COGNITIVE INTERVIEWS WITH EARLY, MIDDLE AND LATE ADOLESCENTS LIVING WITH DISABILITIES

By

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Abstract

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Understanding the complicated developmental needs of adolescents is important in constructing data collection tools for this population, including developing patient-reported outcome measures. Cognitive interviews are often used in the development of measurement tools as they assist in determining if terms are understood by the target population. This project examined adolescent understanding of three target questions taken from the Child Depression Inventory (CDI). A framework of adolescent development in which adolescents were deemed to be in an early, middle, or late phase of development was used to assist in understanding how age related to understanding of terms used in the CDI. The results of this study cannot be fully understood by differences in developmental phase of the respondents. In addition, results indicated that adolescents showed greater understanding of terms when they were asked what they were thinking about when responding to the CDI questions than when they were asked about the meaning of the questions.

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Dedication

This thesis is dedicated to my clients: past, present and future.

CHAPTER ONE

INTRODUCTION

Background

Interest in the health and wellbeing of children and adolescents is at an all time high in the United States and around the world. The World Health Organization (WHO) Department of Child and Adolescent Health and Development (CAH) in the 2009 report indicated there was an increased need to collect and analyze data to better inform policy making, particularly evidenced-based data that would facilitate the design of programs that could increase access to healthcare and be responsive to the particular needs of this population (WHO, CAH report, 2009). At present, adolescent researchers advocate for a multidisciplinary and multi-modal approach to data collection, including self-report assessment screening tools to track commonly occurring symptoms, like depression, in patients with life-long physical disabilities (Cella, Yount, Rothrock, Gershon, Cook, Reeve et al., 2007; Johnson, 2002; Lack & Green, 2009; Lahey, Flagg, Bird, Schwab-Stone, Canino, Dulcan et al., 1996; Miller & Glinski, 2000; Porter, Fein & Ginsburg, 1996).

At the forefront of the initiative to develop instruments designed to gather this important information is The Patient-Reported Outcomes Measurement Information System (PROMIS) network, one of the missions of the National Institute of Health (NIH) "Road Map for Medical Research" established in 2002 (Ader, 2007). A primary PROMIS assertion is that in order to develop new and understand current successful disease interventions, clinical researchers must improve how they measure disease process and treatment outcomes to more fully capture a patient's subjective experience and discover what is truly of importance to the patient's quality of life (Ader).

A subset of the PROMIS network was working to develop patient-reported outcomes (PRO) scales for the pediatric population (Ader, 2007) as it was commonly recognized that the use or adaption of instruments originally developed for adults to be used with children or adolescence were not adequate (Eiser & Morse, 2001; Varni, Limbers, & Burwinkle, 2007). Research into the development of self-report measurement tools for children and adolescents was underway, in part, through the University of Washington Center on Outcomes Research and Rehabilitation (UWCORR). UWCORR had the broad, long-term objective of providing clinical researchers with better tools or methods to measure patient-reported outcomes (PRO) in children and adults with chronic disease and disability. This was accomplished by (a) using modern measurement theory and other sophisticated approaches to improve instruments and approaches to measure pain and fatigue, and by (b) increasing scientific understanding of associations between pain and fatigue, and their impact on important outcome variables.

The UWCORR project was a prospective, long-term study of more than 100 youth between the ages of 8 and 20 who have physical disabilities. The aim of this study was to refine, revise and retest item banks developed for the specific domains of pain and fatigue in individuals with disabilities (Cella et al., 2007). Youth were interviewed during six time points across approximately two years using a core set of measures that asked about experience with pain and fatigue, participation in activities, general mood, coping skills and outlook on life. Measurement tools were altered for use at different time points based, in part, on results from a concurrent cognitive interview study that illuminated areas of misunderstanding of item content (Eddy, Khastou, Cook, & Amtmann, in review, 2010). Parents of participants were also given an opportunity to complete a separate survey at each time point.

The effort to design developmentally appropriate tools to track PROs in children and adolescents is timely; however, whether pediatric self-report surveys can be developed to meet the needs of both children and adolescents in one measurement tool remains in question. In a January 2009 article reporting on the progress of item bank development for the pediatric population for the PROMIS project, cognitive interviews were preformed with children and adolescents ages 8 to 17 to determine understanding of terms related to a variety of health related concerns including physical functioning, emotional and social health, fatigue, pain and asthma-specific symptoms (Irwin, Varni, Yeatte & DeWalt, 2009). The findings revealed issues with word comprehension and word meaning but study authors concluded that children as young as eight did respond to most questions with apparent understanding. However, in a comprehensive review statement by the Department of Health in the United Kingdom reviewers acknowledged the difficulty in determining if instruments captured true outcomes and not merely advances in normative development (Schmidt, Garratt & Fitzpatrick, 2001). Still, neither investigation made a distinction between school-aged children and adolescents in spite of the fact that adolescents are a unique group (Katzman, 2003).

Research to date has made little distinction between children and adolescents but may be beginning to change in its understanding of the needs of adolescents as they transition into adulthood (Galambos & Leadbeater, 2000; English, Park, Shafer, Kreip &D’Angelo, 2009). In fact, adolescents are neither children nor adults and how we design research studies, school programs, health interventions and assessment tools should capture and reflect their unique perspective (Caskey & Rosenthal, 2005; Mack, Giarelli & Bernhardt, 2009; Peterson & Leffert, 1995). Their input about health related subjects is especially important because they are beginning to make decisions that can have far reaching implications for their physical and emotional health and quality of life well into adulthood (English et al.).

