RELUCTANCE OF ADOLESCENTS WITH CEREBRAL PALSY TO PARTICIPATE IN AN ONLINE INTERVENTION ON SELF-MANAGEMENT: LESSONS LEARNED FROM A RANDOMIZED CONTROL TRIAL

A Dissertation Presented

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Say Yes to Your Adventure:
Encouraging Self-Management in Adolescents with Cerebral Palsy

A Dissertation Presented

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ABSTRACT

Purpose: Assess the effectiveness of an online intervention to encourage self-management in adolescents with cerebral palsy (CP).

Specific Aims: (a) assess effectiveness of an online intervention to promote readiness for self-management in adolescents with CP, (b) describe health literacy and associations with readiness to assume self-management, and (c) evaluate adolescents' exposure to the online intervention.

Hypotheses: (a) intervention subjects would demonstrate improvement in self-management, and (b) subjects with higher health literacy would demonstrate higher self-management capabilities.

Framework: Transtheoretical Model of Health Behavior Change

Design: Randomized control trial, performed in a multidisciplinary CP clinic at a university based children's hospital. Instruments used: (a) Transition Readiness Assessment Questionnaire (TRAQ) and (b) the Health Literacy Skills Instrument-SF (HLSI). Due to low engagement, the study terminated early. Intervention subjects were interviewed to assess their limited engagement.

Results: Seventy-five percent of subjects demonstrated inadequate HL. Mean baseline TRAQ score (n=24) was 2.71 (SE = .24). Positive associations were found between TRAQ and age (.47, p = .00) and TRAQ and HL (.48, p = .00).

Conclusion: Failure to engage with the intervention appeared to be related to: (a) low HL, (b) low TRAQ scores (indicating subjects in contemplation stage) (c) inconsistency between subjects' preference for learning and delivery of information, and (d) low motivation for self-directed learning. Online interventions should be easy to use and include learning preferences. Lessons learned will inform future development of interventions for this population.

KEY WORDS: Self-management, Cerebral Palsy, Transition Readiness, Health Literacy, Transtheoretical Model

Say Yes to Your Adventure: Encouraging Self-Management in Adolescents with Cerebral Palsy – Dissertation Proposal

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Dissertation Proposal

Introduction

Abrupt transition from pediatric to adult health care providers without accessible, adequate teaching, preparation and planning results in feelings of abandonment by their health care provider among young adults with cerebral palsy (CP) and their parents (DiFazio, Harris, Vessey, Glader, & Shanske, 2014). Ninety percent of youth with special health care needs (YSHCN), such as those with CP, now survive into adulthood (Sawicki et al., 2011). At 18 years of age, most YSHCN should transition to an adult health care provider. Despite national policies to facilitate health care transition (HCT), most YSHCN are not receiving guidance (McManus et al., 2013). Poised between the patient and the realm of health care, nursing can play an important role in education, coordination and navigation of the transition process (Betz, 2013).

Cerebral Palsy

CP is a static encephalopathy, a disorder of movement that can be accompanied by progressive changes in cognitive function, as well as other medical comorbidities, including seizures, gastrointestinal and pulmonary issues. The number of children diagnosed with CP has remained steady since 2006 with a prevalence rate of about 2 cases per 1000 live births (Haak, Lenski, Hidecker, Li & Paneth, 2009). Studies provide evidence of increasing survival among children with CP due to progress in technology and medical care (Hemming, Hutton, & Pharoah, 2006; Brooks et al., 2014). While the prevalence of CP remains steady, more children are surviving and reaching adulthood.

Transition and CP

As children with CP age through adolescence, they should begin a process of HCT, culminating in transferal to adult health care. HCT was defined by Blum et al. in 1993 as "…the purposeful, planned movement of adolescents and young adults with chronic physical and

medical conditions from child-centered to adult-oriented health-care systems" (p. 570) and this definition continues to be used most frequently (Ladores, 2015). Safety and security, mastering skills needed to self-manage health concerns, and knowing what to expect as an adult with CP have been emphasized by both parents and adolescents as important topics to be addressed in a transition program (Horsman, Suto, Dudgeon & Harris, 2010; Rehm, Fuentes-Afflick, Fischer & Chesla, 2012).

For many adolescents with CP, parents continue to be responsible for tasks related to medical care. One study found that, while adolescents may overestimate their ability for self-management, parents may underestimate the adolescent's ability (Sawicki, Kelemen, & Weitzman, 2014). Adolescents the importance of self-management skills, and express the desire to learn (DiFazio et al., 2014). Introducing adolescents to new self-management behaviors, and teaching and encouraging the practice of new self-management skills should be a priority for any transition program.

Self-care is a broad term, defined as "the ability to care for oneself and the performance of activities necessary to achieve, maintain or promote optimal health…" (Richard & Shea, 2011, p. 261), and refers to healthy lifestyle choices. Hanna and Decker (2010) define assumption of responsibility for self-care as a gradual process specific to the adolescent and the health condition, with the goal of autonomy in behavior and decision-making. Self-management is one aspect of self-care. For YSHCN, self-management is defined as "…management of symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with a chronic illness" (Barlow, 2001, p. 547). This includes the ability to perform tasks associated with daily living. Skills like problem solving, using resources, and working together with a healthcare provider are all included in self-management (Omisakin & Ncama, 2011).

Health literacy (HL), defined as "the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions" (Berkman, Davis & McCormack, 2010), is an important consideration in the development of materials for teaching adolescents about accepting responsibility for self-management. Huang et al. (2014) used the Test of Functional Health Literacy in Adults (TOFHLA) in a cohort of 12-20 year olds with chronic disease (inflammatory bowel disease, cystic fibrosis, and type 1 diabetes) testing a generic Web-based disease management intervention over 8 months. Adequate HL resulted in greater improvements in disease management, measured by the Transition Readiness Assessment Questionnaire (TRAQ). There are no studies focusing on the HL of adolescents with CP transitioning musculoskeletal/orthopaedic health care.

Teaching adolescents to accept responsibility for self-management involves encouraging them to reach a decision to change and learn new behaviors. Prochaska and DiClemente's Transtheoretical model (TTM) (1986) describes 5 stages in the process of changing behaviors. The TTM has been used in studies focused on changing addictive behaviors and education of new healthy behaviors. Prochaska et al. (2004) demonstrated reduction in binge drinking among college students after implementation of a staged program following the processes of change outlined in the TTM. Kidd, Reed, Weaver, Westneat, and Rayens (2003) used the TTM to develop an intervention for behavior change for high school agriculture classes. They were able to demonstrate progression from the contemplative stage to the action stage for the implementation of safe behavior changes using an instrument they developed specifically to reflect agricultural safety. This theory can be applied to research focused on changing behaviors in adolescents and on encouraging them to accept new self-management responsibilities.

The Transition Readiness Assessment Questionnaire (TRAQ, Sawicki, et al., 2011) assesses self-management and self-advocacy skills and is designed for adolescents with chronic medical issues anticipating transition. Responses were designed to mirror the stages of change in the TTM and can be used to measure change in readiness to develop and use the skills needed to progress to self-management health care. It has been successfully used to evaluate the effect of educational interventions in a population of adolescents with congenital heart disease (Mackie, et al., 2014), and in the evaluation of a Web-based transition intervention designed to deliver information on chronic disease management to adolescents aged 12–20 years (Huang, et al., 2014).

Lemly, Weitzman and O'Hare (2013) looked at barriers to transition and offered suggestions to providers for tracking of steps taken to move toward the transferal of health care. Educating adolescents in disease related information and skills they will need to manage their health as they become adults is an important part of this process. In their study of the effect of an educational intervention for adolescents with congenital heart disease, Mackie, et al. (2014) found improvement in both self-management and self-efficacy skills 6 months post-intervention, compared to a control group receiving usual care using the TRAQ. There are, however, no RCTs investigating the effect of theory based interventions on facilitating progression toward assumption of self-management in young adults with CP anticipating transferal from pediatric musculoskeletal/orthopaedic care to an adult provider. Therefore, the goal of this study is to assess the effect of an online intervention guided by the TTM to enhance readiness of an adolescent with CP to assume responsibility for self-management. The Specific Aims of this study are:

Specific Aim 1: Determine the efficacy of a computer-based intervention guided by the Transtheoretical Model in promoting change in stage of readiness to assume responsibility for self-management among adolescents with CP in an orthopaedic clinic, as measured by the Transition Readiness Assessment Questionnaire (TRAQ).

Hypothesis: Adolescents with CP who participate in the computer-based intervention over a 3 month period will demonstrate a significant improvement of 1 stage in readiness to assume responsibility for self-management compared to a control group.

Specific Aim 2: Describe the HL (measured with the Health Literacy Skills Instrument – Short Form [HLSI-SF]) and any association with baseline and change in readiness to assume responsibility for self-management in a convenience sample of adolescents with CP in a pediatric orthopaedic clinic.

Hypothesis 1: Subjects with a higher HL at baseline will have higher score in readiness to assume responsibility for self-management.

Hypothesis 2: The effect of higher HL will result in a greater between group difference in change in readiness to assume responsibility for self-management.

Specific Aim 3: Describe the time spent and retention of subjects throughout the 3 months of an online intervention. Time spent is defined as the total time subjects signed into the intervention over the 3 month interval it was available to them. Retention is defined as the number of "modules" viewed.

This computer-based intervention, informed by theory, evidence and clinical expert opinion, is designed to increase readiness of adolescents with CP to assume responsibility for self-management in anticipation of transferal of orthopaedic care to an adult provider. It is designed to provide an accessible, convenient means of teaching and promoting many of the

skills needed while recognizing the autonomy of the individual. Knowledge of the efficacy of this intervention will allow potential use beyond adolescents with CP, as it has potential to be adapted for other YSCHN as they begin assuming self-management of their health care. Examination of the reliability of the TRAQ and the HLSI in a population of adolescents with CP will provide a basis for determining the appropriateness of using these instruments with this target population which is different than the reference groups used during initial test development. The expected outcomes from Aims 2 and 3 will provide the basis for refinement of the intervention for a future study of facilitating assumption of self-management of health care across multiple clinics involving adolescents with special health care needs and their families.

Background and Significance

The Pediatric Patient with CP

Transition of patients with CP is unique because this population demonstrates varying cognitive, communicative and physical abilities. A global classification system for the description of the motor abilities of children and adolescents with CP, the Gross Motor Function Classification System (GMFCS) is useful not only in identifying ability and limitations, but as a standard communication of functional motor ability among clinicians. The GMFCS makes meaningful distinctions in current, usual performance of active movement, emphasizing sitting, transfers and mobility in children with CP (Palisano, et al., 1997) (see Appendix A).

