicts HCT outcomes could confirm the validity of the HCT readiness

construct (Schwartz et al., 2011). Also, characteristics of HCT readiness and of the HCT process may have varied associations with specific dimensions of HCT outcomes.

Taken together, research indicates that a single measure of HCT outcomes is inadequate. Studies that focus on a single outcome (e.g., HbA1c) neglect the multidimensional nature of HCT outcomes, and a measurement system assessing all dimensions of HCT in T1D outcomes would be valuable.

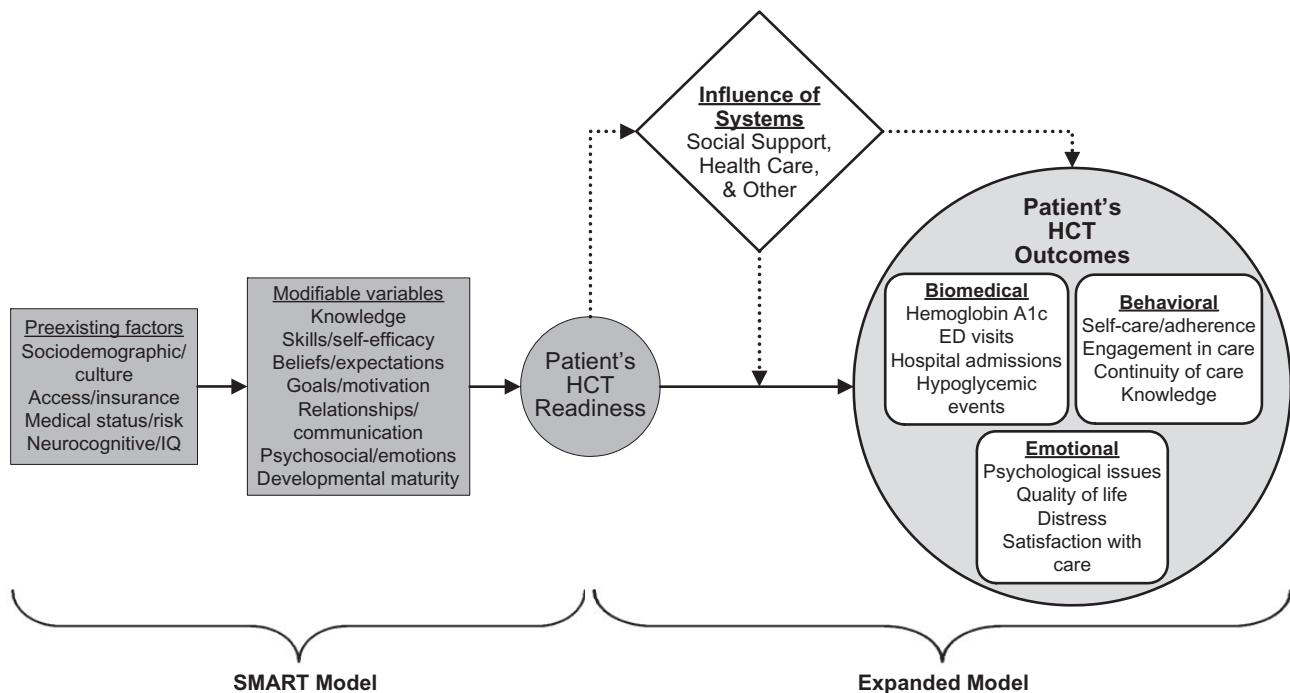
### Influence of Multiple Stakeholders and Systems on T1D Outcomes of HCT

Consensus statements and review papers acknowledge that transition is a multi-systemic process involving patients, caregivers, and health care providers, but most of the research on HCT neglects the systemic nature of the HCT process (Schwartz et al., 2011). Thus, there is a need to examine HCT outcomes that are of major importance to each stakeholder group to establish the relative weight of each outcome dimension and to determine if specific HCT outcome dimensions are affected by specific predictor variables (e.g., SMART preexisting factors, modifiable factors, and level of HCT readiness). Schwartz and colleagues (2013) found divergent opinions among patients, parents, and providers on the most important HCT components in pediatric cancer survivorship, supporting the value of considering multiple stakeholder perspectives.

