

Review

Three practical principles in planning and developing health care transition: our personal perspectives

Yukihiro Hasegawa¹, and Helena Gleeson²

¹*Division of Endocrinology and Metabolism, Tokyo Metropolitan Children's Medical Center, Tokyo, Japan*

²*Department of Endocrinology, Queen Elizabeth Hospital, Birmingham, UK*

Abstract. Health care transition (HCT) is defined as an uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive process that is needed to assist the transition of young people from child to adult-centered care. Its importance has been discussed in pediatrics over the past decades but it is still a challenging subject to realize. In this mini-review, the authors present their personal opinions on HCT. The following are their three core suggestions: (1) patient-centered support and monitoring; (2) hospital-centered infrastructures with key personnel; and (3) flexibility in planning and modifying HCT procedures. We believe our recommendations could apply to most of the pediatric endocrine disorders, which usually require lifelong follow-up. This approach will be verified in the future.

Key words: health care transition, patient-centered, hospital-centered, flexible approach

Introduction

It is estimated that 10% of adolescents and young adults with chronic diseases need medical support (based on data from the United States) due to improved survival rate over the past decades (1). The transition from child to adult care is a crucial step; as they mature, children's need for support from their pediatricians and parents becomes less so that they can successfully transition to adult care. In our field of pediatric

endocrinology, many conditions require lifelong follow-up; thus, it is vital for pediatric endocrinologists to be conversant with health care transition (HCT) for patients with a variety of conditions including type 1 diabetes, Turner syndrome, and hypopituitarism (2).

The Japanese Society for Pediatric Endocrinology created the HCT committee in 2015, in which one of the authors, YH, has been involved. The authors provide the readers their personal opinions on HCT in this mini-review.

Definition of HCT and How to Facilitate It

HCT is defined as an uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive process that focuses on the medical, psychosocial, and educational/vocational needs of adolescents and young adults as they transition from child to adult-centered care (3). The initial planning

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Corresponding author: Yukihiro Hasegawa, MD, PhD, Division of Endocrinology and Metabolism, Tokyo Metropolitan Children's Medical Center, 2-8-29 Musashidai, Fuchu, Tokyo 183-8561, Japan
E-mail: yhaset@gmail.com

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Table 1 Three core principles for a successful health care transition (HCT)

Start the process early around the time patient enrolls in secondary school and recognize any family, socioeconomic, or health issues that may require additional support.

Make sure that all care providers have undergone training in adolescent health, and that a transition policy has been prepared and agreed to by all.

Identify and share the differences between child and adult services with the patients and their family to facilitate the transition, including how to make appointments, seek advice, and access emergency care.

must begin early and continue into providing adult health care services until the transition is complete. The minimal medical goal of HCT is to ensure a smooth transition while continually providing medical treatment of comparable quality. Developmentally appropriate healthcare (DAH) is essential in supporting young patients to achieve independence and understanding of their disease during the HCT period (4); DAH considers young patients' 1) maturity level, 2) cognitive abilities, 3) psychological status, 4) needs with regard to long-term conditions, 5) social and personal circumstances, 6) caring responsibilities, and 7) communication needs (5). HCT is challenging, in part because, to be effective, it needs to meet the changing needs of young patients as they achieve greater independence in their ability to manage their medical condition and other aspects of their life (6). Evidence suggests that poor HCT planning may be associated with deterioration of the patients' medical condition (6, 7).

To facilitate HCT, several tools have been used, including checklists for transition readiness and transition summaries (8, 9). Transition summaries can contain 1) patients' medical history, 2) current information on their health, educational, and social care needs, 3) emergency care plans, and 4) a description of the HCT support that has been provided so far and what needs to be done post-transition. Although these well-known tools are undoubtedly useful in facilitating HCT, it is also widely acknowledged that they alone are not sufficient for a successful HCT for all institutions, medical providers,

caregivers, and young patients.

Consequently, we offer three principles that we believe will contribute to a successful delivery of HCT (Table 1). In addition, this mini-review outlines our three core suggestions for ensuring successful HCT not only in Japan but throughout the world.