Many children with CP have numerous comorbidities and require multidisciplinary care. Because CP is a disability primarily affecting movement, children and their families often see a pediatric orthopaedist, and/or a physiatrist. Pediatric orthopaedists evaluate and treat musculoskeletal (bone, joint, or muscle) problems in growing children (American Academy of Orthopaedic Surgeons, 2010). The goal of pediatric orthopaedics is to preserve functional mobility in a child with CP to maximize ability to interact with the environment. Physiatrists are

physicians trained in physical medicine and rehabilitation and treat disorders of nerves, muscles, bones and brain without surgery to decrease pain and restore function (American Academy of Physical Medicine and Rehabilitation, 2015). Children with CP often see a physiatrist for the treatment of spasticity and tone management. Together, orthopaedics and physiatry can have a great impact on the comfort and ability of a child with CP to grow and function. However, as children mature and stop growing, the need for continued treatment by pediatric orthopaedic specialists becomes limited, and issues of tone management take precedence over bony surgery. Physiatrists are well suited to continue tone management for adolescents with CP as they become adults (Cassidy, Campbell, Madady & Payne, 2015).

Aging with CP

As individuals with CP age into their twenties, it is important for them to begin assuming responsibility for self-management in anticipation of transfer to adult health care providers, according to their abilities. Adult providers will continue to monitor the general health of the young adult for changes associated with aging that are not routinely assessed by a pediatric provider, such as heart disease, diabetes, cancer and reproductive issues. In addition to preexisting medical conditions, adults with CP may experience symptoms of aging at a younger age than expected. This is due to secondary medical conditions which cause a decrease in functional ability (Gajdosik & Cicirello, 2001). These secondary conditions include chronic pain, fatigue and depressive symptoms. Pain can result from early arthritis or degenerative joint disease from overuse injuries and abnormal joint movements, or fractures related to osteoporosis. Fatigue can promote progressive immobility, resulting in obesity and constipation, as well as cardiovascular inefficiency (Strax, Luciano, Dunn & Quevedo, 2010). Van der Slot et al. (2012), who studied Dutch adults aged 25-45 years with spastic CP, determined the prevalence

of chronic pain, fatigue and depressive symptoms was high compared to a control group without musculoskeletal issues, and that severity of fatigue was associated with depressive symptoms.

Adolescent Transition

In many institutions offering pediatric care, transition to an adult provider may not occur exactly as a child reaches his or her 18th birthday but may continue until 22 years of age or longer, depending on individual institutional policy. In their early consensus statement, the American Academy of Pediatrics (2002) recognized that some of the most complex children may never transfer out of a practice, but rather may continue with realignment of care that is developmentally and age appropriate.

Transition programs should promote self-determination through teaching skills of self-management and self-advocacy (Sharma, O'Hare, Antonelli & Sawicki, 2014) while maintaining ethical considerations of respect for the individual. A literature review of ethical issues in health care for adolescents with neurodevelopmental disabilities undertaken by Lariviere-Bastien and Racine (2011) resulted in six categories of ethical concerns, including equitable access to health care, lack of transition programs and adult providers, need for communication directly with the adolescent, maintaining a trustful relationship, respect for privacy/confidentiality and respect for adolescent autonomy and informed consent. Lariviere-Bastien, Bell, Majnemer, Shevell and Racine (2013) carried out a qualitative study of ethical considerations important to adolescents aged 18-25 years with CP going through health care transition. Subjects wanted to feel valued and respected, with attention paid to the emotional changes and mixed feelings they had about transitioning health care. Of the 14 subjects in the study, 9 subjects had completed transition to adult care. While the authors list the small size of the study as a limitation, the subjects' views given in retrospect are informative.

The importance of learning to master skills needed to self-manage health issues has been emphasized as an important topic to be addressed in a transition program (Gajdosik & Cicirello, 2001; Horsman et al., 2010). Rehm et al., (2012) completed a qualitative field study to investigate priorities for transition to adulthood for 64 youth with chronic health care needs ages 14 – 26 years, their parents, and healthcare providers, using ethnographic methods of data collection. Youth reported they struggled to master the skills needed to manage as adults and recognized they would need continued assistance. The authors conclude there was a lot of uncertainty in the responses: parents were unsure of their child's abilities, adolescents were unsure about the process of becoming an adult, and clinicians were unsure how to instruct them. This study was limited; only 48% of the youth subjects were verbal, thus much that was reported was from the parental perspective.

Horsman et al., (2010) report adults with CP feel it is important to learn as adolescents what health changes can occur in the future. The authors used descriptive phenomenology to investigate the lived experiences of adults with CP. The subjects were a purposeful sample of adults with CP over 25 years of age who had begun to experience a change in their functional abilities as they aged as a result of pain, stiffness and fatigue. The most striking revelation subjects expressed was fear and frustration at becoming aware of the changes and wishing they had been given information on what to expect as they got older. A qualitative study of young adults with CP aged 19-33 years confirmed this viewpoint (Bagatell, Chan, Rauch & Thorpe, 2017). Subjects discussed balance issues, pain and fatigue and the frustration of not knowing if the changes they were experiencing were normal.

Health Literacy (HL)

Providers can teach adolescents what health changes to expect as they get older and encourage adolescents to begin accepting responsibility for self-management during the transition process. An important and sometimes overlooked component of providing education and developing useful interventions is assessment of the HL of the target population. Health literacy is measured in different ways, including measurements of reading, language, numeracy, and oral comprehension. Results are typically described according to cut points of adequate, limited and inadequate literacy, reflecting ability to obtain, understand and communicate health related information to make health care decisions. Low HL is associated with adverse health outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004) for some health conditions. A systematic review of studies of HL among parents/caregivers of children with complex medical conditions found a wide range of low HL from 5.6% to 49% of the parents/caregivers screened (Keim-Malpass, Letzkus & Kennedy, 2015). The study was limited to diagnoses of asthma, glaucoma, diabetes and ADHD. These populations are similar to CP in that they represent chronic health care needs. The authors identified a need to assess adolescent HL, particularly as they begin to take over self-management of health care.

Chisolm, Sarkar, Kelleher and Sanders (2015) examined the HL concordance between YSHCN and a parent. Assessing print HL by word recognition using the Rapid Estimate of Adult Literacy in Medicine, the authors concluded 52% of adolescents had at least adequate HL, which was positively correlated with parental education and HL. Sixty-nine percent (69%) of teens self-reported competence with numerical HL, compared to 62% who self-reported adequate print HL. But over 50% of the parent-teen dyads had at least one member with less than adequate HL. This study sample included the 15 most common special health care diagnoses in a

Medicaid population. No studies specifically describing the HL of a sample of adolescents with CP were found.

Adolescents with CP need adequate health literacy skills to understand their medical needs and advocate for themselves as they learn to manage their health. Because they may have been cared for in a pediatric orthopaedic practice from a very young age, providers may assume this population has absorbed much of the information that was explained over the years. Transition programs should maximize adolescent-provider communication, and provide information on the individual's medical condition, history of care and future needs (McNaughton, Balandin, Kennedy & Sandmel, 2010). Understanding the health literacy of this population will allow the development and delivery of successful interventions to educate about CP.

Engaging Adolescents

Delivery of information to adolescents should utilize methods that are acceptable and engaging for them, such as computer-based instruction that is fun. The objective of a serious game is to help the user increase skills and abilities, gain knowledge and acquire experience in an entertaining way (Wattanasoontorn, Boada, Garcia & Sbert, 2013). The goal of a serious health game is to provide a dynamic environment for youth to learn about their disease or condition, promoting knowledge and new skills (Zyda, 2005). Huang et al. (2014) used technology such as computer and phone capability to deliver health related information with demonstrated success in increasing disease related self-management and health-related self-advocacy measured with the TRAQ. Charlier, et al. (2016) performed a systematic review and meta-analysis of serious games in health care. The results of nine RCTs were reviewed for effectiveness of serious games in improving knowledge and self-management behaviors in youth

with chronic conditions, including asthma, diabetes and cancer. The authors concluded serious health games were effective at improving knowledge and self-management with young people with chronic conditions, but the studies did not include youth with disabilities. While the proposed intervention is not a game, it is designed to engage subjects by offering an interactive, appealing computer-based intervention for the delivery of information to improve knowledge and encourage greater readiness to assume responsibility for self-management behaviors.

Summary

Transition to adult health care for YSHCN is a process that should be given priority as adolescents mature. Learning about personal health needs, what to expect as one matures, and how to begin managing one's own health all need to be addressed. To interest and involve adolescents, an intervention needs to take into account how they interact with their world and receive information. An effective intervention is most likely one that is enjoyable, interactive, and in electronic format, encouraging independence in exploration and experimentation with new skills.

The next section will describe the Transtheoretical Model of Health Behavior Change (TTM), a unifying theoretical model serving as the framework for this study. The TTM provided the structure for the development of the proposed intervention, and the measurement to assume responsibility for self-management of health care.

Theoretical Framework for Healthcare Transition

The concepts of the Transtheoretical Model (TTM) (Prochaska & DiClemente, 1983) were used to develop the intervention in this study as well as assessment of the outcome, change in readiness to accept responsibility for self-management of health care. The TTM resulted from an attempt to bring cohesiveness to multiple prevailing psychotherapeutic approaches that were

in use at the time to influence behavioral change, particularly in addiction. Five distinct and consistent stages of change were identified. In addition, ten processes of change specific to certain stages were described. This model describes the stages a person goes through when trying to make an intentional behavioral change, occurring as a result of individual decision-making to change an existing behavior or adopt a new, positive behavior. Behavioral change in this study is the assumption of responsibility for self-management of health care.

Stages of Change

As described by Prochaska and Velicer (1997), the stages of Precontemplation, Contemplation, Preparation, Action, and Maintenance are considered circular as relapse to a previous stage is common requiring an intentional decision to begin again at making the desired change. The Precontemplation stage is the earliest stage. Individuals in this stage are resistant to the idea of change, or feel it is not an immediate concern. They are not interested in receiving information, or in attaining new skills. Individuals in the Contemplation stage think about change and consider making a change within 6 months. They are very interested in information and are ready to accept education. Ambivalence is common and can result in some individuals spending a prolonged period of time in the Contemplation stage. For example, an adolescent may be happy to allow a parent to take the responsibility of making appointments and keeping track of medications. This may hold the adolescent back from progressing to a decision to learn those skills. The Preparation stage is the time when people anticipate making a change within 30 days. The decision to make a change is perceived as something positive. Those in the Action stage are trying out new skills, actively making changes for up to 6 months. The Maintenance stage represents individuals who have been actively changing behaviors for more than 6 months. Relapse is commonly seen at this time, and strategies to help support and sustain the new skills

and behaviors are important. As individuals progress through the stages of change, they gain increased confidence and self-efficacy. Prochaska and DiClemente (1983) also identified 10 processes used by individuals as they advance through the stages of change. The processes correspond to specific stages. Understanding which stage an individual is in leads to an understanding of which processes are the most effective for developing interventions (See Appendix B).

There is great potential for the nurse to educate, empower and support the individual during behavior change. This is consistent with the process of Helping Relationships which "…combine[s] caring, trust, openness and acceptance as well as support…" for the individual (Prochaska & Velicer, 1997, p.40). As Prochaska and DiClemente (1986) explain, "knowing that there is at least one person who cares and is committed to helping serves to ease some of the distress and dread of taking life-changing actions (p.167). Specific examples of information included in this intervention for the adolescent with CP along with associated stages and processes are found in Appendix C.

