

Abstract:

GROWING UP AIN'T EASY: TRANSITION in ADOLESCENTS WITH CHILDHOOD-ONSET DISABILITIES

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Background and aims: Transition is a planned movement of youth with chronic medical conditions from child-centered to adult-oriented healthcare systems. Most transition models applied for youth with chronic medical conditions, and recently also applied to childhood onset disabilities (COD). Most COD data come from developmental conditions (DC). This study describes transition clinic multidimensional process of youth with COD on account of both DC and acquired disabilities (AD).

Methods: Data of adolescents with COD treated in a Transitional Medicine Clinic (N=40, mean age: 17.47 ± 2.38) were examined. Patients were interviewed and filled-up the "Ready-Steady-Go" questionnaires according to age (ages 12-14, 15-17, and ≥ 18). The questionnaire describes knowledge and needs regrading medical condition, self-management, life-skills and etc. Participants' general visit characteristics, transition level, and appointment attendance were examined. Differences between adolescents with DC and AD in the transition level were assessed.

Results: Most adolescents had DC (60%). Seventy-two percent had previous records in the rehabilitation department. The rest were referred from health-care professionals outside of the hospital (28%), the internet (10%), and word of mouth (10%). The mean number of visits to the clinic was 2.82 ± 1.44 . Reason for coming to the clinic was mainly for follow-up (71%). In 12-14 age group, in comparison to adolescents with AD, adolescents with DCD presented better transition scores (34.85 ± 8.57 vs. 27.25 ± 2.75). Themes brought up in the interview included lack of knowledge regarding sexual health, plans for the future, differences between child and adult health-care, and the transition process.

Conclusions: The transition clinic is being attended mainly by youth with DCD. Only a small percentage of the clinic's patients heard about the clinic from outside of the hospital's sources. Meaning, there is not enough knowledge regarding transitional medicine. Overall, most adolescents know very little about the transition process and adult healthcare.

Keywords: Transition, childhood onset disabilities