Concordance Between Youth and Parents' Scores and Responses on the Am I ON TRAC for Adult Care Questionnaire

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Purpose: The Am I ON TRAC for Adult Care questionnaire, a measure of readiness for transition from paediatric to adult care for youth with special health care needs, has both youth and parent versions. The purpose of this study was to examine the concordance between youth and parent ON TRAC questionnaire scores and responses.

Methods: During clinic appointments 200 adolescents ages 12-19 and their parents/guardian (n=191) were recruited from waiting rooms of four outpatient clinics (diabetes, neurology, gastrointestinal, cardiology) at BC Children’s Hospital, Vancouver for a study of transition measures. Participants completed a study package, which included demographic information and the Am I ON TRAC for Adult Care questionnaire. The ON TRAC questionnaires consist of a knowledge scale and behaviour index. The youth and parent questionnaires ask youth and parents respectively to report on the youth’s health and self-care related knowledge and behaviour. Each youth-parent dyad was treated as a matched pair and dependent t-Tests were performed to examine the concordance between youth and parent ON TRAC scores and responses.

Results: Of the162 youth-parent dyads that were examined most accompanying parents were female (77%), 54.5% were accompanying sons, and the parent reported mean youth age was 15.2 (SD=1.9). Participants were distributed across the clinics, with 37% from diabetes, 27% cardiology, 27% gastroenterology, and 9% neurology. Results from dependent t-Tests of ON TRAC knowledge and behaviour scores found on average, youth scores were significantly higher than parent scores, i.e., youth reported they possessed more health and self-care knowledge (t(152)=3.32, p=.001, r=.26) and consistently engaged in health care behaviours more frequently (t(161)=4.66, p<.001, r=.34) than their parents reported. Dependent t-tests were also performed for each individual item. Of the 22 ON TRAC items, 17 had higher youth mean scores and 5 had higher parent mean scores, but only 8 items had significantly different mean scores; for 7 of these, youth had the higher mean scores reporting greater knowledge about their medications and consistently taking medications on their own, getting to appointments as well as contacting clinics when symptoms worsen, asking health care providers health related questions more frequently, and thinking beyond high school. Only one item, “I talk to friend(s) about my problems or worries,” was rated higher by parents. There was a wide range in youth-parent difference scores, and extreme differences between youth and parent scores (> 2 SD) were identified for 5.2%, 5.5%, and 3.1% of the knowledge, behaviour and cut-off scores respectively.

Conclusions: Youth with chronic conditions and their parents appear to have different assessments of adolescents’ health-related knowledge, self-management skills and consistency of self-care behaviours.
Using both youth and parent versions of the ON TRAC questionnaire could help clinicians initiate important conversations between adolescents and their parents about the youth’s level of health-related knowledge, self-management skills and behaviours, and where large discrepancies in assessment exist between them, clarify potential differences in perspective. Such conversations could be pertinent to preparing adolescents and their families for the transition to adult medical care.

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**Do Parents of Adolescents with Cancer Know What their Teens Want?**

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**Purpose:** To examine the congruence between adolescents with cancer’s needs for end-of-life care and their families’ perception of those needs.

**Methods:** We surveyed adolescent/parent dyads recruited from an urban hospital-based adolescent outpatient and inpatient settings, using the Lyon Advance Care Planning Survey. Thirty-four participants (n=17 adolescent/parent dyads) randomized to the intervention study arm of a randomized clinical trial were surveyed. The survey was administered separately to adolescents and their parent by a trained facilitator. Kappa statistics determined congruence between adolescents’ responses and their families’ perceptions of how their adolescent would respond.