The Transtheoretical Model has been used successfully in studies involving adolescents. Pan and Chen (2010), designed curriculum for exercise behavior change based on the stages of change for 50 public high school students in Taiwan. In their quasi-experimental research study, the control group received traditional physical education only, while the experimental group received the addition of a physical fitness curriculum. The researchers found a significant difference in the experimental group in pre-post test scores on self-efficacy and perceived benefit of exercise ($p < .05$). Results showed a 50% decrease in number of students in the Precontemplation stage and an increase in the number of students in the Preparation stage from 3

to 11 students. The researchers did not report a priori sample size calculation, however, making it difficult to conclude the validity of the treatment effect.

Doyle, Siegel and Supe (2006) promoted the TTM to transition adolescent patients with obesity and hypertension to adult health care, in conjunction with the use of motivational interviewing and cognitive-behavioral techniques. They describe the Bronx Nutritional and Fitness Initiative for Teens at the Children's Hospital of Montefiore, targeting overweight adolescents who may also be followed by a multidisciplinary team for associated medical conditions. As a follow up to that publication, Rieder et al., (2013) describe the results of a quasi-experimental, longitudinal study of 91 obese African American and Hispanic adolescents in the program. The intervention had multiple components; initial phase was 3 months, followed by a 9 month maintenance program. The program resulted in significant improvements in BMI, healthy nutrition and physical activity during the 12 months. However, there was a high dropout rate, and BMI increased among subjects 9 months after the program completed indicating longer interaction might be needed. Despite limitations, the researchers concluded the intervention was effective in decreasing obesity and improving lifestyle behaviors in adolescents preparing to transition to adult health care.

The TTM describes intentional behavioral change, occurring as a result of individual decision-making to change. This change happens on a continuum, and progresses as an individual matures, based on that individual's determination of urgency. Individuals do not have to be in the same stage for all behaviors. The following section will discuss the methods for this study, including a more detailed description of the instruments that will be used, the intervention and the mode of delivery.

Methods

Design

A randomized control design will be used to assess the effect of an online intervention to enhance readiness of the adolescent with CP to assume responsibility for self-management of health care. The study proposal will be submitted to the Boston Children's Hospital (BCH) Nursing Scientific Review Subcommittee for scientific review. Subsequently, IRB approval will be obtained from BCH and the University of Massachusetts, Worcester.

Sample

A convenience sample of 66 adolescent males and females with CP will be sought, identified by their treating orthopaedic physician from the clinic visit schedule. The physician will confirm the potential subject as appropriate to approach for the study. If unable to recruit the required number of subjects in a 6 week period, the study will be amended to include a population of adolescents with spinal muscle atrophy (SMA) seen at BCH. SMA is a genetic motor neuron disease causing weakness and atrophy of the voluntary muscles, resulting in difficulty with movement. This population shares very similar musculoskeletal challenges with the CP population.

Setting

The study will take place in the orthopaedic specialty clinic at Boston Children's Hospital (BCH). The BCH Orthopedic Center of Excellence is an urban, hospital-based clinic providing interdisciplinary care for more than 2,500 national and international patients annually.

Inclusion/Exclusion Criteria

Inclusion criteria includes: age 14 to 17 years 6 months, diagnosis of CP, fluent in English, access to a computer or smart phone with internet connection, ability to use phone/computer/touch pad, or use of assistive technology to provide responses to the

instruments, has an email address, agrees to phone, text or email contact, and received orthopaedic care in the CP Center. Age range was chosen to reduce the likelihood of floor and ceiling effects.

Exclusion criteria includes: preoperative or 0-3 months post-operative, in custody of the Department of Children and Families, also seen at another orthopaedic center, have already transferred care to an adult orthopaedist or physiatrist, or have developmental delays that make it too difficult to participate.

Power Analysis

Sample size was based upon anticipated change in self-management as measured by the TRAQ. Mackie et al. (2014) reported a significant change in TRAQ score (p = 0.048) after an intervention with the mean changing from 2.77 (SD +/- 1.07) to 3.59 (SD +/- 0.83) over a 6 month period. Power analysis based on results reported by Mackie et al. (2014) indicate that to detect a difference of a 1 point change in TRAQ score from pre-intervention to post-intervention across treatment and control groups, a minimum of 23 subjects is required per group in order to achieve 90% power (chosen to be consistent with previously reported research using the TRAQ) using an independent t-test for the change in TRAQ score following intervention, assuming a type 1 error rate of 5%. Assuming a 30% attrition rate, the total number to be recruited in each group is 33 subjects.

Recruitment

Potential subjects will be approached during a routine office visit at the BCH Orthopaedic Center. The RA will explain the study and obtain from interested parties both parental and subject consent and assent. Withdrawal from the study at any time will be accepted and subjects will be aware it will not affect future care. The PI will gather information from the

electronic medical record on those who decline to join the study to help assess possible nonresponse bias to include age, gender, GMFCS score, and number of years in the BCH orthopaedic clinic.

Randomization

Randomization will be stratified by gender due to significant gender difference in outcome on the TRAQ (Wood et al., 2014). Two boxes, one labeled "MALE" and the other "FEMALE" will be created. Each box will contain envelopes which contain a piece of paper with either the word 'TREATMENT' or 'CONTROL' randomly assigned, thus creating a random sampling stratified by gender. Assignment will occur as a result of taking the next envelope from the respective box. The social worker, as well as the statistician will be blinded to which group subjects are in.

Procedure

The RA will assign a participant to a group after obtaining consent/assent, and completion of the demographic questionnaire, the HLSI-SF and the TRAQ via an iPad or laptop using Research Electronic Data Capture (REDCap), an electronic data capture tool hosted at BCH. The RA will also ask subjects their preferred mode of contact (email, phone). This preferred mode will be used to send the TRAQ and the Follow-up Questionnaire 3 months after initial interaction with subjects. It will also be used to contact both groups at 1 day and 8 weeks.

Control group

The control group will receive "usual care" (UC). UC consists of a visit during the clinic appointment with a social worker, who explains the transition process, and discusses issues including insurance changes, going to college or work, legal issues such as privacy and medical independence, relationships and saying goodbye (see Appendix D). As is typically done, the

control group will be given the phone number and email addresses of the social worker for any questions they may have. The RA will then present a 15 minute nature video. A phone call/email/text (at the subject's discretion) will be sent by the RA at 1 day and 8 weeks to remind then about the final surveys (see Appendix E). The information developed for the treatment group will be made accessible to the control group upon completion of the study.

Treatment group

The treatment group will receive UC at the time of the visit. The RA will then demonstrate and discuss access and use of the patient portal (see Appendix F) with patient return demonstration. Then, a demonstration of how to access the intervention will be given by the RA and the subject will provide a return demonstration. A Dropbox address and password that can be used to access the intervention will be emailed/texted (preference of subject) to the subjects within 12 hours of their office visit. The intervention may be accessed online by the subjects over 3 months at their leisure. The subjects will be strongly encouraged to view and share the information with a parent or guardian. To reduce potential for cross-contamination, sharing the link and password to the Dropbox site with others will be strongly discouraged. A phone call/email/text (at subjects' discretion) will be sent at 1 day and 8 weeks to assess for any issues and to remind then about the final surveys (see Appendix G).

At 12 weeks, the TRAQ and a Follow-Up Questionnaire will be sent electronically to subjects in both groups. If no response within two weeks, they will receive a reminder call/email/text. This will be repeated 2 more times at 2 week intervals if no response, and then no further attempts will be made to contact the subject. A parking voucher for $10 will be offered at the time of consent and a $50 gift card will be mailed to subjects in both groups after receipt of the second TRAQ and Follow-Up Questionnaires.

Intervention

The intervention will be available to the treatment group online for 3 months and can be accessed via an electronic PREZI© presentation. PREZI© is a cloud-based presentation software and storytelling tool for presenting ideas on a virtual canvas ("PREZI", 2016). The intervention is a self-navigated, online presentation, informed by the TTM and evidence from the literature, and incorporating expert clinical opinion. The presentation offers information for young adults with CP to help them to learn about self-care and self- management of their health. The presentation includes a discussion of the diagnosis of CP, and addresses topics of managing health care, going to college or to work, HIPPA, driving, and how to stay healthy as a young adult. It includes an introduction to one of the adult providers in the area, who addresses some of the things that will be expected as a young adult enters the adult health care system. It also explains the transferal process from BCH Orthopaedic CP Center to an adult physiatry practice (see Appendix H for an outline of presentation content). The presentation includes videos, interviews, and links to websites with information for adolescents and parents. The websites were developed and sponsored by official medical associations and hospitals. The adolescent interviews were led by a clinical expert in physiatry, and present experiences of young adults with CP. Interviews and information offered by clinicians from BCH present expert clinical advice. For content validity the presentation was reviewed by several expert clinicians (physicians, nurse practitioners and physiatrists) experienced in treating adolescents with CP. The presentation is designed to be easily accessible and entertaining to capture and hold interest and can be accessed as often as needed.

Feasibility Assessment

Prior to conducting the larger study, a convenience sample of 5 young adults will be recruited from the BCH Orthopaedic CP Center to assess access and use of the intervention. Subjects will be identified by the orthopaedic surgeon and approached by the RA, who will explain the purpose of the study and obtain consent/assent. The subjects will be asked to access the intervention at least 3 times over a 7 day period. They then will be contacted via phone or email (subject's preference) to provide feedback and guidance on access to the modules, usefulness of the information, thoroughness and/or inadequacy of the information provided, and suggestions for improvement (Appendix I). Efforts will be made to elicit feedback 3 times over 2 weeks. Modifications to the intervention will be made based on feedback from subjects. Subjects will be compensated $30 after completion and receipt of the feedback form and will be exempt from participation in the larger study.

Intervention Fidelity

Efforts to maintain intervention fidelity will follow the recommendations of the NIH Behavior Change Consortium (Bellg et al., 2004). The specifics are outlined in Appendix J.

Instruments

There are four forms that subjects will be asked to complete. All will be administered and completed via REDCap. The forms include a Demographic Form, the TRAQ Version 5.0, the Health Literacy Skills Instrument, and a Follow-up Questionnaire.

Demographic Form

A demographic form was developed to capture self-report data about the subjects' age, gender, ethnicity, type of insurance, type of CP, years in the CP Center at BCH, assistive devices used, activities and hobbies, involvement with friends, organizations and future plans (see Appendix K).

Transition Readiness Assessment Questionnaire (TRAQ)

The TRAQ version 5.0 is a 20 item, patient reported assessment of health care self-management skill attainment (Wood et al., 2014). The TRAQ utilizes a Likert response scale based on the TTM (1 = precontemplation = "I do not need to do this", through 5 = maintenance = "I always do this"). The TRAQ has a Flesch-Kinkaid Grade Level of 5.7. Originally validated as a 29 question instrument (total instrument α= .93), the first version of the TRAQ had two subdomains: Skills for Chronic Condition Self-Management, and Skills for Self-Advocacy and Health Care Utilization (Sawicki et al., 2009). In 2014, the authors refined and revalidated the TRAQ (Wood et al., 2014). Several questions were removed due to consistent missing values, or factor loadings < 0.45. Exploratory and confirmatory factor analysis resulted in five different, more discrete domains: Appointment Keeping (α = 0.90), Tracking Health Issues (α = 0.77), Managing Medications (α = .86), Talking with Providers (α = 0.80), and Managing Daily Activities (α = 0.67). Total instrument Cronbach's α = .937.