The most current guidelines for research with adolescents underscored the importance of integrating adolescent developmental theory into our thinking about the health and wellbeing of this population (Horowitz & Wakefield, 2009; La Greca, Silverman & Lochman, 2009; Mack et al., 2009). However, a limited number of studies have tracked the progression of quality of life issues through the early, middle and late phases of adolescence which may impact our ability to understand their changing healthcare needs as they transition from pediatric care to adult care (Hostler, Gressard, Hassler & Linden, 1989; Kennedy, 2008). This is particularly true for adolescents with chronic health issues even though approximately 14% of children and adolescents live with complicated, life-long physical and developmental disabilities (Child and Adolescent Health Care Initiative, 2007).

Of particular concern for this paper were incidences of depression in this age group (Anagnostopoulos, 2008; Lewinsohn, Rhode, Sheeley & Baldwin, 2001; Kovacs, 1996). Seventy-five percent of young people adapted to the developmental challenges of adolescence without undue stress; however, the remaining 20-25 percent experienced significant psychological maladjustment, including drug and alcohol abuse, depression, anxiety, self harm and suicidal ideation (Sadock & Sadock, 2007). The prevalence of mental health problems in adolescents has resulted in a growing base of research devoted to greater understanding of the phenomenon, effective treatment and prevention (Evans, 2009; Goldston, Daniel, Erkali, Reboussin, Mayfield, Frazier et al., 2009). Successful treatment and prevention of health issues such as depression in adolescence depended, in part, on early diagnosis, intervention and analysis of clinical outcomes.

Assessment and treatment of the complicated needs of adolescents living with disabilities requires that assessment tools, in particular self-report instruments, are designed for their cognitive and psychosocial development. Qualitative research examining the intersection of the developmental process, depression, disability and adolescence was sparse. Augutis, Levi, Asplund and Berg-Kelly (2007) analyzed the psychosocial needs of the adolescent who has experienced a spinal cord injury. Woodgate (1998) examined adolescent perspectives of living with chronic illnesses like Crohn's disease, diabetes, asthma or arthritis. Price (2009) indirectly included disability in a review discussing body image and its relationship to the developmental process. An adequate foundation of understanding into the developmental experience of adolescents with disabilities is fundamental to designing interventions to best support them.

There is, at this time, minimal acknowledgment that children and adolescents differ in their understanding of terms used in the assessment tools under investigation for use in tracking PRO. And even less recognition that adolescents may have cognitive, emotional and psychosocial difference that impact their understanding of the questions asked in the surveys.

Statement of the Problem

Adolescents living with chronic physical disability experienced a host of physical and psychological symptoms that can have an adverse affect on quality of life (Hawley, 2003; Hostler et al., 1989; Jemta, Dahl, Nordahl & Fugl-Meyer, 2007; Ju, Lee, Lo, Wang, Chu & Lin, 2006; Kim, 2003). There was a significant body of research that examined disabilities in children and youth including many studies that explored the prevalence and management of symptoms (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; Merlijn, Hunfeld, van der Wouden, Hazebroek-Kampschreur, Passchier & Koes, 2006;) and how symptoms related to quality of life (Eddy & Cruz, 2006; Goldston et al., 2009).

Depression among adolescents was a particular quality of life concern (Lack & Green, 2009; La Greca et al., 2009) as even a single depressive episode in the teen years was said to have long-term implications for health and wellbeing into adulthood (Goldston et al., 2009; van Lang, 2007; Weissman, 1999). In a recent position paper, The Society for Adolescent Medicine (SAM) reported that adolescents with chronic health concerns and/or disabilities should be considered at higher risk for poor quality of life outcomes than typically maturing adolescents (English et al., 2009).

In an effort to improve and expand our ability to track and measure clinically significant symptoms like depression there was growing interest in instrument development and refinement (Hunter, Cameron, & Norrie, 2007; Spranger, 2008) with special attention devoted to discovering and understanding treatment outcome measures and their relationship to quality of life (Arvidsson, 2008; Christodoulou, Junghaenel, Dewalt, Rothrock, & Stone, 2008; Eiser, 2001). Most of the instruments currently in use were developed for the adult population; there were few published self-reported scales designed and developed specifically for use with children (Eddy et al., in review, 2010). This remains true in spite of the general consensus that it was both appropriate and important to ask children as young as five years old about their health and wellbeing and that they were capable of self-reporting about many aspects of care that had direct consequence to their health status (Varni et al., 2007). Also, few scales were developed specifically for the adolescent population even though the most recent guidelines for adolescent health research were in fact built on the premise that adolescence was a unique developmental phase (English et al., 2009; Johnson, 2002; Mack et al., 2009; Santelli, Rogers, Rosenfeld, Durant, Dubler, Morreale et al., 2003).

Through the use of cognitive interviews researchers developing self-report measures had an opportunity to explore how well individuals or groups understood the items under consideration. Cognitive interviews were particularly helpful with children and adolescents who may not understand words that adults commonly use to describe health concepts (Irwin et al., 2009). Like children, adolescents posed an interesting challenge to the process as they often presented with varying degrees of physical, social and cognitive maturity, however, unlike children there was often a perception that because adolescents looked like adults and engaged in adult like behaviors that they were also able to think and reason and problem solve like adults did (English et al., 2009).