Studies of HCT in T1D indicate that differences between pediatric and adult health care may impede successful HCT outcomes. For example, patients report less support and guidance, lack of time to discuss T1D management (Pacaud, Yale, Stephure, Trussel, & Dele-Davies, 2005), and accessibility issues in adult health care systems (Hilliard et al., 2014). However, there is no research examining the perspectives of pediatric and/or adult providers regarding their opinions on the various dimensions of HCT outcomes or of criteria for defining successful HCT. Studies in other chronic illnesses have revealed a number of health care system issues that likely contribute to HCT outcomes. Providers endorse discomfort in treating emerging adults (Okumura et al., 2008), acknowledge that the HCT process is poorly coordinated (Oskoui & Wolfson, 2012a), report inadequate training in providing care for emerging adults (Chira, Ronis, Ardoin, & White, 2014; Oskoui & Wolfson, 2012b), and cite insufficient human resources, lack of reimbursement for extra time, and continued parental involvement as barriers to successful HCT outcomes (Chira et al., 2014; Clarizia et al., 2009). If pediatric and adult providers have unique perspectives on HCT readiness, processes, and outcomes, it is important to consider their perspectives in addition to those of patients and families when defining transition outcomes.

### Expanded Model of HCT in T1D

We offer an expansion of SMART to account for the multidimensional nature of HCT outcomes in emerging adults with T1D and to specify systemic influences on these outcomes. In our expanded model (Figure 1), the patient's HCT readiness directly affects HCT outcomes, but multiple systems including social support (e.g., evolving relationships with families, friends, and significant others), health care systems (e.g., quality of the transfer to adult care, relationships with providers, differences between pediatric and adult health care), and other systems (e.g., managed care, postsecondary education, and workplace) moderate and/or mediate these outcomes. For example, Garvey and colleagues (2013) found that gaps



**Figure 1.** Expansion of the social-ecological model of adolescents and young adult readiness for transition to include health care transition outcomes.

in health care continuity were predicted by lack of an adult provider name or contact information (i.e., health care systems influences), competing life priorities (i.e., college and workplace influences; social support influences), and insurance problems. Moreover, Hilliard and colleagues (2014) suggest that parents, friends, and romantic partners may play critical roles in T1D self-management across emerging adulthood and should not be ignored during the HCT process (i.e., social support influences). Our model proposes that an emerging adult who has demonstrated HCT readiness may be successful throughout the HCT process and may therefore demonstrate successful HCT outcomes. However, we further propose that the moderational and/or meditational influence of those systems may serve as risk or protective factors for a successful HCT and/or help explain how and why certain HCT outcomes are or are not successful. This would imply that interventions and programs designed to target components of these systems may promote successful HCT outcomes.

We propose that HCT outcomes include biomedical (e.g., HbA1c, severe hypoglycemia, ED visit frequency, and hospital admissions), behavioral (e.g., self-management/adherence, engagement in care, continuity of care, and disease knowledge), and affective components (e.g., satisfaction in adult care, psychological functioning, quality of life, and distress), which may reveal the contributions of HCT readiness and process variables. It is unknown if or how these various HCT outcome dimensions are associated or independent, as no single study has thoroughly explored that question.

### An Agenda for Future Research

One method to advance research on HCT in T1D outcomes could be a stakeholder engagement strategy designed to validate our expanded HCT model. This would involve a systems approach that focuses on key stakeholder perspectives (patients, caregivers, pediatric providers, and adult providers) of the multiple components of successful HCT outcomes, which could be used to form an

operational definition of the multidimensional HCT outcomes construct. This information would then guide the development and validation of an evidence-based, multi-informant assessment method that yields a multidimensional profile of HCT outcomes in T1D (Table 1). Perspectives of key stakeholders could be incorporated in the validation of the SMART expansion and the development of an HCT outcomes measure via a mixed-methods approach (e.g., qualitative interviewing, expert review, cognitive interviewing, and multi-informant design). Such a measure could be developed using Patient Reported Outcome Measurement Information System (PROMIS) methods (Cella et al., 2007), which are standards set by NIH for developing patient-reported outcomes and are an ideal tool for pediatric psychologists given the multidimensional (i.e., biopsychosocial) nature of the outcomes we measure (Forrest et al., 2012). Such an HCT outcomes measure could provide an empirically valid, standard index of outcomes in future HCT research that could allow researchers and clinicians to utilize a consistent method for evaluating the multidimensional construct of HCT outcomes.

The development and validation of a standard index of HCT outcomes could be an important contribution to HCT research in T1D. There are advantages to initially applying the development of transition outcomes measures to T1D because patients are expected to engage in regular, perhaps quarterly, follow-up visits (Peters et al., 2011). However, development of a measure of HCT outcomes that is not tied to a specific diagnosis might have broader scientific value. Combining this work with the work of Schwartz et al. (2011, 2013) and others on HCT readiness could advance HCT research by providing a means for assessing the relationships of HCT readiness to outcomes. Such a measure could facilitate the design of longitudinal studies, which are needed to determine the predictive validity of HCT readiness assessment and the efficacy of HCT readiness interventions. Validation of HCT readiness and outcome measures could lead to a clearer understanding of the mechanisms affecting HCT outcomes. This work will directly inform the design and evaluation of appropriate interventions targeting those mechanisms.

*Conflicts of interest:* None declared.

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