The 20 item TRAQ scale is scored by assigning one increasing point to each of the Likert scale responses, representing stages of change, beginning with "I do not need to do this" for 1 point and proceeding to a score of 5 points for "I always do this when I need to" (Wood et al., 2014). The total TRAQ score is calculated as an average of all completed items in the scale and is reported as 1-5. A mean total TRAQ score of all subjects is calculated by determining the average of the total TRAQ scores and dividing by the number of subjects. Wood et al., (2014) reported a mean total baseline TRAQ score of 3.23 (SD 0.91) (out of a possible 5.0), for adolescents less than 18 years who had not undergone a transition intervention. Mean scores were found to be significantly higher in those 18 years of age or older versus younger than 18 years (3.99 vs. 3.23, $p < .0001$ overall, $p < .001$ to .01 for subscales). Females scored

significantly higher overall ($p < .008$). There was no difference in overall or domain scores by race or insurance type. Age was found to be a predictor of high scores in a multivariable ANOVA with age, sex, race and insurance as independent variables. Wood et al. (2014) concluded the TRAQ version 5.0 demonstrated good internal reliability in 4 of the 5 subscales, and good criterion validity.

The Health Literacy Skills Instrument

The Health Literacy Skills Instrument (HLSI) was developed as a 25 item self-administered instrument (McCormack et al., 2010). HL is defined here as encompassing print and oral literacy and Internet information-seeking skills. Construct validity was determined by ANOVA comparing health-literacy scores by independent variables of sociodemographics. Non-Hispanic white subjects, higher education level, married and employed subjects had higher scores. Those who were disabled demonstrated the lowest scores. Good discrimination was found with Item Response Theory (IRT) parameters of 1.00 or higher on almost all items. Confirmatory factor analysis (CFA) identified five skill set factors, print-prose (0.98), print-document (0.98), print-quantitative (0.95), oral (0.85) and Internet-based information seeking (0.81). Cronbach's α was determined to be 0.86 (McCormack et al., 2010).

A 10 item short form of the instrument was reviewed by scale development experts for item wording and content validity. CFA found good factor loading on all items except Item 6 (0.36). IRT found all items except Item 6 to have slopes near or above 1.0, indicating good discrimination. Item 6 (testing numeracy) had a lower slope and demonstrated slope-related differential item functioning by race and education, indicating those with a high school education or lower may find it more difficult to complete, and it can more effectively distinguish HL levels for white respondents that non-white respondents. The item was retained, however, as the

authors felt it did test a skill important to literacy. The 10-item instrument was found to have a Cronbach's α of 0.70, which is lower than the original, likely due to the inclusion of only 10 items. Each item is scored as correct (1) or incorrect (0). Both raw score and percentage correct may be reported. Cut-off values of raw scores of 7-10 correct (70-100%) indicate adequate HL, and raw scores 0-6 correct (<60%) indicate inadequate HL. ANOVA was again used to determine construct validity. The short form, unlike the long form, did not find significant difference in scores among those who were Hispanic or unemployed. Disabled subjects again were found to have the lowest mean scores (Bann, McCormack, Berkman & Squiers, 2012).

Follow-Up Questionnaires:

Subjects will be asked to complete a Follow-Up Questionnaire 3 months into the intervention along with the TRAQ (Appendix L). Questions are related to use of material and resources throughout the study period. The questionnaire will help ensure treatment fidelity through subject self-report of receipt of delivery of control/treatment intervention, whether subject obtained other information on transition, and self-report of behavioral/cognitive skills used during the study.

Data management

A unique identifying ID number will be assigned to each subject for all data. All responses entered onto the iPad will be saved directly in REDCap and downloaded into SPSS on a secure UMass research drive. The ID numbers will be stored in a locked drawer in a locked room at BCH, accessible only to the primary investigator and RA. All study materials will be kept for a minimum of 6 years and then electronic files will be erased, and the list of ID numbers, consent and assent forms, and HIPAA forms will be shredded. The results of the data collection will be kept confidential, except for where it may be required by law to make them

available. In the event of a breach of confidentiality, the UMass IRB, as well as the BCH IRB will be notified and if necessary the subject/family will be notified.

Statistical Analysis

Descriptive statistics will be used to describe the characteristics of the cohort and to summarize each of the variables. The distribution of the data will be checked for normalcy. Statistical analysis will be accomplished using SPSS (IBM, version 24). Statistical significance will be accepted at the 95% level. A Cronbach's alpha will be calculated for the TRAQ and for the HLSI-SF in this population. Demographics, health literacy and TRAQ scores are anticipated to be complete, but in the event there are missing items on the TRAQ, and Cronbach's alpha is sufficiently high, items will be filled in with the observed mean.

Specific Aim 1:

To answer Specific Aim 1, description of means, range and deviation of TRAQ scores and distribution of the change in scores will be given. A 2-sample t-test will compare mean within-subject change in TRAQ score between baseline and 3 months within subject and between groups. ANCOVA will adjust for predictors of age, gender, type of CP, GMFCS level, years in clinic, and whether outside information on HCT was sought from other sources (i.e., Internet, other families, etc.) with scatter plots for continuous predictors vs. change in TRAQ scores.

Specific Aim 2:

To answer Specific Aim 2, the means, range, and deviation of HL scores will be described. Using the suggested cut off points from the literature, the percentage of adequate vs. not adequate literacy scores will be computed. ANCOVA will adjust for HL as a predictor for baseline TRAQ score.

ANCOVA will be used to test the effect modification of HL by adding an interaction term between HL and treatment assignment in the analysis for aim 1.

Specific Aim 3:

To answer Specific Aim 3, retention will be defined as the number of "modules" viewed and will be self-reported. Time spent is the total time of log-in to the intervention over the 3 month period and will be verified by monitoring Dropbox. Mean, range and distribution will be calculated.

Human Subject Considerations

The principle investigator (PI) also acts as a provider in the clinic, therefore, a research assistant (RA) will assist with recruitment and data collection to eliminate bias. Parental and subject consent/assent will be obtained per IRB and NIH ethical guidelines for use of children in research (National Institutes of Health, 1998). Ethical considerations for adolescents with CP include respect for autonomy and privacy. The only additional risk to patients enrolled in this study is potential loss of confidentiality. All measures to ensure confidentiality will be employed. The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule will be enforced (US Department of Health and Human Services, 1996). If at any time, the subject or their family/caregivers demonstrate or state that the study is causing distress, they will be advised that they may discontinue the study. Referral to a social worker or mental health professional at CHB will be offered to any patient/parent experiencing emotional discomfort during the study.

Research Team Training

The PI will obtain CHeRP training. All members of the research team will complete training in research with human subjects and Good Clinical Practice (GCP) via the Collaborative Institutional Training Initiative (CITI) Program. The PI will train the RA on how to access and

use the on-line intervention, and the protocol to be used in administering the HLSI-SF and the TRAQ and for follow up contact. The PI will oversee collection and handling of data and perform statistical analysis and interpretation of findings. Participating physicians will be made aware of the aims of the study and the inclusion/exclusion criteria via a short presentation conducted by the PI at a team meeting prior to recruitment of subjects. The social worker will not have access to the intervention to minimize potential treatment cross-contamination.

Limitations and Strengths

Limitations include convenience sample, single institution, short duration, and use of a subset of adolescents with CP. The TRAQ is a self-report instrument, subject to situational response factors such as social desirability bias and attention seeking, and cognitive factors such as comprehension, retrieval, decision-making and response generation individual to the subject. It is important to note, however, that adolescent self-report has been determined to be a valid and informative perspective (Brener, Billy & Grady, 2003). The instruments and intervention are accessed electronically, which enables some who cannot use paper and pencil to participate. Older subjects may score higher on the readiness instrument as a result of maturity. Subjects may be lost due to transfer of care during the study period. Selection of subjects may result in a disparate experimental sample; randomization should alleviate this concern. The control group may obtain information about transition and self-management that affects the post-test readiness scores. This data will be collected in the Follow-up Questionnaire and controlled for it as appropriate. Social desirability response bias will be minimized by assuring confidentiality. The intervention is self-administered and self-directed; researcher bias is controlled. The intervention is an accessible delivery of information encouraging autonomy.

Budget and Funding

This study is funded by the Peabody Foundation, Inc., William V. Tripp III Fund for the Advancement of Pediatric Orthopaedic Nursing at Boston Children's Hospital.

Expenses	Funding
Envelopes/paper/stamps	$ 30.00
PREZI© presentation download x 12 mo.	$ 160.00
Dropbox x 12 mo.	$ 180.00
Compensation for feasibility study subjects	$ 150.00
Compensation for main study subjects	$3960.00
Research assistant	$2500.00
Total	**$6980.00**

Summary

YSHCN require information and guidance as they transition from pediatric to adult health care. Information should be easily accessible and presented in an interesting format. This study investigates the effect of an online intervention on readiness to accept responsibility for self-management of health care among adolescents with CP transitioning from pediatric to adult musculoskeletal/orthopaedic care. Further, description of the HL of a population of adolescents with CP will bring to light a potential barrier to transition that has not been addressed in this population. Finally, this study will contribute to development of a patient-centered program for transition, encouraging this vulnerable population to develop the knowledge and skills needed to gain confidence in the adult world of health care.

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EXECUTIVE SUMMARY

Reluctance of Adolescents with Cerebral Palsy to Participate in an Online Intervention on Self-management: Lessons Learned from a Randomized Control Trial

A Dissertation Presented By

Cynthia T. Thompson

Submitted to the Graduate School of Nursing

University of Massachusetts Medical School

The following table summarizes the changes made to the original research proposal and rationale for the changes.

Executive Summary

Proposal	Change	Rationale
Specific Aim 1: Determine the efficacy of a computer-based intervention guided by the Trans theoretical Model in promoting change in stage of readiness to assume responsibility for self-management among adolescents with CP as measured by the Transition Readiness Assessment Questionnaire (TRAQ).	Baseline readiness was assessed, and associations with age, gender, and diagnosis were described. Interviews with subjects randomized to the intervention group were conducted to determine reasons for lack of engagement and suggestions for improvement. Lessons learned were then reported.	Reluctance of subjects to engage with intervention necessitated early termination of study. Unable to assess effectiveness of the intervention at promoting change.
Specific Aim 2: Determine the effect of HL (measured with the Health Literacy Skills Instrument – Short Form [HLSI-SF]) on baseline readiness and change in readiness to assume responsibility for self-management.	Baseline HL was reported, and its association with baseline readiness to assume self-management was described.	Due to early termination, this study could not determine association HL with change in readiness to assume responsibility for self-management.
No preliminary assessment of intervention.	Added preliminary assessment of intervention: Before commencing the RCT, we obtained Institutional review Board (IRB) approval to ask a convenience sample of 5 adolescent patients from a multidisciplinary CP clinic at a tertiary care, university based children's hospital to review the online intervention over 7 days and provide feedback.	Added to provide feedback for face validity.
Subjects will be **compensated $30** after completion and receipt of the [feasibility] feedback form…	Offered $40 after the feasibility form returned.	Offered to promote participation.