There was ample research about how vitally important it was for clinicians and researchers who worked with adolescents to have working knowledge of adolescent development (English et al., 2009; Horowitz & Wakefield, 2009; Katzman, 2003). In addition there were many guidelines having to do with the transition of care between adolescence and early adulthood (Galambos & Leadbeater, 2000). There were few current studies that examined how cognitive and psychosocial development through early, middle and late adolescence affected adolescents' understanding of questions asked about their health and well being in self-report instruments. A self-report instrument designed to be sensitive to the developmental variability in the early, middle and late adolescent may provide researchers and clinicians with valid and useful data and ultimately affect treatment effectiveness.

Statement of the Purpose

The purpose of this study was, through the use of the qualitative method of inquiry known as the cognitive interview, to explore adolescents' level of understanding of questions from the Child Depression Inventory (CDI). The CDI was a 27-item self-report inventory designed to measure depression in children. It has been used in a large number of studies measuring cognitive, behavioral, and neuro-vegetative signs of depression (Kovak & Beck, 1977).

To further explore how adolescents understand questions in the CDI, developmental theory was used to facilitate the analysis of the information gathered through the interviews. Respondent responses were divided into one of the three phases of adolescence based on an Oregon Department of Human Services development chart (Appendix D): early (10-14) middle (15-17) and late (18-21) depending on their age at the time of the interview. We compared the content of responses to the cognitive developmental milestones of each phase to address the following question: Do adolescents in different phases of development respond to CDI questions differently? Depression among adolescents was a particular quality of life concern There were few current studies that examined how cognitive and psychosocial development through early, middle and late adolescence affected adolescents' understanding of questions asked about their health and well being in self-report instruments.

Conceptual Framework

Theory of adolescent development was used as the conceptual framework for this study. Based on fields of medicine, psychology and human development there were three phases of adolescence: early (11-14), middle (14-17) and late (17-21) (Vaughn & Litt, 1990). Of note, the phases used in this study are based on those found in Appendix D and are slightly different than those defined in Vaughn and Litt. According to developmental theory the maturational phase of adolescence was characterized by the emergence of adult-like ability as evidenced by refined cognitive functions, capacity for measured judgment, identity formation, social awareness and physical maturity (National Research Council and Institute of Medicine, 2009). However, these changes are thought to be tempered by the fact that emergence of adult-like ability was inconsistent across early, middle and late adolescence (Vaughan & Litt). There is little consensus about the distinct phases of early, middle and late adolescents but there is consensus that adolescents begins around age 11 and extends into the early 20's (National Research Council and Institute of Medicine).

The typical adolescent was a sometimes misunderstood and complicated individual caught between the perceived security of childhood and the hoped for certainty of adulthood. Faced with the formidable task of becoming an adult, adolescents relied, for better or worse, on both internal and external resources to navigate through the physical, cognitive, emotional and social changes necessary to prepare them for adult responsibilities (National Research Council and Institute of Medicine, 2006, 2009). These resources manifested through genetic inheritance of qualities like temperament; through social interaction with family systems and peers; through brain development and through daily experience (Casey, Getz & Galvan, 2008; Gestsdottir & Lerner, 2008; Petersen & Leffert, 1995). The early adolescent often experienced the brunt of physical changes and subsequent social awkwardness; the middle adolescent was moody, concerned with self-image, with what is happening *now* with inconsistent regard for consequences, and was just beginning to think about their own values; the late adolescent was often more comfortable in their physical being, was more differentiated from parents, and was intellectually approaching more complicated philosophical dilemmas, thinking about the future and deeper questions about autonomy and the self, especially in relationship to others (Caskey &

Rosenthal, 2005; Peterson & Leffert, 1995; Oregon Department of Health and Human Services, 2010).

Caskey and Rosenthal (2005) acknowledged that research with adolescence was a challenge and as such they made thorough recommendations to researchers who intend to perform research involving this population. One such recommendation was to possess a strong working knowledge of adolescent physical and psychosocial development especially with regard to decision making ability and capacity. Continued interest regarding the complex developmental needs of this population were reflected in the most recent position paper by the Society for Adolescent Medicine which stated that in order for adolescents to successfully develop and transition into adulthood, attention must be given to the services they receive (English et al., 2009).

As early as 1993 the American Medical Association published Guidelines for Adolescent Preventive Services (GAPS). GAPS was a framework for screening and prevention of fourteen separate topics and health concerns, outlined in twenty-four comprehensive recommendations all aimed at early intervention by primary care physicians. The document outlined preventive health services by age and procedure. Age was described as early (11-14), middle (15-17) and late (18-21) adolescence. The recommendation further stipulated that teens should be seen and screened yearly from ages eleven to twenty-one and that, at least once, during early, middle and late adolescence teens should have a complete physical examination. Three screening tools—one for early adolescents, one for middle/late adolescents and one for parents/care givers—were included in the guidelines. While the screening instruments covered the same topics in each version, questions were phrased differently or eliminated in recognition of the significant developmental differences between the early and middle/late adolescent (American Medical Association, 1997 & 1998).

At this time, there are few measures designed explicitly for use with children and adolescents. Rather, many instruments have been adapted from adult tools and were understandably lacking in the quality of data they provided (Bell, 2007; Eddy et al., in review, 2010). It seems reasonable to extend the trend to include a distinction between children and adolescence because, from a developmental standpoint, school-aged children differ significantly in their psychosocial and cognitive capacities from adolescence. Further, recognition that typical adolescent development through the early, middle and late phases was inconsistent in the literature and as a result their unique needs may not be adequately addressed during the design of instruments created to track treatment outcomes.