**Results:** Adolescents with cancer aged 14-21 and their 22-62 year old parents were recruited and enrolled with IRB approved assent/consent. Adolescents mean age was 16.6; 63% male; 58% African-American. Diagnoses were 47% leukemia, 26% brain tumor, 16% solid tumor, 11% lymphoma. Adolescents rated their health as good to very good (94%). “When do you think it is the best time to bring up end-of-life decisions?” Six adolescents, 35% (6/17) and one surrogate did not know. Of those who had an opinion, 56% of adolescents preferred to talk about advance care planning issues earlier in the course of illness (when first diagnosed or ill) or at each stage of their illness. The majority of families (88%) preferred to wait to talk about these issues later (first hospitalized or if dying). Five areas of congruence were found between adolescents and their families: Fear of dying in an institutional setting (7 dyads not sure or not afraid; 4 dyads afraid with 60% congruence Kappa=0.60, p=0.028); If dying, fulfilling personal goals/pleasures (2 dyads not sure or not important; 13 dyads important with 61% congruence, Kappa=0.61, p=0.044); If dying, saying everything I want to say to people in my family (1 dyad not important; 16 dyads important with 100% congruence, Kappa =1.000, p=0.059); Attend religious services (6 dyads not sure or not important; 8 dyads important with 77% congruence, Kappa=0.78, p=0.002); Consider yourself religious/spiritual (3 dyads no; 13 dyads yes with 82% congruence, Kappa=0.82, p=0.006). Congruence without statistical significance was also found:
understanding treatment choices (16/17 congruent), being physically comfortable (16/17 congruent), and being free from pain (16/17 congruent). Survey items important to =90% of adolescents without congruence with families: dying in home and being at peace spiritually. Six adolescents (35%) would want to know if they were dying. Dying a natural death was important for 15 patients (88%).

**Conclusions:** While there are substantive areas of agreement between teens and parents and their decisions, there are important areas where parents don’t know what their teens want. Parents need help initiating these conversations and want to know.

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**Effectiveness of a Structured Educational Intervention Using Psychological Delivery Methods in Children and Adolescents with Poorly Controlled Type 1 Diabetes: A Cluster Randomised Controlled Trial of the CASCADE Intervention**

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**Purpose:** The CASCADE study assessed the feasibility of providing a clinic based structured educational group programme using psychological approaches to improve long-term glycaemic control, Quality of life and psychosocial functioning in young people (yp).

**Methods:** 28 UK paediatric diabetes services were randomised to intervention or control. The study recruited 362 children (8-16 years) diagnosed with Type 1 Diabetes for over 12 months with a mean 12 month HbA1c >=8.5. 43 healthcare practitioners were trained in the intervention of four group education sessions led by a Paediatric Diabetes Nurse with another team member. Primary outcome was HbA1c measured at baseline, 12 and 24 months. Secondary outcomes included hypoglycaemic episodes, hospital admissions, diabetes regimen, knowledge, skills and responsibility for diabetes management, intervention compliance, clinic utilisation, emotional and behavioural adjustment and general and diabetes-specific QOL. Intention-to-treat comparisons of outcomes at 12 and 24 months were completed.

**Results:** The intervention did not improve HbA1c at 12 (0.11, (CI -0.28 to 0.50) P=0.584), or 24 months (0.03, (CI -0.36 to 0.41) P=0.891). Intervention parents at 12 and YP at 24 months have higher scores on the diabetes family responsibility questionnaire. YP report reduced happiness in body weight at 12 months. Only 68% of groups were run. 96/180 families attended at least one module. Reasons for low uptake included difficulties organising groups and work and school commitments. YP with higher HbA1cs were less likely to attend. Parents and YP who attended groups described improved family relationships, improved knowledge and understanding, greater confidence and increased motivation to manage.
diabetes. Twenty four months after the intervention nearly half reported that the groups had made then want to try harder and had carried on trying.

**Conclusions:** A high-quality, complex, pragmatic trial of structured education can be delivered alongside standard care in diabetes clinics. Health care providers benefited from behaviour change skill training and can deliver pragmatic aspects of a structured education programme after relatively brief training. The process evaluation provides insight the model and highlights strengths and aspects that may have contributed to the failure to influence primary and secondary outcomes.

**Sources of Support:** Funding for this study was provided by the Health Technology Assessment programme of the UK National Institute for Health Research.

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**You’re Not Alone: Social Connectedness in a Hospital Based Chronic Illness Peer Support Program**

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**Purpose:** As young people with chronic illness are living longer, there is a growing need to provide care for their psychosocial needs as they enter adolescence and early adulthood. Having a chronic illness may involve lengthy periods away from school and peers, which could isolate the young people from normal social experience and development. A peer support program for adolescents with chronic illness might be an effective way to ameliorate the effects of social isolation. The Chronic Illness Peer Support program (ChiPS) at the Children’s Hospital at Westmead (CHW) in Sydney, Australia commenced in 2005, adapted from the Olssen et al (1998) program. ChiPS at CHW initially comprises 8 weekly “talking group” meetings of 2 hours duration co-facilitated by a nurse and a young adult with a chronic illness located in a hospital setting. Commonly, those who participated in ChiPS have a rare medical diagnosis and have no other obvious access to peer support.

