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**You're in Charge: An EARly Intervention, Family Focused Transition Preparation Program in Canada**

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**Purpose:** PURPOSE: Families and youth frequently experience the transition from pediatric to adult health services with chronic illness as stressful, poorly planned and lacking in preparation. Many literature reviews and empirical studies have been conducted to enhance health care providers understanding of best practice in the area of transitions, and yet the perceptions of youth and families continue to indicate improvements are needed. This purpose of this study was to describe the development of an innovative, early preparation program for young adolescents with chronic illnesses and their families in Canada. Current theoretical and empirical evidence in transition and chronic disease self-management have informed the design and implementation of this program. Findings from the first year and future directions for research and practice are also presented.

**Methods:** METHODS: This intervention study used a pre and post measure design to determine if the intervention resulted in shift towards increased readiness for transition in both youth and parent participants. The specific outcome of interest is readiness for behavioral change related to healthcare transitions. The You're in Charge Program is an early intervention, family focused, transition preparation program for families with young adolescents with chronic illness or childhood onset disability. The multidisciplinary approach in this program includes youth engagement and leadership, parent education, goal setting and action plan development. Implemented in a camp setting, this program is designed to help families initiate the discussions and actions that will prepare them to navigate the transition from pediatric to adult health care.

**Results:** RESULTS: Both youth (n=12) and parent (n=14) participants showed changes in their scores after participating in the program. Youth participants had statistically significant improvements in the behavioral domain items ( $p=.009$ ) while parent participants had statistically significant improvements in the knowledge domain items ( $p=.001$ ). Both groups had improvements in the other domains although these changes were not statistically significant. These results indicated a shift from the preparation to action phase of the readiness continuum.

**Conclusions:** CONCLUSIONS: The early findings from the first year of the You're in Charge program indicate that participants shift in their perceived readiness for behavioral change in preparation for the transition from pediatric to adult health care. It is not known if these behavioral changes are maintained after participation in the program. The need for additional exposures to the intervention is not known. It is also not known if participation in the program affects the actual transition experience later in the adolescents' lives. Qualitative feedback from participants collected in the four-week period following program participation indicates that the goal setting and action planning are particularly effective elements of the intervention. Further investigation of the long-term effects and determination of the potency of program elements is needed to refine the intervention.

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**Patients' Perception of Transition Importance, Readiness and the Likelihood of Future Success: The Role of Anticipatory Guidance.**

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**Purpose:** The Maternal and Child Health bureau has identified transition to adult health care as a core outcome of the community-based system of services required for all children with special health care needs under Title V. This core outcome is measured using 4 items included in the National Survey for Children with Special Health Care Needs (NS CSHCN). These items assess whether the youths' doctors usually or always encourage adolescents to take increasing responsibility for their care, and whether doctors had provided anticipatory guidance about transition to adult health care (i.e. the child's provider had discussed health insurance; the shift to adult health care providers, and the child's changing health care needs as he or she approaches adulthood). While these items represent expert consensus, the relationship to the actual transition process has never been established. Thus, it is unclear whether encouraging responsibility for care or transition anticipatory guidance has an impact on how patients perceive the transition process.

**Methods:** All participants (n=191, mean age 19.0 (1.7)) were enrolled in an urban SSI Medicaid health plan for youth with special health care needs and cared for in a large academic adolescent health center. Participants answered the 4 NS CSHCN transition items and reported their perception of transition importance, readiness and likelihood of future success. Linear regression was used to assess the relationship between a report of provider encouraging responsibility for one's own health and transition anticipatory guidance with patient perception of transition importance, readiness and likely future success. We further evaluated the impact of age and level of care coordination needs on these perceptions.

**Results:** While the majority of participants (n=151) perceived that transition was important, there was no relationship with provider encouragement of responsibility for health care or transition anticipatory guidance. Participants reporting receipt of transition anticipatory transition guidance, either discussing health insurance, the shift to adult health care providers, or the child's changing health care needs as he or she approaches adulthood, were all independently associated with the perception of readiness ( $p < 0.01$ ) and that transition would be successful ( $p = 0.002$ ). For participants ages 19-22yo (n=97), reporting a discussion with their provider about transition predicted a higher perception of readiness ( $p = 0.005$ ) but not perception of likely success. Among participants with high care coordination needs

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(n=41), discussion of transition and changing health care needs predicted perceived readiness ( $p=0.001$ ) and likely future success ( $p=0.004$ ). Reported provider encouragement for increasing responsibility did not predict perception of the transition process.

**Conclusions:** Receipt of transition anticipatory guidance does seem to relate to perception of transition readiness and likelihood of success. For some youth with higher care coordination needs, this anticipatory guidance has the largest impact. Self-management encouragement does not seem to impact transition process perceptions. Future studies need to measure health outcomes, not just perceptions, of transition anticipatory guidance and self-management encouragement.

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### **Mental Health Predictors of Successful Transition from Pediatric to Adult Diabetes Care**

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**Purpose:** It has been observed that adolescents with T1DM may not be ready for the independence necessary to transition successfully to adult care, as evidenced by their struggles with diabetes self-care following transition, as indicated by low diabetes self-efficacy. There is some evidence to suggest that mental health may predict successful transition to adult care. Specifically, adolescents struggling with T1DM who have also been referred for mental health services are less likely to successfully transition to adult care. The current study aimed to: 1) determine whether a number of mental health related factors predict successful transition; and 2) determine whether these mental health factors predict the length of time between the final pediatric and first adult appointments.