Definition of Terms

Bother. The Concise Oxford Dictionary 9th edition defined *bother* as verb (a) give trouble to; worry; disturb; (b) be anxious or concerned; (a) worry or trouble oneself; (b) be concerned; as noun (a) a person or thing that bothers or causes worry; (b) a minor nuisance; (a) trouble, worry, fuss.

Thing(s). The Concise Oxford Dictionary 9th edition defined *thing(s)* as noun (a) a material or non-material entity, idea, action that may be thought about or perceived; (b) an inanimate material object; (c) an unspecified object or item (d) an act, idea or utterance.

Work out. The Concise Oxford Dictionary 9th edition defined *work out* as (a) solve (a sum) or find out (an amount) by calculation; (b) solve or understand a person or problem; (a) to be calculated; (b) give a definite result; (c) have a specified result (d) provide for the details of

(e) accomplish or attain with difficulty (f) exhaust with work (g) engage in physical exercise of training.

Doing. The Concise Oxford Dictionary 9th edition defined *doing* as (a) an action, the performance of a deed; (b) activity, effort.

OK. The Concise Oxford Dictionary 9th edition defined *OK* as an *ad.j* expressing agreement or acquiescence; all right; satisfactory.

Meaning. The Concise Oxford Dictionary 9th edition defined meaning as (a) what is meant by a word, action or idea (b) significance (c) importance; (a) expressive, significant.

Thinking. The Concise Oxford Dictionary 9th edition defined thinking as (a) using thought or rational judgment; (a) opinion or judgment (b) thoughts, course of thought.

Literature Review

Review of literature addressed the development of measurement tools designed to track patient reported outcomes, the cognitive interview method and the use of cognitive interviews with children and adolescents in the measurement design process, adolescent cognitive and psychosocial development, including current guidelines for research with adolescents, and incidence of depression in the adolescent population.

Patient Reported Outcomes. A patient-reported outcome (PRO) is a direct report from a patient about how well or how poorly they are functioning, about their feelings, especially in response to their health and the effectiveness of the treatment they have received (Valderas, Alonso & Guyatt, 2008). The use of PRO is increasing and has led to a plethora of research initiatives to design measurement instruments, implement use of instruments in research and clinical practice and to track the benefits and challenges to use of such instruments (Bottomley, Jones & Classens, 2008; Greenhalgh, 2009; Lohr & Zebrack, 2009; Scoggins & Patrick, 2009).

In late 2009 The United States (US) Food and Drug Administration (FDA) released draft guidance on the use of PRO in the development of medical products labeling. While the guidelines were only meant for instruments used in the development of medical products during clinical trials, the document provided a substantial resource for best practice design of PRO measurement tools. Of particular interest for this review was the suggested use of patient interviews, focus groups and cognitive interviews during the development and refining process to assure target population understanding of concepts contained in the items (FDA, 2009). Of additional interest were the guidelines regarding the PRO tool's conceptual framework and its relationship to item clarity (FDA). This report outlined the need for a clear conceptual framework to insure the measured concepts were matched in their complexity to the desired outcomes. For example, a PRO instrument designed to capture a specific concept like depression through the use of multiple domains, like emotional wellbeing, social functioning, and physical symptoms may in fact not be adequate to support findings associated with the desired outcome measurement (FDA). In addition, item clarity was shown to be inadequate when patients interpreted items and/or made responses to items that were inconsistent with the PRO conceptual framework (FDA).

Finally, the report confirmed the need for PRO measures intended for use with children and adolescents to address the use of age-appropriate language, ability to comprehend health concepts and understand time period recall (FDA, 2009). Of singular interest to this review the report made explicit that a narrow age grouping was important to account for developmental differences (FDA).

Recently, the use of PRO in clinical practice is being established (Feldman-Stuart & Brundage, 2008; Korolija, Wood-Dauphinee & Pointner, 2007). The literature revealed concerns regarding PRO usefulness in the clinical setting and because of this recommendations for further research into how PRO's might best benefit practice is ongoing (Greenhalgh, 2009; Lohr & Zebrack, 2009).

Rose and Bezjak (2009) reported PRO's in clinical practice have been used mostly to track patient satisfaction with their treatment and that their use in detecting mental health issues, predicting treatment risks and benefits, monitoring cost or informing clinical decisions has not been seen except in a few settings. Of continued debate is the question of appropriate and useful application of PRO in clinical practice (Greenhalgh, 2009). Greenhalgh used a theory driven approach to describe six different applications of PRO in the clinical setting and reported six applications: as screening tools, monitoring tools, promotion of patient-center care tools, as a decision aid, a communication aid between multidisciplinary team members, and as a monitoring device to track quality of care. Results indicated that PRO were effective in the detection of and the resultant discussion regarding health related quality of life issues but had less influence over management of patient concerns and the outcomes of patient treatment of those concerns (Greehalgh). However, results from the Hunter et al. (2009) schizophrenia outcomes differed. Results from this naturalistic study indicated that even among patients with schizophrenia, a notably disabling mental health disorder, patient-reported outcomes, provided useful data for clinicians and had impact on interventions in this severely disabled population.