A convenience sample of 66 adolescent males and females with CP will be sought, **identified by their treating orthopaedic physician** from the clinic visit schedule.	Potential subjects were identified from the chart, and confirmed by the orthopaedic MD.	Done per usual practice at this institution.
If unable to recruit the required number of subjects in a 6 week period, the study will be amended to include a population of **adolescents with spinal muscle atrophy (SMA)** seen at BCH.	Only patients with cerebral palsy were approached.	Difficulty coordinating social work and the research assistant in a separate clinic, and not enough SMA patients that met the inclusion criteria for age. We also wanted to maintain consistency of diagnosis.
Inclusion criteria: age **14 to 17 years 6 months**.	Inclusion criteria changed to 14 – 22 years.	Wanted to include more potential subjects. Some adolescents with CP do not transition until 22 years. Because of varying cognitive abilities, it was thought there would not be a ceiling effect.
…a $50 gift card will be mailed to subjects in both groups after receipt of the second TRAQ and Follow-Up Form.	A $ 60 gift card was offered.	Offered to promote participation.
The RA will then present a **15 minute health care video**.	The RA presented a 10 minute video on stress relief.	Maintained consistency of time spent with each group.
A **Dropbox address and password** that can be used to access the intervention will be emailed/texted (preference of subject) to the subjects within 12 hours of their office visit.	Statistics embedded within the intervention platform were used to track exposure.	The feature became available for use after the proposal was approved, and provided a more efficient method of analysis.
The RA will then demonstrate and discuss access and use of the **patient**	Use of the patient portal was eliminated from the study.	There was no way of objectively measuring whether the subject actually logged into the portal. Also, explanation and demonstration/return

portal with patient return demonstration.		demonstration too time consuming and increased burden of the study. Gave a more accurate score.
In the event there are missing items on the TRAQ, and Cronbach's alpha is sufficiently high, items will be **filled in with the observed mean**.	Missing items on the TRAQ were left blank and the total mean score was determined with the number of questions answered.	Resulted from early termination of the study.
Predictors of attrition will be identified using crosstabs and t-tests and will be included in **multivariate models** for study outcomes to reduce drop-out bias.	Unable to determine predictors. No multivariate models were required in this study.	Unable to do this easily in SPSS.
Statistical analysis will be accomplished **using SPSS (IBM, version 24).**	SAS (Version 9.4) was used to assess 2 x 3 contingency tables.	
Continuing study to completion.	**Early Termination.** All enrolled subjects were allowed to complete the study.	Subjects in the intervention group were not engaging in the intervention: many in both intervention and control groups were lost-to-follow-up despite 3 attempts to contact via email or phone. It took 5 months to obtain 24 subjects and of the 7 randomized to the intervention group, only 1 subject spent more than 5 minutes reviewing the online materials over the 3 months of the study. Study terminated early, resulting in a small n, subjects did not engage with the intervention, so final TRAQ scores were not used as they were not meaningful.
Specific Aim 1: A 2-sample t-test will compare mean within-subject change in TRAQ score between baseline and 3 months within	Non-parametric tests were used for the TRAQ analyses. Mann-Whitney U was used to test equality of TRAQ means	

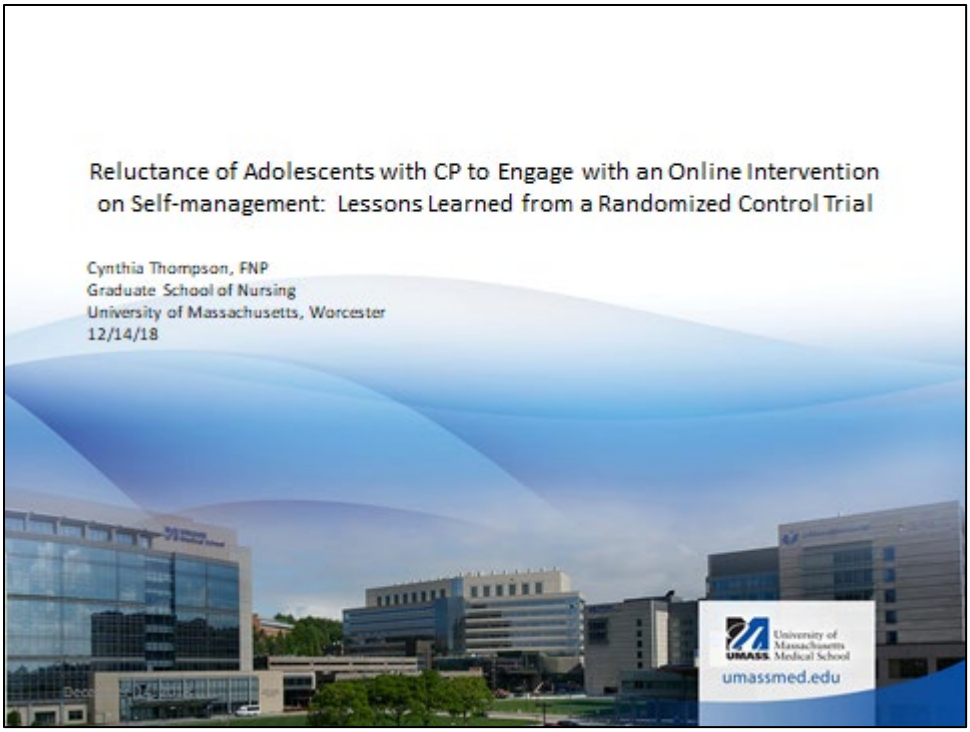
subject and between groups. ANCOVA will adjust for predictors of baseline TRAQ score, age, gender, type of CP, type of insurance, GMFCS level, years in clinic, and whether outside information on HCT was sought from other sources (i.e., Internet, other families, etc.) with scatter plots for continuous predictors vs. change in TRAQ scores. Distribution of within-subject change in TRAQ score as a function of baseline or within-subject mean will be checked, using plots such as Bland-Altman, and analysis will be adapted accordingly if an association is found.	between genders. Kruskal-Wallis analysis of variance was used to determine significant difference in TRAQ scores by type of CP. Kendall'sTau was used to determine the relationship between TRAQ scores and age, and TRAQ and HL scores.	Unable to test for effect modification as study terminated early and final intervention group TRAQ scores not meaningful.
Specific Aim 2: ANCOVA will adjust for HL as a predictor for baseline TRAQ score. ANCOVA will be used to test the effect modification of HL by adding an interaction term between HL and treatment assignment in the analysis for Aim 1.	HL scores were analyzed as both categorical (adequate versus inadequate) and interval data. The relationship between HL and gender was analyzed using crosstabs and independent t test. Fisher's Exact Test was used to analyze the relationships of HL to type of CP and age, and was conducted using SAS.	Unable to calculate dose response as the study was terminated. The patient portal was not used, as described above.
Specific Aim 3: Retention will be defined as the number of "modules" viewed and will be tracked electronically. Time spent is the total time of log-in to the intervention over the 3 month period and will be tracked electronically. The number of times the intervention and the patient	Exposure is defined as the number of times the subject logged on, viewed the modules, and time spent interacting with each module.	

portal was accessed will be tracked electronically. Mean, range and distribution will be calculated. The association of time spent with change in TRAQ score will be estimated, to assess dose response.

No planned interviews.

The 7 subjects in the intervention arm of the study were offered an additional $10 gift card for participating in a brief follow-up interview (see Appendix M) coincident with their next scheduled clinic visit.

Goal: To determine reasons for lack of engagement with the online materials, preferred learning methods and modalities, and suggestions for improvement.



Background

- Increasing survival of children with CP due to progress in technology and medical care (Brooks et al., 2014) .

  Prevalence CP in 2 cases per 1000 live births (Haak, et al., 2009).

  Comorbidities include seizures, gastrointestinal, pulmonary issues, cognitive impairment

- Adolescents with CP should transition to adult providers

> "...the purposeful, planned movement of adolescents young adults with chronic physical and medical conditions from child-centered to adult- oriented health-care systems"(Blum et al., 1993)

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Transition to adulthood includes learning skills needed for self-management of one's health (Modi et al, 2012)

- Self-management includes

"managing symptoms, treatment, physical and psychological consequences and lifestyle changes inherent with living with a chronic illness" (Barlow et al., 2001)

- Consideration of health literacy important when developing educational tools and interventions (Chisolm et al., 2015)

"the degree to which individuals can obtain, process, understand and communicate about health-related information needed to make informed health decisions" (Berkman, Davis & McCormack, 2010).

The Problem

- Few proven interventions exist that introduce adolescents with CP to self-management and teach skills needed to transition to adult health care systems
  - No randomized control trials investigating effect of theory-based intervention on encouraging self-management in youth with CP.
  - No studies describing the health literacy of this population.

Purpose: facilitate adolescents readiness to assume more responsibility for self-management of their health

Specific Aims:

1. Assess effectiveness of an online intervention to promote readiness to assume self-management in adolescents with CP using a randomized control trial design.
2. Describe Health Literacy and association to readiness to assume self-management.
3. Evaluate adolescents' exposure to the intervention, defined as the number of times the subject logged on, viewed the modules, and time spent interacting with each module.

Transtheoretical Model of Health Behavior Change

(Prochaska and DiClemente 1983)

Stage	Process of Change	Aim
Precontemplation	Use processes of change the least.	Can be resistant to idea of change. Not interested in information or discussion.
Contemplation	Consciousness Raising	Education: why change needs to occur
	Dramatic Relief	Increases individual's emotional response
	Environmental Reevaluation	What does change mean to others?
	Self reevaluation	What does change means to the individual?
Preparation	Self liberation	Commitment and belief change can be done
Action	Social Liberation	Opportunities to empowered individual
	Counterconditioning	Learning new independent behaviors
	Stimulus Control	Using new skills instead of old behaviors
	Contingency Management	Positive reinforcement
	Helping Relationships	Available clinician support when needed
Maintenance		Potential for relapse Review motivation and identify barriers Develop coping strategies

Intervention

Module

Methods: Establishing validity of the intervention

- Content validity:
  - Only used websites developed and sponsored by official medical associations and hospitals,
  - Adolescent videos led by clinical expert in physiatry,
  - Clinicians offered expert advice
- Face Validity:
  - Reviewed with RN, clinicians
  - Invited a convenience sample of 5 adolescents with CP to review content and presentation of material
    - 2 participated. Result: Nutrition section was revised.
    - They provided positive feedback on other topics and presentation of material.

Sample Size

- Based on anticipated change in self-management measured by the Transition Readiness Assessment Questionnaire (TRAQ).
- 23 subjects needed per group to achieve 90% power
- Type 1 error rate of 5%.
- Assuming 30% attrition rate, total number recruited in each group was intended to be 33 subjects.

