A USEFUL TECHNIQUE FOR PATIENT ACTIVATION AND ENGAGEMENT IN YOUNG ADULTS WITH CONGENITAL HEART DISEASE: INSTRUCTIONAL CONVERSATION USING THE CONGENITAL HEART HEALTH ACTIVATION TRANSITION TOOL

Aims Adolescents and young adults (AYA) with congenital heart disease (CHD) are a high-risk group particularly during the transition period from pediatric to adult care. We aimed to create a clinic-based tailored CHD transition program to improve adolescent knowledge and activation, increase participation in shared-decision making, and facilitate patient empowerment through Instructional Conversations (IC).

Methods We conducted a needs assessment with key stakeholders (pediatric and adult cardiologists, parents, and adolescents with CHD) to identify potential barriers to transition. A three-pronged approach was taken to spearhead transition education: (1) Streamlining dedicated transition visits; (2) Creating individualized learning plans (ILP) to encourage shared decision making and patient engagement; and (3) Utilizing motivational interviewing (MI) and instructional conversation (IC) to administer a novel patient activation tool: CHHATT. The Congenital Heart Health Activation Transition Tool.

Results Six Plan-Do-Study-Act (PDSA) cycles were conducted and included streamlining educational/assessment materials, modifying teaching style, implementing MI and IC, and creating the CHHATT tool. During PDSA cycles, three major themes emerged regarding patient activation and engagement. First, families better received transition services if given advanced notice. Thus, we built separate clinic visits for program introduction (14 year old) and serial education/training visits (15 year old). Second, having a streamlined script for education of various CHD diagnoses and creating ILPs resulted in increased patient engagement and shared decision-making. Third, patient self-assessments poorly revealed true knowledge deficits. MI was used to reveal these deficits through creation of a CHHATT tool, which reveals knowledge/skills gaps and reinforces education through guided IC. Patients demonstrated increased confidence when using the CHHATT to teach-back to parents and ask physician questions. Parents’ verbalized satisfaction in the increased empowerment teens demonstrated after serial visits using CHHATT.

Conclusion We created a CHD transition program for AYA with streamlined serial education, individualized learning plans, and motivational interviewing and instructional conversation. Patients demonstrated increased activation and engagement using our novel tool CHHATT. We strive to lead transitional clinical care and further patient success by (1) introducing additional assessment tools for health literacy and resilience and (2) guiding clinical practice by sharing our sustainable/billable program model for CHD transition programs.

Factors Associated with Low Physical Activity Among In-School Adolescents

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Introduction/Aim Despite the established health benefits of physical activity, the health risks of inactivity and the various interventions to encourage physical activity, a substantial proportion of young people remain insufficiently active. Studies have attempted assessing factors associated with physical activity but do not provide explanations for the dynamics of underlying factors. Similarly, interventions do not show significant difference in control. This study therefore was undertaken to determine factors associated with physical activities among the target population using health promotion theories to provide explanations of their dynamics.

Methods The study was a community-based cross-sectional study which employed a validated instrument developed to measure level of physical activity, assess patterns of sedentary lifestyle and personal-level and environmental-level dispositions of the respondents towards physical activity. Cronbach’s alpha internal consistency measure of the instrument was 0.814 and all statistical tests were set at p= 0.05 level of significance as cut off.
Result Respondents (n=532) were male (50.8%) and female (49.2%) whose age ranged from 13-18 years Prevalence of physical activity was 49.59%, while sedentary lifestyle was 71.34%. We found that 39.9% of the respondents spend over 10 hours daily in school and at lessons with majority of their parents working away from home; respondents’ mother whose job required them staying away from home most of the time in a day were 72.0% while 81.6% of respondents’ fathers had jobs that warrant them being away from their home majority of the time in a day. The study showed a significant relationship between levels of physical activity and personal-level disposition (R-value 0.205) and environmental-level disposition (R-value 0.395) respectively at P=0.0001.

Conclusion Considering the low prevalence rate for physical activity among adolescents and the health risk of sedentary lifestyle, it is important to adopt a more intentional approach to intervention using health promotion tested theories adopted in this study. Such interventions should be aimed at harnessing individual interest and environmental dispositions within the context of school, home and neighbourhood.

Aims Developing self-management skills is part of growing up for many young people with long-term conditions (LTCs) such as chronic kidney disease (CKD). However, young people can find it challenging to become independent at managing their LTC and there is limited evidence for how health-care professionals (HCPs) can support this process. This study aimed to find out how young people take on responsibility from their parents for managing their CKD and the HCP’s role during this process.

Methods A qualitative study, using a grounded theory approach. In-depth individual and dyad interviews were conducted with nine young people aged 13-17 years old with CKD, 11 parents and ten HCPs from renal multidisciplinary teams. Participants were recruited from two UK children’s renal units.

Results The transfer of self-management responsibility between young people, parents and HCPs is a fluid and bi-directional process. Both parents and HCPs view it is as their ‘job’ and believe they have a responsibility to support the young person to become more involved in their health-care. Opposing tensions contribute to the complexity of the process, including: 1) Timing: parents consider the process of handing over self-management responsibility within a wider context of their child growing up and gaining independence. However, transition frameworks and statutory responsibilities impact on how HCPs support the transfer of responsibility and means that timing is service-led, rather than based on family’s needs. 2) Approach: young people, parents and HCPs appear to have different priorities and approaches; families initially focus on what self-management activities the child can ‘do’, whereas HCPs’ starting point looks at what the child ‘knows’. 3) Outcome: differing understandings and expectations around ‘effective’ self-management and what it means to be responsible can impact on what young people, parents and HCPs each hope to achieve.

Conclusion The parent-to-child transfer of self-management responsibility is a complex process, shaped by various tensions. Establishing positive relationships between young people, parents and HCPs through building and maintaining trust appears essential in supporting young people to develop independence in managing their LTC.