Three Core Suggestions in Planning and Developing HCT

Patient-centered support and monitoring

The central figures in HCT are the young patients, who should make their own choices and decisions regarding the care and support they receive during HCT, including how they want their parents/caregivers to be involved. Parents/caregivers should be involved in this process and be ready to serve as an important source of support. Therefore, it devolves upon the medical professionals to listen to the patients and their parents/caregivers and ask them about their preferences in HCT.

One aspect of patient-centered care is to understand better the young person's current situation and needs. The psychosocial interview is useful for assessing risk and resilience and should begin by developing rapport with the patients by talking to them alone and explaining confidentiality issues before commencing the assessment. Home, Education/Employment, Eating, Activities, Drugs, Sexuality, Suicidal ideation and Safety [HEEADSSS; cf. ref. (10)] is an established psychosocial interview framework for adolescents and young adults that can be

useful at this stage.

HCT should also be customized for the individual patient, as indeed ideally every other medical process should be. The medical, social, and psychological backgrounds of young people are diverse. For example, the timing of the transition should be determined individually with each young patient when they are medically, socially, and developmentally stable.

In addition to the patient-centered support described above, monitoring progress before and particularly after the transition is essential for the success of HCT. For example, if a patient has been transferred to adult services but does not show up for appointments, the patient and his or her family should be contacted; besides, the medical outcomes should be followed-up in the long-term, and the satisfaction level of the patient and caregivers with the HCT process should be analyzed. The resulting data may contribute to improving future patient-centered HCT.

Hospital-centered infrastructures with key personnel

While clinicians are on the frontline in establishing the HCT process, the whole hospital should be involved. Both pediatric and adults health care centers should nominate one senior executive to champion and develop HCT strategies and policies as well as one manager to provide practical leadership in delivering HCT (5). In our experience, administrative staff is crucial; at our hospital, they have facilitated the creation and distribution of informational pamphlets on HCT, made appointments with nurse transition clinics, and collected data on HCT. Our definition of staff includes the receptionist, who is often the first contact point for any appointments.

Regular, hospital-wide meetings involving senior executives and managers from both child and adult services across as well as within specialties should be organized to encourage the sharing and implementation of adequate

practices to refine the HCT process for the benefit of all concerned. Within specialties, the opportunity for exchanging information on young patients in HCT with challenging circumstances, such as special physical or mental health needs involving social care services is invaluable.

Although there should be a team approach to the HCT process, one liaison worker should preferably be assigned to each young patient. Again, this is especially important for those with complex social or medical needs, who are likely to require care from various specialists. The assigned liaison worker, who can be any practitioner, nurse, social worker, general practitioner, or even an administrator, can coordinate the HCT process and support the patient. The role of the liaison worker would be to oversee the HCT process and help the young patient connect with various medical and social providers as required, and serve as an additional source of support during HCT (5, 8). The liaison worker can also provide continuity as the patient and caregivers navigate the HCT process and meet different members of the medical team.

Flexibility in planning and modifying HCT procedures

There is no one model of HCT superior to the others. The chosen model should be adapted to the capacity and environment of the relevant institution or specialty. There is evidence that small teams often provide better continuity of care than larger teams. Even if the team only consists of doctors and nurses, the delivery of DAH and HCT planning is possible using the self-completed checklists and signposting to other resources as required.

Another important consideration is encouraging a meeting between the child and adult care teams before the transition, which is recognized as crucial to a successful HCT; this may take the form of a joint clinic, joint appointment, or arranging a visit to the child and adult-care centers on the same day.

Finally, evidence related to HCT needs to

increase so that the process can be improved (11). There are a few randomized controlled trials (RCTs) on HCT to date as far as we know. Future studies on HCT should not only examine medical outcomes and continuity of care but also the assessment of patients' satisfaction level as well as potential educational/vocational and psychosocial outcomes. Future studies should also focus on both child and adult services with the ultimate aim of achieving better quality medical care.

Conclusions

In the present mini-review we proposed three core-suggestions based on our experience with HCT: (1) patient-centered support and monitoring, (2) hospital-centered infrastructures with liaison workers, and (3) flexibility in planning and modifying HCT procedures. We believe our recommendations could apply to most of the pediatric endocrine disorders, which usually require lifelong follow-up. These proposals will be verified in the future.

Conflict of Interest: There are no conflicts of interest to disclose.

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