The PROMIS project is a relatively new initiative intended to support the development of item banks and computer adapted testing for PRO's (Lohr & Zebrack, 2009). The domain mapping for the PROMIS project came out of the long-range health promotion framework developed by the World Health Organization that included three over arching categories of importance: physical, mental and social health (Ader, 2007). Out of the three areas of concern, the PROMIS teams developed their own framework of self-reported health concepts to focus on: pain, fatigue, emotional distress, physical functioning, social role participation and global health perceptions (Ader; Cella et. al, 2007).

The PROMIS project was one of few research initiatives to pay attention to the development and design of PRO measures for use in the child and adolescent population as there was general agreement that children and adolescent did not generally comprehend terms and health related concepts typically used by adults (Ader, 2007; Irwin, Varni, et al., 2009; Walsh, Irwin, Meier, Varni & Dewalt, 2008). The use of focus groups and cognitive interviews during the PRO development process was standard practice for questionnaire development and refinement and included children and adolescents (Irwin et al.; Walsh, et al.).

Cognitive Interviewing. In general, surveys are meant to gather information about individuals and groups; the information accumulated through surveys and questionnaires is used in every day life as well as in all manner of research including health, epidemiology studies, and clinical trials (Jobe, 2003; Miller, 2003). As the development of self-report instruments advances use of the cognitive interview process during the design and refinement of measures was found to be almost standard practice (Beatty & Willis, 2007; Drennan, 2002; Knafl, Deatrick, Gallo, Holocombe, Bakitas, Dixon, et al., 2007).

In particular, measurement validity was enhanced through the use of cognitive interviews (Beaty & Willis, 2007; Collins, 2003; Drennan, 2002). At its most basic, a cognitive interview is a verbal inquiry preformed by a trained interviewer with a selection of respondents to see if respondents understood the questions being asked in the survey. Responding to questions on a survey involved an elaborate cognitive process. There was substantial cognitive theory developed out of cognitive psychology to support the concepts used in the cognitive interview process (Willis, Royston & Bercini, 1991).

In spite of increased understanding of cognitive processes, there was still some controversy about what constituted best practice with regard to cognitive interviews (Beatty &Willis, 2007; Presser, Couper, Lessler, Martin, Martin, & Rothgeb et al., 2004). The literature cites two methods used to interview respondents: the think-aloud and the probe. Both methods were used either concurrently, while the respondent was filling out the survey or retrospectively, after the respondent had answered the questions (Beaty &Willis; Willis, 2005). The intent with either method was to discover the respondents understanding of the directions, specific items, domains, response choices and overall assessment of the survey (Irwin et al., 2009).

The concurrent think-aloud method required the respondent to verbalize the thought process that he/she engaged in during all aspects of answering the survey questions such as while reading, comprehending and responding to the questions (Collins, 2003; Jobe, 2003; Willis et al., 1991). The interviewer did not guide the responses in any manner, rather, it was their position to listen and intervene if and when prompting to continue was necessary. The retrospective think-aloud differed only in that the respondent had already answered the question or questions and later explained their thought process as it applied to answering the question (Collins; Jobe; Willis et al.).

The probe method was a direct mode of inquiry that relied on the interviewer to ask direct and specific questions about the content of the survey (Beatty & Willis, 2007). Typically, the probes were intended to illicit how a respondent came up with their answer, what their understanding of a specific term was, what the question meant to them, how might they rephrase the question, how sure they were that they answered correctly, did the responses match the questions and/or what time frame were they thinking of when responding to the question (Beatty & Willis; Collins, 2003). Probes were used either concurrently or retrospectively.

Given the amount of data a cognitive interview can produce, there were limitations to the cognitive interview method. There was also no standard process by which interviews were preformed or the data utilized (Beaty &Willis, 2007; Collins, 2003; Presser et al., 2004). However, common problems in comprehension, interpretation, logic or structure of questions often became evident and were sufficient to initiate changes in survey questions.

Cognitive Interviewing with Children. There is evidence to show that cognitive interviews preformed with children do assist in gathering data sufficient to change and enhance the quality of the instrument (Bell, 2007; Irwin et al., 2009). Until recently, much of the data gathered about children's health was reported by parents or care-givers, also known as proxy reporting (Stewart, Lynn & Mishel, 2005; Cremeens, Eiser, & Blades, 2006). In spite of frequent reports in the literature of inconsistencies between the child self-report and the proxy report, the data from a proxy report served as a valuable resource especially for children too young or cognitively compromised to self-report (Varni, et al., 2007). Parent proxy for the adolescent population was less likely to provide helpful information (Chang & Yeh, 2005). In a quality of life study comparing parent report and child self-report of 141 children and adolescents with cancer and 141 of their parents, Chang and Yeh found consistent bias for proxy reports to underestimate the impact of disease related distress; this was especially true for the adolescent population. The findings in the Change and Yeh study underscored the need for instruments designed to capture patient reported outcome measures from the intended population.

Because of the controversy involved in proxy reporting and because children as young as five are known to be capable of self-reports about their health and wellbeing in a reliable and valid manner there is growing initiative to develop instruments for the child population (Stewart, Lynn &Mishel, 2005; Varni, et al., 2007).

The use of CI was a standard method of refining tools for use in the child and adolescent populations; for example, in a large (for the cognitive interview process) study conducted by Irwin, et al., (2009) for the PROMIS project. Eighty-eight cognitive interviews with 77 children and adolescents (8-17 years old) across 2 sites reviewed 318 items from a bank of questions related to physical functioning, emotional health, social health, fatigue, pain and asthma-specific symptoms. The project used retrospective probe questions and resulted in the deletion of 25 items and the revision of 35; a total of 293 items were retained and presented for field testing. In the area of item comprehension or word meaning, at least 14 words were revised. The following is a random list of just a few: “frightened” was changed to “scared” and “exhausted” changed to “tired” and “rely” changed to “trust”. Ambiguous words were also addressed but how they were altered is not evident e.g., “activities” could mean sports or hobbies; “clothes” could mean pants, shirts or both; and “hard to have fun” does not specify if it is hard due to physical or emotional issues.