Eligibility criteria for potential participants

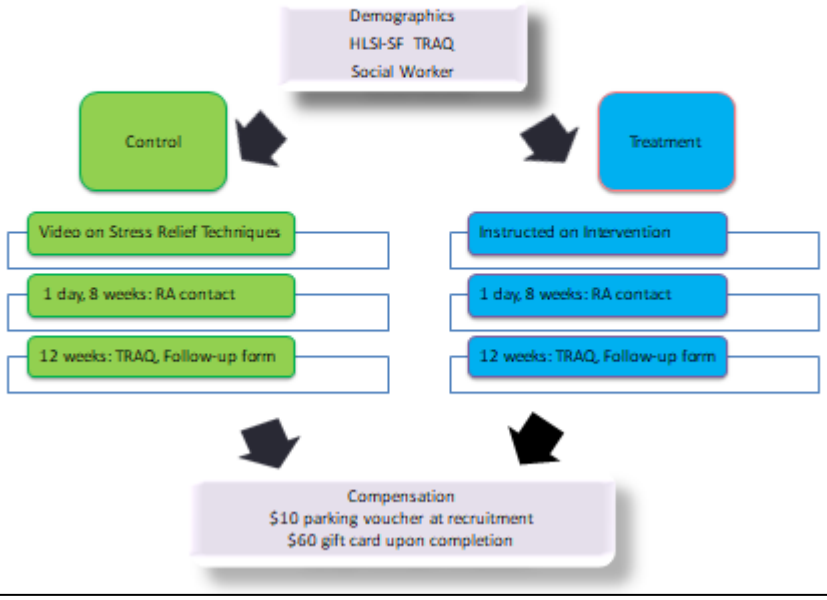
Inclusion criteria:

- Age 14 to 22 years with CP, English-speaking
- Access to Internet via computer or smart phone
- Active email address
- Developmentally able to participate

Exclusion criteria:

- Preoperative or 0-3 months post-operative (except Botox)
- Custody of the Department of Children and Families
- Seen at another orthopaedic clinic, or already transferred care to an adult provider

Procedure



Potential Social Work Topics

Topics for Social Worker Discussion
1. Manage your own medical care
2. Transition services
3. Medical decision making
4. Disability services
5. Massachusetts Rehab Commission
6. Relationships and saying goodbye
7. Social Security
8. Disclosure/employee rights/insurance
9. Privacy issues

Transition Readiness Assessment Questionnaire (TRAQ)

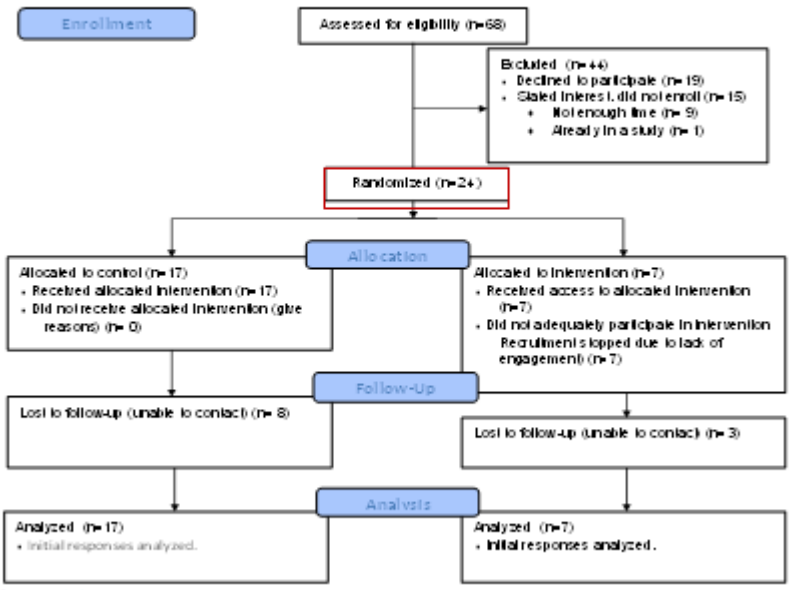
- TRAQ version 5.0 is a 20 item, patient reported assessment of health care self-management skill attainment (Wood et al., 2014).
- Likert response scale based on the TTM (1 = precontemplation = "I do not need to do this", through 5 = maintenance = "I always do this").
  - Flesch-Kinkaid Grade Level of 5.7
  - Total instrument Cronbach's α = .94
- 5 domains: Appointment Keeping
  Tracking Health Issues
  Managing Medications
  Talking with Providers
  Managing Daily Activities

Health Literacy Skills Instrument-Short Form

(McCormack et al., 2010; Bann, McCormack, Berkman & Squiers, 2012)

- Measures print and oral literacy and Internet information-seeking skills.
  - 10 item, multiple choice
  - Cronbach's α = 0.70
- Five skill set factors: print-prose
  print-document
  print-quantitative
  oral
  internet-based information seeking

CONSORT Flow Diagram



Sample Characteristics	Total n	Total %	Intervention Group (n = 7) n	Intervention Group (n = 7) (%)	Control Group (n = 17) n	Control Group (n = 17) (%)
Gender						
Male	14	(58)	4	(57)	10	(59)
Female	10	(42)	3	(43)	7	(41)
Race						
Caucasian	17	(71)				
Black	2	(8)				
Asian	1	(4)				
Other	4	(17)				
Age (years)						
14 - 18	18	(75)	5	(71)	13	(77)
19 - 22	6	(25)	2	(28)	4	(24)
Type of CP						
Diplegia	13	(54)	4	(57)	8	(47)
Hemiplegia	7	(29)	2	(28)	5	(29)
Quadriplegia	4	(16)	1	(14)	4	(24)
GMFCS						
Level 1	5	(20)	2	(28)	3	(18)
Level 2	7	(29)	2	(28)	7	(41)
Level 3	6	(25)	2	(28)	3	(18)
Level 4	5	(21)	1	(14)	3	(18)
Level 5	1	(4)			1	(6)
Years Followed in Clinic	Mean 12.6 Mode 12 Range 1 – 20					

Dooer

Subjects' activities of interest

Activities	Yes n	Yes (%)	No n	No %
Volunteer	7	29	17	71
Work	1	4	23	96
Driving	4	17	19	83
Hobbies	21	88	3	12
Clubs	11	46	13	54
Hang with friends	22	92	2	8
Post high school goals				
Junior College/University	13	62		
Work	3	14		
No plans	5	24		

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Preliminary results led to termination of trial.

- 24 subjects recruited in 5 months
- Of 7 in treatment group only 1 spent > 5 min with intervention over 3 month period
- Subject did not engage with Intervention Many lost to follow up
- Recruitment terminated after 5 months

Results: Day 1 and Week 8 Follow-up Responses

- **Day 1: Recall social worker discussion : 17 subjects**
  - 13/17 able to correctly report some of topics discussed.
- **Week 8: Recall of allergies and medications: 14 subjects**
  - 10/14 subjects correctly stated whether or not they had allergies.
  - Of the 7 who did have allergies, 3 could identify their allergies.
  - 1/12 who took medications could correctly identify all the prescribed medications.

Health Literacy Measure (n = 24)

Normal curve

- 75% (n=18) with **Inadequate Health Literacy**
- No significant association of HL with
  - **gender** (p = 1),
  - **age** (p = .62),
  - **type of CP** (p = .24)

Self-management (TRAQ) (n = 24)

Not normal curve

- **Subjects' mean TRAQ score**

  2.71 (SE .24, range 1.15 – 5.00) Contemplation Stage

- **gender** (p = .5)
- **type of CP** (p = .32)

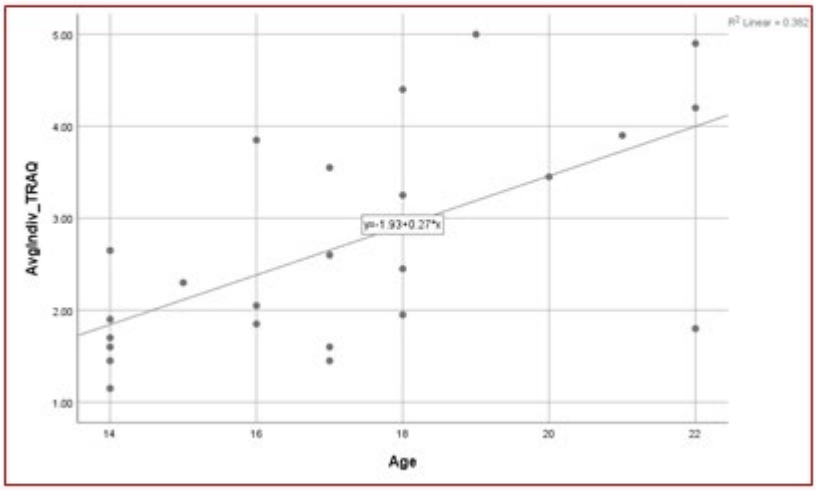
TRAQ and Age
TRAQ and Total HL

Correlations

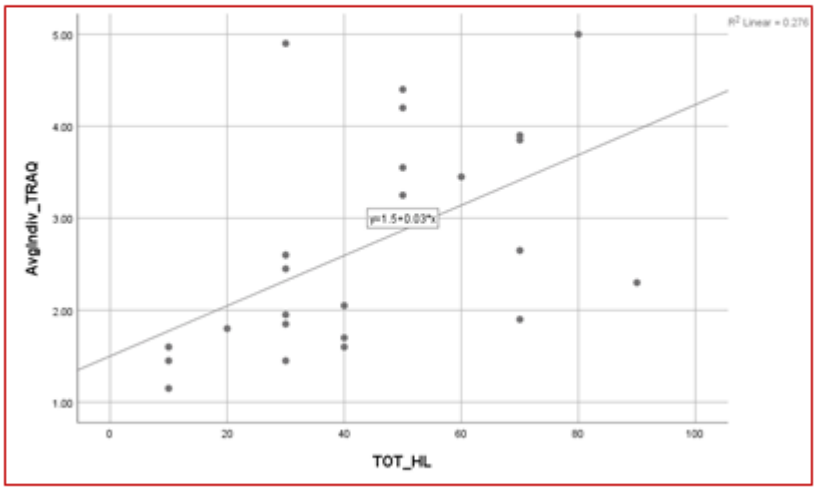
			Age	AvgIndivTRAQ Score	TOT_HL
Kendall's tau_b	Age	Correlation Coefficient	1.000	.469**	-.004
		Sig. (2-tailed)	.	.002	.980
		N	24	24	24
	AvgIndivTRAQScore	Correlation Coefficient	.469**	1.000	.477**
		Sig. (2-tailed)	.002	.	.002
		N	24	24	24
	TOT_HL	Correlation Coefficient	-.004	.477**	1.000
		Sig. (2-tailed)	.980	.002	.
		N	24	24	24

**. Correlation is significant at the 0.01 level (2-tailed).

TRAQ and Age



TRAQ and Health Literacy



Follow-up Questionnaire revealed some recognition of upcoming transitions

- n = 13, 4 = Intervention, 9 = Control
- 9 were comfortable talking to their ortho MD about transition
- 8 spoken with a clinician about health care transition
- 4 in the intervention group stated they had not thought about transition of orthopaedic care before the study