**Methods:** Adolescents with T1DM visiting a diabetes transition clinic at a pediatric hospital were invited to participate in this study. During this visit an Adolescent Medicine Specialist and an Adult Endocrinologist interviewed participants separately. Adolescents who agreed to participate also completed a series of questionnaires pertaining to mood, anxiety, and eating disorder symptoms.

**Results:** 163 eligible adolescents participated in the study, of which 72 were lost to follow-up. Patients who associated appropriated diabetes self-care with positive outcome expectations were more likely to successfully transition to adult care within 12 months of being seen by the diabetes transition clinic. Patients who reported feeling general ineffectiveness and affective problems were more likely to take longer to transition to adult care.

**Conclusions:** To our knowledge, this is only the second study observing the effect of mental health difficulties on transition from pediatric to adult diabetes care among adolescents with T1DM. The present study suggests that cognitions regarding diabetes outcome expectancy and personal

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effectiveness, as well as mood, both contribute to markers of transition. These suggest opportunities for intervention to assist youth in successfully transitioning from pediatric to adult diabetes care.

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72.

### **Work With Me: Improving Self-management Skills through Youth Centered Communication**

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**Purpose:** Autonomy, the expression of choice and freedom in one's actions is a key element of the successful transition to adulthood and adult healthcare. The extant literature suggests that youth are lacking autonomy and are therefore ill-prepared for the transition to adulthood. This lack of preparation can have negative effects of their health. Therefore, in this study we sought to examine the relation between patient-centered communication and autonomy among youth with and without mobility limitations, hypothesizing that relatedness would serve as a mediator in this association.

**Methods:** Data come from the MyPath project, a longitudinal survey study that investigates the transition to adulthood and from pediatric to adult centered healthcare for youth with and without mobility limitations. The community-based sample from the Midwest includes 543 young people (52% female, 92% White) with (n=286) and without (n=267) mobility limitations between the ages of 16 and 24. Participants completed an online survey at baseline and at six months following enrollment. The dependent variable, healthcare autonomy, is defined by a 4-item scale ( $\alpha = .74$ ) measured at 6-months. Predictor variables measured at baseline, include patient-centered communication (PCC)(3 items,  $\alpha = .81$ ) and relatedness (6 items,  $\alpha = .76$ ). Covariates included age, sex, geographic location, maternal education level, and assistive equipment use. Multiple regression models tested whether the association between patient-centered communication and autonomy was mediated by relatedness.

**Results:** Bivariate analyses demonstrated that PCC was significantly related to youth's reports of relatedness and autonomy for youth with and without mobility limitations. We found evidence of partial mediation among youth without mobility limitations. However, for youth with mobility limitations, relatedness was not a significant mediator in the relation between PCC and autonomy, and it was not associated with health-related autonomy independent of PCC.

**Conclusions:** Health care providers who communicate with adolescent and young adult patients in a patient-centered way increase the likelihood that patients will feel connected to providers and want to take charge of their own health care. More frequent patient centered communication was related to both higher levels of relatedness and health-related autonomy for young people with and without mobility limitations. For youth without mobility limitations, the association between how frequently they experienced patient-centered communication from their health care provider and their self-reports of autonomy six months later was partially mediated (explained) by their sense of relatedness to their

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health care providers, suggesting that a young person's connection to her healthcare provider contributes to higher levels of autonomy around managing her own health. However, this was not the case for youth with mobility limitations. Independent of feelings of connection to health care providers, having experienced more frequent patient-centered communication resulted in higher levels of health-related autonomy for young people with mobility limitations. These findings suggest that medical education should consider assuring that health care providers know how to communicate in a patient centered manner in order to support all youth, regardless of disability, in the transition to adult healthcare.

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73.

### **Got Transition? Using Readiness Assessments for all Adolescents**

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**Purpose:** Transition is a hot topic in the era of health care reform. In the past few years there has been a great deal of research and new initiatives focusing on the process of transitioning from pediatric to adult health care. The majority of this research has been done with patients with special healthcare needs (SHCN). Review of the literature reveals a paucity of research looking at youth without special health care needs, or well youth. We were interested in how well youth navigate this transition, as this is a time when many patients drop out of the health care system. It is our belief that these well youth are equally under prepared for the transition as their peers with SHCN.

**Methods:** For this study, children with special health care needs were defined in accordance with the definition from the Maternal and Children's Health Bureau, as " those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." Well patients were those patients identified as having no chronic medical needs beyond the typical adolescent. The patient population included patients ages 14-21 from the Georgetown Adolescent Clinic. Patients were identified as Well or SHCN. Patients in both groups were identified through medical records and from an internal registry of patients with SHCN. To assess patients' readiness for transition a readiness assessment containing 19 questions was used. This assessment is a modified version of the checklist used in The Got Transition Program, a national effort to support the transition process in patients with SHCN. The answers for each question were assigned a score of one to four. The mean score was calculated in each category and for the readiness ruler among both the well and SHCN groups. The means of the two groups were then compared for each category using a two sample T-test.

**Results:** The well group scored lower in readiness on thirteen of the questions while the SHCN group scored lower on five questions. For the questions where the SHCN had lower scores, none were

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significant while for the well group, five were significant. The data showed that the adolescents without SHCN were slightly less prepared in the transition process than those with SHCN. Specifically, well adolescents need more support in understanding how and when to make appointments and in understanding their insurance status.

**Conclusions:** A smooth and effective transition from pediatric to adult care is essential. Currently well youth and those with SHCN are under prepared for this transition. Research and transition initiatives are needed for all youth.

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