In a very small study (n=6) of a children’s self-report instrument, Stewart et al. (2005) used children (ages 8-16) as content experts to test content validity and found that the children were able to perform the review task effectively. Twenty items were accepted by five out of six of the children and two items were put forward for review based on their input. While this research was not related to cognitive interviewing it did further illustrate the importance of including children when developing measures meant to track data specific to their care, life perspective and well being.

The retrospective probe method as previously described by Willis (2005) and used in the Irwin et al. (2009) cognitive interview study was used in this research project as it is an effective way to derive feedback that can show understanding or misunderstanding of questions.

Piaget's theory of cognitive development. Through careful and lengthy observation, Jean Piaget (1976) described four distinct stages of development: sensori-motor (birth- 2yrs), pre-operational (2-7 yrs), concrete operational (7-11 yrs) and formal operational (11 and up). His work influenced psychology, science and school curricula and continues as the standard to which most research in developmental and cognitive psychology must compare itself. Though there is now a more flexible view of Piaget's stages (Flavel, 1971) as far as Piaget was concerned the stages he described were not fluid; rather they occurred often as abrupt shifts from one stage to the next. Piaget also believed a child was unable to move forward without significant mastery of the previous stage. Of concern for this review was Piaget's description of the shift between the concrete operational and the formal operational stages. Piaget felt the ability to decenter (see from another's perspective) was the hallmark of reaching the concrete operational stage, this change manifested, at first, through the child's interaction with her environment. While Piaget believed this child at times continued to think rather concretely (e.g. a dog has four legs so all four legged animals are dogs) she had begun more consistently to classify objects according to logical features and she generally understood logic as it pertained to simple problem solving and basic principles inherent in her environment. For example, she understood the concepts of conservation, that four marbles remained four marbles even when they were spread across the table or that milk poured into a tall skinny glass from a short wide glass had the same amount of milk in it (Piaget). Bee (1989) reported that the child who had fully reached the concrete operational stage understood cause-and-effect relations, reversibility of action and was capable of inductive reasoning.

According to Piaget (1976), the formal operational thinker had begun to classify objects according to more abstract features, she had begun to test hypotheses, consider the future and issues of an ideological nature. Her thinking had become much more systematic and flexible and she was more capable of deductive reasoning. Many individuals were thought to never reach or fully access their ability to think in this manner. In addition to more sophisticated cognitive ability, Stone and Lemanek (1990) reported the adolescent was in the process of developing a more complex understanding of herself in relationship to her own thoughts, feelings, beliefs and actions and how her behavior affected others.

Piaget's contribution to current thinking in adolescent development is undeniable. Our understanding of cognitive process and how it informs critical decision making and emotional regulation remains at the forefront of developmental science (Compas, 2009; Flavel, 1971; Woolard, 2010).

Erikson's theory of psychosocial development. In his book, *Childhood and Society* (1993), Erikson outlined eight ages of man. The preadolescent was moving out of the stage called industry vs. inferiority which was a period of time marked by accomplishment and acquisition of new skills (industry) or a sense of inadequacy (inferiority) from lack of ability to develop skills or to attain status among peers. Erikson considered industry vs. inferiority crucial in the formation and understanding of socially constructed behaviors like division of labor; he believed through interactions between peers a sense of cultural and social identity and possibility would emerge. Erikson also believed there was significant danger to individuals and society when during this stage a child began to feel the color of her skin or her economic status was more relevant to her burgeoning identity than was her desire and ability to learn new skills.

The true conflict to be resolved during adolescence, according to Erikson (1993), was identity versus role confusion. Until the end of the stage of industry vs. inferiority, Erikson believed development was primarily affected by what was done to the child while the hallmark of identity vs. role confusion was that further development now depended almost wholly on what the child did for herself. Couched in the reality of the physical changes experienced in adolescence, Erikson, regarded the emerging awareness of the substantial adult tasks ahead shifted her focus away from who she felt she was, to how she felt she was perceived by others and how she was to take her place in the social roles set out for her.

Erikson (1968) saw the essential task for an adolescent was to find her place in the world as separate from her family. Erikson (1993) felt the adolescent began to see herself as capable of pursuing her dreams, establishing independence and having experiences based on her own ideals in order to foster the development of personal philosophies (identity) so that living within the constraints of social reality became the norm rather than something to fight against (role confusion). Erikson (1993, 1968) believed the inherent risks of role confusion during this stage were tolerated and enhanced, in part, by strong identity with peers, rigid concepts of what was acceptable social behavior including outward appearance, and a willingness to try on multiple identities. Withdrawal from formative experiences and from the social milieu (for any number of reasons) could lead to confusion about the future (Erikson, 1993,1968).

An inability to establish a sense of self in the world during the identity vs. role confusion stage lead to further problems as the adolescent matured into Erikson’s (1993) next stage, intimacy and solidarity vs. isolation. A poorly differentiated adolescent might find the task of developing intimate relationships difficult and the result often manifested as isolation (Erikson, 1968).