Exposure to Online Intervention was minimal

Subject number	Total view time	Number of views
1	2 min 2 sec	1
2	3 min 10 sec	2
3	1 min 16 sec	1
4	4 min 50 sec	2
5	30 sec	1
6	2 min 2 sec	2
7	23 min 10 sec	3

Interviews with 4 subjects from intervention group reveals lack of interest in online intervention

- Intervention easy to use, topics interesting (n = 4) but "a little confusing" (n =2)
- Overwhelmed thinking about transitioning health care:
  - "I don't want to grow up. It's scary going to adulthood. All the responsibilities. It's stressful enough."
- Response to different learning modalities:
  - Online (n =3)
    - "not interested in hunting it down" (n = 1)
  - Videos (n = 3)
    - "It should be more visual, to understand it more clearly"
    - "If there is too much information, she gets lost"
  - Audio (n=1)
    - "He doesn't read well, and doesn't like to read. In fact, he prefers audiobooks"

Learning Preferences

Learning Preferences to obtain information		
Verbal information given by doctors, nurses, teachers, family	Written information	Do NOT want to talk/learn from their peers
4 (100%) (Johnson, et al., 2015)	1 (25%)	3 (75%)

A self-directed online intervention to learn about transition was not preferred mode of learning (N=4)

Discussion: Comparison to previous work

- Mean TRAQ scores lower than previously reported

Table 6

Comparison of TRAQ Mean Scores

AGE (years)	TRAQ mean score	Range	Previously reported TRAQ mean score
14 - 18	2.32 (SD .91)	1.15 – 4.40	3.23 (SD .91)[a]
			2.79 (SD .78)[b]
			2.50 (SD .66)[c]
19 - 20	3.88 (SD 1.18)	1.80 – 5.00	3.99 (SD .96)[a]

[a]Wood et al, 2014
[b]Beal et al, 2016, Spina Bifida, mean age 15 yo
[c]Beal et al, 2016, Autism Spectrum Disorder, mean age 16 yo

- Related to developmental delays, low health literacy

Lesson Learned:
A feasibility study should have been done first!

Would have identified:

- Recruitment challenges
- Difficulties engaging with the intervention
- Learning style preferences
- Learning modality preferences
- Ideal frequency of reminders to engage
- Interest and appropriateness of the topics

Implications

- 1. Lack of self-motivation: contemplation stage, Ambivalence?
  - Teach family and adolescent together
  - Dose information to readiness, comprehension
  - Allow practice opportunities

- 2. Mode of Delivery
  - 5th grade level (The Joint Commission, 2010)
  - Videos, pictures, audio files
  - Cultural/language barriers (Kraemer & Blacher, 2008)
  - Computer, games (Charlier et al, 2016)

Implications

- 3. Varying demands on family/adolescent
  - Tailor delivery to the adolescent and family
    - Telemedicine?
- 4. Develop intervention to promote engagement
  - Bright colors, videos, info quick and easy to find
  - simple, interesting format
  - Feedback, praise and reward (Kelder et al, 2012)

Conclusions

1. Assess effectiveness of an online intervention to promote readiness to assume self-management in adolescents with CP using a randomized control trial design.
   - Unable to determine, low engagement. Could describe the baseline self-management scores of the subjects.
2. Describe Health Literacy and association to readiness to assume self-management.
   - Low health literacy in this group. Positive correlation with self-management scores
3. Evaluate adolescents' exposure to the intervention, defined as the number of times the subject logged on, viewed the modules, and time spent interacting with each module
   - Low engagement/exposure. Mode of delivery not preferred. Low literacy, a factor.

Limitations

- Small single site study
- Difficulties with recruitment and retention
- Unable to answer first Aim
- Low engagement
- Terminated early
- Randomization was unbalanced

Future research

- Assess health literacy of parents/caregivers
- Role of anxiety in procrastination of transferal of care to adult providers
- More effective mode of delivery of information

Dissemination

- Preliminary work was presented at the Canadian Doctoral Nursing Network Conference, Saskatchewan, Canada, June 2018
- Submitted to Journal of Pediatric Health Care
- Presented to clinicians at BCH

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Thank you

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- Thank you to the clinicians of the CP clinic at BCH for their help
- Thank you to the adolescents and families of the CP clinic
- Thank you to my cohort for their support, Helen Flaherty, Colette Dieujuste, and Michelle Glowny

- Funding: Peabody Foundation, Inc., William V. Tripp III Fund for the Advancement of Pediatric Orthopaedic Nursing at Boston Children's Hospital.

Thank you for your attention!

DISSEMINATION PLAN

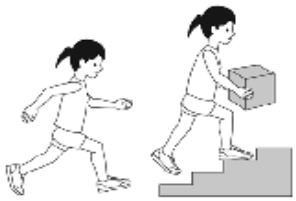
The primary description of this dissertation work was submitted as a manuscript on January 9, 2019, to *The Journal of Pediatric Health Care* for review and consideration for publication.

APPENDICES

Appendix A

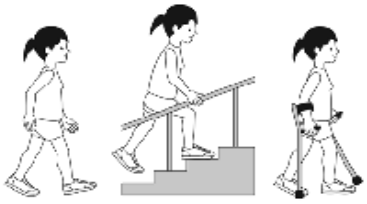
The Gross Motor Function Classification System

GMFCS E & R Descriptors and Illustrations for Children between their 12th and 18th birthday



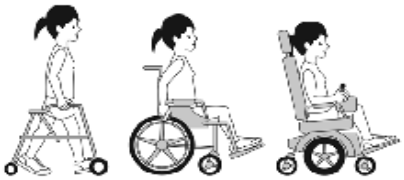
GMFCS Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.



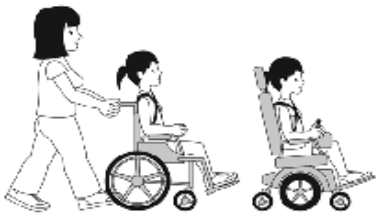
GMFCS Level II

Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.



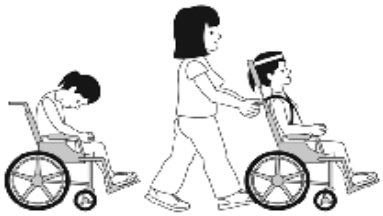
GMFCS Level III

Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.



GMFCS Level IV

Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.



GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

GMFCS descriptors copyright © Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations copyright © Ken Graham, Jill Reid and Adrienne Harvey,
The Royal Children's Hospital, Melbourne

(CanChild Centre for Childhood Disability Research, McMaster University, 2007)

Appendix B

Trans Theoretical Model Stages and Processes of Change

Stage	Process of Change	Aim
Precontemplation	Use processes of change the least.	• Can be resistant to idea of change. Not interested in information or discussion.
Contemplation	Consciousness Raising	• Education: why change needs to occur
	Dramatic Relief	• Increases individual's emotional response
	Environmental Reevaluation	• What does change mean to others?
	Self-reevaluation	• What does change mean to the individual?
Preparation	Self-liberation	• Commitment and belief change can be done
Action	Social Liberation	• Opportunities to empower individual
	Counterconditioning	• Learning new independent behaviors
	Stimulus Control	• Using new skills instead of old behaviors
	Contingency Management	• Positive reinforcement

	Helping Relationships	• Available clinician support when needed
Maintenance		• Potential for relapse • Review motivation and identify barriers • Develop coping strategies

Appendix C

Influence of TTM on Interventions and Associated TRAQ Responses

Stage of TTM	Pre-contemplation	Contemplation	Preparation	Action	Maintenance
Interventions used	Introduction to transition Words from providers Parents and kids talk about transition changes	What is CP? What are your rights? Nutrition Activity Going to school Going to work Financial Insurance Driving	Interviews of adolescents who have transitioned	PREZI for skills Videos Teen Advisory Council Email to nurse Phone number for questions	Peer to Peer Teen Advisory Council
Processes in play	*Consciousness raising*	*Consciousness raising* *Dramatic relief* *Environmental reevaluation* *Self-reevaluation*	*Self-liberation*	*Contingency management* *Helping Relationship* *Counter conditioning* *Stimulus control*	*Contingency management* *Helping relationship*
TRAQ Response	"I do not need to do this."	"I do not know how, but I would like to learn."	"I am learning to do this."	"I have started doing this."	"I always do this when I need to."

Appendix D

Social Worker Interaction Usual Care Checklist

Information provided by the social worker:

- Legal:
  - Privacy (HIPAA)
  - Medical decision making (guardianship, limited guardianship, health care proxy)
  - Advanced directives
- Benefits/Insurance
  - Social Security benefits
  - Insurance (private vs MassHealth)
- Education
  - Transition services through school system (688 referral)
  - Disability services at the post-secondary level
- Going to work
  - (Mass) Rehabilitation Commission
  - Disclosure/rights as employee/FMLA
- Medical Independence
  - Managing medical care independently
- Relationships and saying goodbye

Appendix E

Phone call follow up for Control group

Initial contact next day:

Hello, this is _____, the research assistant from Boston Children's Hospital who spoke with you in the orthopaedic clinic about the transition study.

[What did you talk about with the social worker?]

If you or your parents/caregivers have any questions about transition feel free to email the social worker at -------. childrens.harvard.edu, or call and leave a message at . We will be contacting you again in 2 month to remind you about the second set of surveys.

Thanks for being a part of this study.

At 8 weeks:

Hello, this is _____, the research assistant from Boston Children's Hospital who spoke with you about the transition study. I am calling to remind you that I will be sending the follow up surveys to you. Please answer the questions the best you can, and send it back to me. When I get your survey, I will send out your gift card.

Thank you again for being an important part of this study!

Appendix F

Content for Portal Instructions

MyChildren's Account Creation Process

Thank you for your interest in MyChildren's, a Web portal that allows you to view key portions of your own or your child's medical record, send secure messages to a clinician, request an appointment, view demographic information and pay your balance online.

To register, please follow these steps:

Step 1: Create a MyChildren's Account

- Go to *mychildrens.org*, click **Sign up for an account**, and then complete the Self-Registration information screen.
- If you've already created a MyChildren's account, go to Step 3 to add a dependent/patient.

Step 2: Set up your password and security questions and log in

- You will receive a confirmation email with a Personal Identification Number (PIN). Set up your password and security questions, then log into MyChildren's.

Step 3: Add dependent(s)/patient(s)

- Click the **Enroll another patient** link. Enter the following single-use token and the patient's Date of Birth to register the patient:

  6119895931 This single-use token expires on 12/28/2016

If your token expires, or you don't have a token:

- Go to *mychildrens.org/accounts/enrollPatient.cfm*
- At the *Do you have a token?* Prompt, click **No**, then select whether or not you are the patient

OR

- Request another single-use token at your next clinic visit.

If you need help, go to *mychildrens.org/help* and complete the **Contact Us** form.

Thank you,
The MyChildren's Team

P: M B**

Appendix G

Telephone/Email Contact Protocol Form Intervention Group

Initial contact Day 1:

Hello, this is _____, the research assistant from Boston Children's Hospital who spoke with you in the orthopaedic clinic about the transition study.

