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Introduction

As reported in the literature, people with disabilities (PWD) may be at risk for negative medical outcomes as they transition from the pediatric to adult care system¹. According to the American Academy of Pediatrics, Health Care Transition (HCT) is a process that includes preparation, planning, tracking, and follow-through for all youth and young adults². HCT requires a shared responsibility among patients, caregivers, pediatric and adult care clinicians to provide and continue support for developing self-management skills and to prepare young adults to make their own medical decisions³. Primary care physicians (PCPs) play a crucial role in the HCT process. Several studies affirm that more training and professional development opportunities for adult providers are needed, not only on how to guide youth through HCT, but also on how to provide care to these patients as adults⁴.

Purpose

This study sought to examine the experiences of Connecticut (CT) adult PCPs in the HCT process for PWD as well as to assess the level of and type of training they have received to provide care to their adult patients with disabilities.

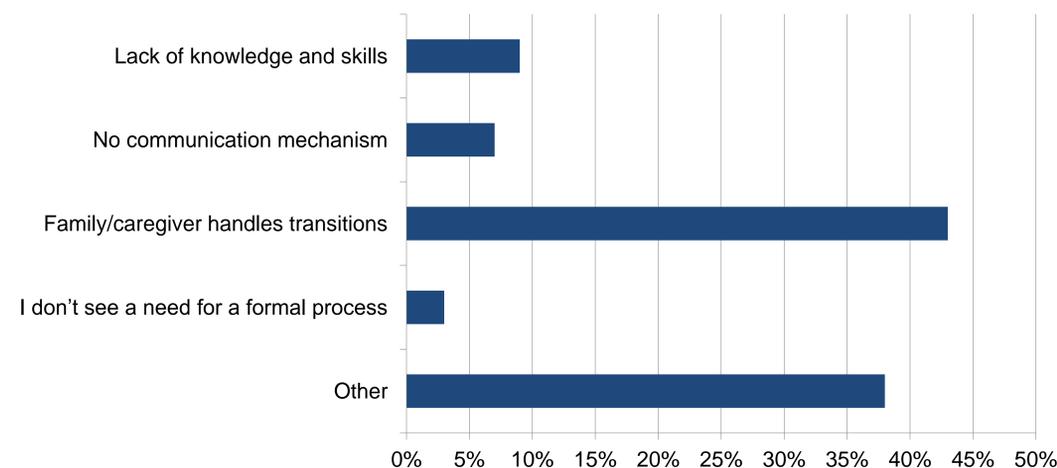
Methods

Licensed CT physicians who currently provide primary health care to adults, defined as either internal medicine or family medicine physicians, were invited to participate in an online survey. Their email contact information was provided by the Connecticut Department of Public Health. The final sample (n=79) of participants consisted of a majority of internal medicine physicians (75%) who have been practicing for an average of 25 years (range 2-43 years).

Results

The majority of participants reported that they do not participate in the HCT process. Figure 1 describes reasons why participants do not participate.

Figure 1. I do not participate in the HCT process because



Participants who responded "other" in Figure 1 provided further details. Several reported that as adult care providers, HCT is not part of their scope of practice. Statements from these participants included:

"I am not a pediatrician,"

"I see adults only,"

"I am internal medicine, not pediatrics or family medicine," and

"don't see pediatrics."

Nearly 18% indicated that there is no formal HCT process or procedure at their place of employment. For those who responded that there is a formal HCT process at their place of work, components of their HCT process are included in Table 1.

Table 1. HCT at my work includes

Formal process and procedures	11%
Written materials for patient/family about adult care	18%
Formal communication between pediatric and adult providers	9%
Periodic evaluation of the process	15%
Care/transition coordinator	14%
Unsure	18%

Results continued

Regarding previous training in the care of adults with disabilities, 58% reported that their own professional experience served as their training while 30% responded that they never received any training.

Conclusions and Next Steps

In order to provide quality primary care to adults with disabilities, it is important to understand that the HCT process includes the participation of the patient, caregiver, and health care providers including adult PCPs. Formal training opportunities for adult PCPs about the HCT process and their role in this transition are needed so that PCPs can provide better health care experiences for PWD. It is also essential for PCPs to consider developing a formal HCT process in order to meet the medical needs of their adult patients with disabilities. As these results are specific to CT, future studies regarding HCT should be done at a national level as well as focus on the experiences of PWD themselves in order to improve the health and quality of life of adults with disabilities.

References

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