Erikson’s contribution to the understanding of life identity formation continued to support new and emergent thinking in the field. For example, in a proposal to establish a new developmental stage called emerging adulthood, Arnett (2000) used Erikson as part of a foundation for his argument in favor of such a distinction. In recent decades the our understanding of identity formation and the consequences of not establishing a strong sense of identity and of not having independent ideal forming personal experiences were discovered to have a negative impact on quality of life, and in particular correlated with incidence of depression in this age group (Gestsdottir & Lerner, 2008; Holmbeck, Johnson, Wills, McKernon, Rose, Erklin et al., 2002; Packman, 2004).

Current adolescent development theory. Current adolescent developmental theory continued to rely on the early work of Piaget and Erikson as nearly every article examined in this review cited one or both of them. However, research has advanced and now embraces a more ecological model that assumes an individuals social setting and contextual factors significantly impact the developmental process (National Research Council and Institute of Medicine of the National Academies, 2006).

Lerner and Steinberg (2010) outlined the long history of developmental science as it related to the adolescent and espoused that the study of adolescent development has evolved in the last decade into a distinct and vitally important field. Even so, it seems more questions than answers remain. Recent brain development studies have indicated the brain continued to develop until the age of 25 (Beaty & Chalk, 2006; Casey, Tottenham, Liston & Durston, 2005) supporting the notion that adolescents were not fully mature until later than previously believed.

The results of this research have found their way into the political and public policy arena and have spurred controversy over the long enduring questions about how and when adult-like thinking, reasoning and moral ability develops; the as of yet undiscovered answers will have far reaching implications (Steinberg, 2009; Steinberg, Cauffman, Woolard, Graham & Banich, 2009).

It seems the very mercurial nature of adolescents is mirrored in societies' wide and varied age ranges in which adolescents are able to assume adult responsibilities for example, in most states individuals can be charged in a court of law as an adult at the age of 14 but they can not drink alcohol until they are 21. Steinberg (2009) remarked that the most common societal age related constraints such as age at which one can marry, drive a car, join the military, see an R-rated movie, vote, buy tobacco, rent a car, enter into contract and make medical decisions had little to do with developmental science.

It was found to be uncommon in health related research for researchers to make an overt distinction between a child and an adolescent. Within any given study designed with children and adolescents the terms adolescent and youth seemed to be interchangeable but a participant could be called a child, a younger child or an older child, children and adolescents, or part of a pediatric population (Ader, 2007; Eddy, et al., in review, 2010; Irwin et al., 2009; Walsh et al., 2008).

Irwin et al. (2009) did cognitive interviews with 8-17 year olds to gain feedback on items related to general psychical, social and emotional functioning and asthma specific symptoms. Sixty-eight and 78% (respectfully) of the samples were 12 years old or younger. Important changes were made to items based on the results of the cognitive interviews mostly due to misunderstanding of terms by the younger children (Irwin, et al., 2009). The relatively modest sample of adolescents in comparison to that of the children was perhaps a limitation as it was generally recognized that adolescents are a distinct group and have varying degrees of ability to relate to adult influenced terms and concepts (Caskey &Rosenthal, 2005; Mack, et al., 2009).

The Walsh et al (2008) focus group project compared children and adolescents with asthma and those from the general population and did distinguish between two age groups 8-12 and 13-17. The decision to separate the age groups was made based on an acknowledgment of the psychosocial and emotional differences between the two age groups (Walsh et al., 2008). However, in this sample there were also relatively fewer adolescents in the asthma group (35%) compared to children (65%) however, in spite of their acknowledged differences in ability, all participants were asked the same questions.

Memory. Another aspect of cognition is the complicated and not very well understood development and function of memory. Much of our understanding about timeframe recall with children comes from forensic science research with the young child. Forensic research related to cognitive interviewing is primarily focused on cognitive ability and memory in the context of remembering perceived or witnessed experiences (Jones & Pipe, 2002; Fivush & Schwarzmueller, 1995). Even very young children are often capable of remembering details for long periods of time but are apt to remember more accurate information in an open ended question format (Jones & Pipe, 2002).

Further, there is evidence to support a child's ability to give useful information within a time frame as it relates to their physical and emotional health and not just a witnessed or lived experience. In a cross sectional study of cognitive interviews with children ages 5-11 (N=114) Rebok et al. (2001) found that children age 8-11 were able to articulate specific symptoms and behaviors within a 4-week time period. Irwin, et al, (2009) in the development of an item bank for child health concerns for the PROMIS project, confirmed that children as young as 8 years old were able to report accurate information using the 7 day recall period.

Depression in adolescence. At this time the criteria outlined for major depression in the Diagnostic and Statistical Manual of Mental Disorders IV-TR (DSM-IV-TR) has not established stand alone, specific criteria for the child and adolescent population (APA, 2000). Even though research reported that children and adolescents often presented with different symptoms of depression than adults, including poor social functioning, poor self-esteem, defiance, decline in school work, anger, early pregnancy, substance abuse and an increase in somatic complaints (Anagnostopoulos, 2008; Calonge, Petitti, DeWitt, Deitrich, Gordis, Gregory, et al., 2009). Moreover, in the adolescent population depression can often be confounded by normative developmental and psychosocial changes (Anagnostopoulos; Carlson, 2000; Goldston et al., 2009; Lewinsohn et al., 2001).