I am checking in to see if you were able to open the Dropbox account and look at the program about transitioning and taking over your health care as you get older. Please look at the program as many times as you want to over the next 3 months. Please try to read through everything.

If you or your parents/caregivers have any questions feel free to email the nurse practitioner at .childrens.harvard.edu, or call and leave a message at . We will be contacting you again in 2 months to remind you about the follow up surveys.

Thanks for being a part of this study.

At 8 weeks:

Hello, this is _____, the research assistant from Boston Children's Hospital who spoke with you about the transition study. I am calling to follow up once again. Have you been able to look at the program in Dropbox? Any problems? You can keep looking at it for another 4 weeks. Then, I will be sending the follow up surveys to you. Please answer the questions the best you can, and send it back to me. When I get your survey, I will send out your gift card.

Thank you again for being an important part of this study!

Appendix H

Outline Prezi© Presentation Intervention

Welcome	• Video (Brian Snyder, MD)
Contents	
Assurance	
What is CP?	• Video (Benjamin Shore, MD)
Managing your Healthcare	• Video (Teen Advisory Council)
Things to Know about Taking Over Your Medications	• Link to website: Take Medicine as Directed
Doctor's Visits	• Link to website: Take Control of Doctor's Visits
HIPAA: Learn About Your Right to Privacy in Healthcare	• Video (Web)
Going to Work	• Link to website: Americans with Disabilities Act
Video: Young Adult Experiences	• Link to Website: By Youth for Youth: Employment
Driving programs	• Links to websites: local assessment • Video (Web)
Going to School	• Link to website: Guide for students with disabilities • Link to website: BCH Dr. O'Hare's tips for going to school

	• Videos: Young Adults' experiences
Health Insurance	
Staying Healthy: Eating Right	• Link to website: American Heart Association tips on healthy eating • Calcium and Vitamin D Video: Erin Patisteas, FNP
Staying Healthy: Keep Moving	• Video: Rachel Tombeno, PT • Link to website: You're With Us • Link to website: Special Olympics • Link to website: Adaptive Sports of New England
Benefits of Volunteering	• Video: Young Adults' Experiences
Staying Healthy: Staying in Touch	• Video: Young Adults' Experiences
Depression	• Link to website: Teenagers Guide to Depression
Emergency Information	• Link to website: What to do in a medical emergency
What Should I Expect as I Get Older?	• Video: David Fogelman, MD
What Can I Expect When I See an Adult Physiatrist?	• Video: Jason Frankel, MD
How to Start Transferring Care	• Video: Julia Phelps

Appendix I

Feasibility Feedback Form

1. Was the presentation easy to use? If not, what was hard about it?
2. Did all of the videos and website links work?
3. Were the videos helpful?
4. Did the websites have helpful information?
5. Were any parts confusing or hard to understand? Which?
6. Were any parts clear and easy to understand? Which?
7. Is there anything we should add to the presentation?
8. Were any parts insulting or offensive?
9. What was the best part of the presentation?
10. What could we change to make this presentation better?
11. Do you think this presentation has good information for teenagers with CP?

Appendix J

Plan for Ensuring and Maintaining Intervention (Treatment) Fidelity (Bellg et al., 2004)

Design Goal	Strategy
Ensure same treatment dose within conditions Ensure equivalent dose across conditions Plan for implementation setbacks	• Contact with subjects will be the same for both groups on recruitment day, day 1, and at weeks 8 and 12. • Plan equal number of contacts by RA. • Record any contact initiated by subject. • Deliver fixed information to treatment/control group. • RA to use scripted treatment manual and scripted follow-up calls and record any deviation. • PI will monitor encounters (both groups) and follow up calls weekly. • Subjects will verify treatment received (both treatment and control groups). • Collect on follow-up questionnaire if/how and when subject obtained additional information on transitioning.

Provider Training

Standardize training

Ensure provider skill acquisition

Minimize "drift" in provider skills

Accommodate provider differences

- All members of research team will complete standardized CITI Program and GCP training.
- Scripted training of RA on how to teach access to Dropbox and use of PREZI© and patient portal.
- PI will observe RA use of treatment manual with subjects in pilot study and use a priori checklist to assess adherence and provide feedback.
- PI will observe RA and social worker interactions with subjects (control and treatment) 2x/month and provide feedback re any drift from script.
- RA and social worker complete self-report and subjects confirm receipt of delivery of intervention (control and treatment).

Delivery of Treatment

Control for provider differences

Reduce differences within treatment

Ensure adherence to treatment protocol

Minimize contamination between conditions

- Monitor any complaints.
- RA, social worker to work with both treatment and control groups. Scripted

	protocol and manual used, for treatment and control groups. • RA, social worker to complete a checklist of intervention components delivered, and report deviations from treatment manual. • Social worker will not have access to the treatment content to minimize contamination across treatment/control conditions. • Use of pamphlet to describe how to access treatment • Access to treatment content password protected.
<u>Receipt of Treatment</u>	
Ensure subject comprehension Ensure subject ability to use cognitive skills Ensure subject ability to perform behavioral skills.	• RA will use "teachback" to ensure comprehension of content explained and document success on checklist • Follow up contact (phone, text or email) on day 1, and 8 weeks to inquire about issues with accessing intervention. • Subjects will indicate treatment received via follow-up phone call/email/text, and via follow-up questionnaire.

<u>Enactment of Treatment Skills</u>	
Ensure subject use of cognitive skills Ensure subject use of behavioral skills	• Self-report of use of cognitive and behavioral skills introduced in interventions (control and treatment) in questionnaire • completed by subjects at completion of the study period.

Appendix K

Demographic Form

1. How old are you?

_____years _____months

2. How long have you been coming to the CP clinic at BCH? ____

3. What type of CP do you have?

Monoplegia __ Diplegia __ Quadriplegia __ Don't know__

4. Do you have any devices or braces? ___ Yes ___ No

Check which ones you have.

__ Hand splints __ Spinal brace __ AFO (brace for your foot or feet)

__ Walker __ Gait trainer __ Crutches (sticks, Lofstrands)

__ Knee immobilizer(s) __ Manual wheelchair __ Motorized wheelchair

__ Other (please describe) _____

5. Are you going to physical therapy? Yes__ No__

5. Do you belong to a gym/YMCA or fitness center? Yes__ No__

If Yes, how often do you go to the gym/YMCA or fitness center?

__ Less than 1 x per week __ 1 X per week __ 2 x per week __ More than 2 x per week

6. Do you stretch/exercise at home? Yes__ No__

If Yes, how often do you stretch/exercise at home?

__Less than 1 x per week __ 1 X per week __ 2 x per week __ More than 2 x per week

7.Do you play any sports? Yes __ No __

If Yes, what do you play? _____

8. Do you hang around with friends outside of school? Yes __ No __

9. Do you have hobbies? Yes __ No __

If Yes, what are they? _____

10. Do you belong to any clubs? Yes __ No __

11. Do you volunteer anywhere? Yes __ No __

12. Do you have a job? Yes __ No __

If No, will you look for a job in the next 12 months? Yes __ No __ I'm not sure __

13. Do you drive? Yes __ No __

If No, have you been tested to see if you are able to drive? Yes __ No __

14. What is your goal after high school?

__ Go to work __Go to Junior College/College/University

__ I am not sure __ I have no plans __ I really have not thought about it yet

15. How do you want to be contacted?_____

Cell phone (number)_____Land Line (number)_____

Email address_____Text_____

16. What insurance do you have? _____

17. I identify my gender as…

Male_____ Female _____ Transgender_____

18. What is your race?

Native Hawaiian/Pacific Islander

Black or African American

Asian

American Indian or Alaskan Native

White

Mixed/Biracial

Other

19. What is your Ethnicity?

Hispanic or Latino

Not Hispanic or Latino

Appendix L

Follow-up Questionnaires

Control group

- Had you thought about transitioning to an adult provider before this study?
- Are you comfortable talking to your orthopaedic doctor about transitioning to an adult provider?
- Did you talk with a social worker during your last clinic visit to discuss transition?
- Did you contact a social worker during the 3 months of the study?
- Did you contact the nurse practitioner during the last 3 months to talk about transition?
- Did you talk with the transition coordinator during the last 3 months?
- Have you talked with your primary care doctor about transition in the last 3 months?
- Have you looked online or talked with other families about transitioning?
- Have you talked with your parents about transition of your orthopaedic care to an adult provider?
- Have you started the transferal process?

Treatment group

- Had you thought about transitioning to an adult provider before this study?
- Did the on-line material make you interested in transition?
- Did your parents see some or all of the presentation?
- Have you talked with your parent(s) about transition of your orthopaedic care to an adult provider?
- Are you comfortable talking to your orthopaedic doctor about transitioning to an adult provider?
- Did you talk with a social worker during your last clinic visit to discuss transition?
- Did you contact a social worker during the last 3 months to talk about transition?
- Did you contact the nurse practitioner during the last 3 months to talk about transition?

- Did you talk with the transition coordinator during the last 3 months?
- Have you talked with your primary care doctor about transition in the last 3 months?
- Have you looked online or talked with other families about transitioning?
- Have you started the transferal process?

Appendix M

Follow-up Interview Guide For Subjects in the Intervention Group

Opening statement:

"Hello, my name is Cynthia. I'm interested in learning about your experience using the on-line transition presentation so that I can make changes to make it better. I am also interested in learning about the different ways that you would like to learn/get the information about the things that you will need to know to be able to take care of your health when you get older. The interview will be kept confidential and will not affect the care that you receive in the cerebral palsy center. Let's begin."

1. What did you think when you first looked at the presentation?

   Probes:

   (a) Were you curious to click on any of the sections to see what they were about?

   (b) Was it easy to use?

   (c) Was it too much information?

2. When you look at things online, what is it that grabs your attention and makes you want to check out the site?

   Probes:

   (a) Did you think the information in this presentation was what you need to know now? Later? Ever?

   (b) Was any of the information hard to understand?/

   (c) Was it helpful information?

3. Did you read any of the information in the on-line presentation?

Probes:

(a) IF YES: Was it easy to read?

Was it new information for you?

(b) IF NO: Tell me why you decided not to read it.

4. Did you watch any of the videos in the on-line presentation?

Probes:

(a) IF YES: Were they easy to understand?

Was the information helpful?

(b) IF NO: Tell me why you decided not to watch any of the videos.

5. Did you go to any of the websites in the on-line presentation?

Probes:

(a) IF YES: Were they easy to understand?

Were they helpful?

(b) IF NO: Tell me why you chose not to open any websites.

6. Tell me how you would like to learn/get the information you will need to know to be able to take care of your health when you get older.

Probes:

(a) Would you prefer to sit and talk to someone about what you will need to know/do?

(b) Would you rather have written information on a piece of paper that explains everything?

(c) Would you like to meet with other teenagers and have them tell you about their experiences?

(d) What do you think would be the best way for you to get the information you need?

(e) Who would you prefer to get this information from (your doctor, a nurse, a social worker, your parents, your friends…?)