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Health care transition planning and outcomes: What's next?

Although the concept of health care transition (HCT) was introduced about 30 years ago, many fundamental issues persist related to the practice and research in this field.[1–3] Elemental questions that persist, require attention and pertain to the use of reliable/valid measurements of the HCT process and readiness, what constitutes successful HCT outcomes and the factors that facilitate or hinder acquisition of HCT skills. The answers to these questions require close collaboration between a broad range of constituents representing youth, young adults and adults with childhood-onset conditions, parents/caregivers, healthcare professionals/administrators from the pediatric- and adult-focused systems, and those who address issues concerning education, employment, community living, rights, and protections.

While worldwide efforts tried to achieve consensus on what constitutes a successful HCT, there are a number of factors affecting quantification of evidence-based outcomes.[4–6] These factors include systems of care that vary considerably worldwide, not only in terms of public or privately funded health services; but also, the extent of health condition involvement and social determinants of care. It is evident that idealized HCT outcomes are not only a challenge to identify or attain, but they may be limited in their scope of application in the global setting.

Importantly, this dialogue has been primarily rooted in pediatric healthcare systems, with scant perspectives offered from the adult-focused systems. It is essential that the viewpoints of experts (adults with childhood-onset conditions and their families) and information generated from various data sources (e.g., large condition-specific databases or lifestyle national registries) enhance the empiric evidence of HCT.

This HCT practice and research issue closely aligns with what constitutes a successful HCT process and transfer of care to adult-focused services. Experts question current views of the metrics pertaining to care access from primary and specialty health care providers. Colleagues from the adult-focused systems health, employment, postsecondary education, and community living systems could provide relevant input and engagement with the child-focused systems.

A myriad of questions remains unanswered regarding longitudinal data collection on HCT. Foremost among the issues to be determined, is the extent of follow-up data gathered on adults with childhood-onset conditions who transferred to adult-focused systems of care. Earlier investigation suggested that attendance on the first follow-up visit to an adult-focused provider was considered a successful HCT outcome.[4] Recent beliefs cast doubt on that indicator, suggesting a more substantial period of time for measurement, not just the simple act of attending the first clinic appointment.[7,8] However, longitudinal data on access to healthcare is a challenge for those who transfer into an adult-focused systems without the same electronic health registry or patient identifier.

HCT outcomes that have been proposed include establishment of services with primary and specialty care providers, enrollment in a health insurance plan, appropriate use of emergency department services, and planned hospitalizations. However, the feasibility of follow-up by pediatric providers/systems has been a challenge. Furthermore, the HCT literature has been heavily influenced by pediatric-based evidence. To address this shortcoming, the adult-focused providers/systems could initiate investigations to inform the pediatric-focused systems about the clinical and psychosocial profiles of adults with childhood-onset conditions. Incidentally, scant evidence exists regarding the psychosocial outcomes associated with adults with childhood-onset conditions.

To date, examination of survival data among adults with childhood-onset conditions has focused exclusively on physiological/clinical outcomes. Despite the improved survival rates of these patients, other long-term metrics associated with adulthood such as quality of life, employment, level of education, socioeconomic status, and social relationships, fall short when compared to the typical adult population. When examining quality of life issues, evidence demonstrates the shortsightedness of viewing quality of life as a physiologic construct. In fact, the Delphi process by the International and Interdisciplinary Healthcare Transition Research Consortium with patient, caregiver, and providers' input, identified quality of life as the top outcome of HCT,[9] followed by health-related knowledge/skills, health service outcomes and a social outcome. These lifestyle outcomes are relevant when viewing the concept of health in the fullest sense.

Insights from the perspective of adult-focused providers regarding survivors of pediatric-onset conditions' HCT/self-management knowledge gaps, would provide feedback on issues to be addressed in both the pediatric- and adult-focused services. For example, given that brain maturation occurs in the mid-twenties, should promotion and acquisition of HCT/self-management competencies occur only by the pediatric-focused community? Or should those services also take place in adult-focused communities? What gaps in condition management could be discovered by exploring the dimensions of unanticipated health circumstances, disrupting typical patterns associated with the individual's health-wellness continuum and informing practice improvements? Could more thorough investigations be conducted into this population's pattern of unanticipated and unjustified hospitalizations or emergency departments visits? Would exploring psychosocial factors and social determinants of health associated with adverse events, provide insights on improving HCT preparation and long-term health self- management?

Investigations examining the barriers and challenges that adult-focused providers report, uncovered insights about the provision of care to adults with childhood-onset conditions.[10–12] As the findings

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demonstrate, one of the major reasons reported by providers' reluctance to accept adults with childhood-onset conditions, is the lack of comfort and competence to treat this population. This admission is a Rubicon for addressing the training needs of adult-focused providers. Acquisition of expertise requires a multifaceted approach to solving this service impasse that adversely affects adults with childhood-onset conditions. One of the answers is to advocate for curricular modifications in medical, nursing, psychology, and other health disciplines' school curriculums. Advocating for curricular changes can be accomplished with active involvement by health-related associations/societies and local, regional, state, and national level organizations. Few examples of intergenerational service focus are provided in the literature to be emulated.[13,14]

As the adult-focused side of the HCT process is investigated, there will be a broadening of research pertaining to this field, resulting in more collaboration and interest to learn from each system of care. For example, questions are likely to be raised as to what the age parameters are to be examined by adult-focused clinical and research scientists. Other questions include: up to what age should be the cutoff for outcomes associated with HCT planning?; what is the lifespan of issues that warrant investigation and long-term planning?; are practice changes needed in pediatrics to facilitate a less disruptive continuum of care into the adult-focused system?; Should practice elements associated with the adult-focused model of care be integrated earlier into the pediatric system of care?; or do HCT guidelines need to be formulated that incorporate adult-focused components of care such as visits scheduled solely with patients or appointments made by patients?

This editorial highlighted the myriad of questions and unresolved issues to be addressed next, in the field of HCT practice and research. Engagement of adult-focused providers/systems of care is needed to advance the evidence that will support the development and implementation of complementary service models, bridging the discontinuity between pediatric and adult-focused healthcare.

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