**Methods:** We conducted a Realistic Evaluation of the 8 week ChiPS program at CHW to describe which aspects of the program work, for whom, and in what circumstances. We collected qualitative data from focus groups with ChiPS participants, their parents, and interviews with the hospital workers who facilitate the program. Data was subject to a thematic analysis using a framework approach.

**Results:** Preliminary findings indicate that the program works for 12-15 year olds with chronic illness who are able to attend an additional evening group in the hospital, with many relying on parents who are willing to seek it out and facilitate their attendance. It works for those who engage with the idea of accepting they have an illness, and that they can have that in common with other people around their age. The program functions as a social process during that initial 8 weeks, bringing together adolescents who have illness experience, but not diagnosis in common, creating a sense of belonging. The location in the paediatric hospital and facilitation by a nurse engendered a sense of both physical and emotional
safety, while integrating games and fun into the discussion increased motivation and inspired the participants to contribute, and continue to attend.

**Conclusions:** The 8 week program was seen as a way to establish a social network for the peer leaders, enabling them to meet and socialise as they negotiate their adolescent and early adult years with a chronic illness. Future work to develop this peer support program could examine the impact of different locations, studying it with specific appropriate and measurable goals for the program, and more explicit integration of a strengths-based approach, raising awareness in participants and parents of the role of ChIPS as facilitating a safe place to talk and develop skills to generalise to wider social settings.

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**78.**

**The Effect of Biofeedback Therapy on Depression and Anxiety in the Pediatric and Adolescent When Used to Treat Migraines, Chronic Headaches and Chronic Abdominal Pain**

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**Purpose:** Chronic headaches, migraines and chronic abdominal pain can be associated with anxiety and depression. Biofeedback therapy teaches coping skills for pain through instruction on controlling the body’s physiological function and may help alleviate associated depression or anxiety. We looked for an effect of biofeedback therapy for patients with migraines, chronic headaches, or chronic abdominal pain on pain frequency and intensity and on associated depresson or anxiety.

**Methods:** In this retrospective chart review, 32 pediatric and adolescent patients referred to the biofeedback clinic between 2011-2013 who completed 5-7 biofeedback sessions underwent chart review. Intake and exit data on pain intensity and frequency as well as the Children’s Depression Inventory (CDI) and Multidimensional Anxiety Scale for Children (MASC) questionnaires were abstracted. Change in pain scores was measured at the sessions where the CDI and MASC forms were administered and paired t-tests were used to compare total and subscale scores within subjects at these two time points. We also examined differences specifically among the patients who at intake has elevated CDI and MASC scores.

**Results:** The mean age was 14.3 years (range: 10-18) with 22 females and 10 males. 19.4% had migraine with aura, 38.7% had migraine without aura, 12.9% had episodic headaches, 6.5% had post-concussive headaches, 32.3% had chronic daily headaches, 9.7% had tension-type headaches, 25.8% had abdominal pain, and 3.2% had abdominal pain with rumination. Chief complaint mean length was 40.3 months (range: 3 months-10 years). The mean length of time between intake and exit was 122 days (range: 76-241 days). Of the 32 study participants, 13 experienced a 50% or greater reduction in pain frequency.
and 9 experienced a 50% or greater reduction in pain intensity. The mean CDI score was 55.94±1.97 at intake and 48.94±1.34 at exit (t(df)=31, p=0.0001). All of the CDI subscales besides the interpersonal problems subscale had statistically significant differences between intake and exit. 11 participants had an intake CDI T-score of 60 or above, which designates onset of depression on the CDI scoring scale. These participants had a mean score of 68.6±2.14 at intake and 53.3±2.15 at exit (t(df)=10, p=0.0002). The mean MASC score was 53.66±1.93 at intake and 51.69±1.72 at exit, a difference that was not statistically significant (t(df)=31, p=0.19). However, two MASC subscale scores (physical symptoms: tense/restless and social anxiety: humiliation/rejection) did indicate statistically significant differences between intake and exit. 9 participants had an intake MASC T-score of 60 or above, which indicates above average anxiety according to MASC guidelines. These participants had a mean score of 67.7±1.43 at intake and 60±2.02 at exit (t(df)=8, p=0.02).

**Conclusions:** Biofeedback therapy, partially effective for pain reduction, was associated with a statistically significant decrease in depression in adolescents with migraines, chronic headaches and chronic abdominal pain. Biofeedback therapy appeared to be particularly effective in psychological symptom reduction for patients that were most severely affected by anxiety. This suggests that biofeedback therapy may be beneficial for patients that are experiencing chronic pain along with high levels of associated anxiety or depression.

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