There was a significant body of research examining the symptoms and trajectory of depression from childhood through adolescence and into young adulthood specifically addressing the implications of developmental changes and their affect on depression and suicidality (Dhossche, Ferdinand, van der Ende, Hofstra, & Verhulst, 2001; Kovacs, 1996; Lwinsohn, Gotlib, & Seeley, 1995; Sorensen, Becker Nissen, Mors, & Thomsen, 2005; Sourander, Helstela, Haavisto & Bergroth, 2001). Results from several longitudinal projects supported an association, albeit complicated, between developmental age and depressive symptoms.

Depression and symptoms related to depression increased with age. The early adolescent had fewer incidence of depression and symptoms of a more somatic nature while the middle or late adolescent had increases in depression and more cognitive and nuerovegitative symptoms

(Carlson, 2000; Nrugham, Larsson, & Sund, 2008; Pullen, Modrcin-McCarthy & Graf, 2000; Sorensen et al., 2005; Sourander et al., 2001). Factors related to age at onset and duration of depression or depressive symptoms painted a more complicated picture. Of note, in a review of relevant literature, Kovacs (1996) found no relationship between age and depressive symptoms but did report that early onset depression was of significant concern. However, there was evidence that depressive symptoms increased with pubertal development and then decreased as adolescents matured into young adulthood; this pattern was also true for suicidal ideation and attempts but was not true for young women who continue to have symptoms of depression in greater incidence than young men well into adulthood (Dhossche et al., 2001; Goldston et al., 2009; Lewinsohn et al., 2001; Nrugham et al.; Patton, Olsson, Bond, Toumourou, Carlin, Hemphill, 2008; Sourander et al.).

Given the common and developmentally appropriate emotional reactivity that the average adolescent experiences there was some controversy in the literature about whether or not to routinely screen for depression (Calonge et al., 2009; Horwitz & Wakefield, 2009). There was also, however, concern that clinicians missed diagnosing adolescents who were suffering with depression (Porter, Fein & Ginsburg, 1997). The concern over missing a diagnosis of depression was greater than the concern for over diagnosing depression as evidenced by the US preventative task force recommendation to primary care providers to screen for depression in adolescents 12-18 but not in children 7-11 and only if systems were in place to insure safe care (Calonge et al). There is some evidence that an adolescent will self-report more symptoms of depression than she will report to her parents and she will experience more symptoms of depression than her parents will observe (Pullen et al., 2000; Bennett, Shroff Pndley & Bates, 1996). Questions regarding how to distinguish between developmentally normal behavior and attitudes and depressive symptoms across the adolescent years remain unanswered.

Research Question

What are the similarities and differences in understanding of health related questions by early, middle, and late adolescents? How are early, middle and late adolescents' answers to questions directed at understanding what was meant by a question different than their answers to questions about what they were thinking when they answered?

http://www.oregon.gov/DHS/ph/ah/growth/adoldevstages.pdf

Significance to Nursing

Nurses are likely to encounter adolescents with disabilities in a variety of settings, most notably in schools, acute care settings and in clinic or rehabilitation facilities. Some young people are cared for 24 hours a day by one or more nurses.

To understand an adolescent's behavior nurses must try to see the youth in the context of their environment and their immediate circumstances (National Research Council and Institute of Medicine, 2009). If the nurse hopes to communicate authentically with this patient they must first approach them as an autonomous person (Caskey and Rosenthal, 2005) and discover what is vitally important to the adolescent, not what the adult or parent or teacher thinks is important. Authenticity with adolescents will allow a nurse access to some of the inner thoughts that may be of concern to them; we cannot make assumptions about what they may or may not know. For example, one young man (12 years old) with cerebral palsy thought his erections were part of his disability (Hostler et al., 1989). It is essential that nurses not shy away from difficult topics as the youth may not be able to discuss her concerns with her parents and may not have another adult to confide in.

Another important aspect of development nurses need to recognize is that adolescents tend, without conscious effort, to make decisions that serve their developmental process in some manner and therefore they may not follow sound advice or adhere to routines that are indicated for their health and well being (McDonagh and Kaufman, 2009). For example, an adolescent may not wear her leg brace because she wants to fit in with her peer group or wants to look attractive and is willing to suffer the consequences of pain and future worsening of symptoms or even worsening disability. A genuine acceptance that the child's identity is not defined by her disability is essential.

We know that support of families, schools and communities and promotion of individual competency and positive mental health is worthwhile intervention for vulnerable adolescence (Evans, 2009). We also know that educating ourselves as nurses about evidenced based practice in mental health and adolescent developmental health will strengthen our practice and assist in the development and use of tools to track valuable PRO.

This study provided a glimpse into how adolescents with physical disabilities at different phases of development interpret questions on the CDI. Further exploration into how the different phases of development influence responses to questions about depression is warranted.

CHAPTER TWO

METHOD OF STUDY

Design

This qualitative, cross-sectional study used cognitive interviews to encourage youth to talk about their responses to three sets of questions from the Child Depression Inventory Short Form (CDI-SF). There is evidence to show that cognitive interviews with children can assist in gathering data sufficient to change and enhance the quality of the instrument under development (Bell, 2007). A qualitative approach was used to allow for responses that capture the thoughts and perceptions of this population (Augutis et al., 2007; Woodgate, 1998).

This study was conducted as part of the larger UWCORR study of pain and fatigue in children with disabilities. Interviews were conducted at approximately 4 month intervals for 6 total interviews. Participants were sent the UWCORR survey at least one week prior to and no more than one month ahead of the scheduled interview. The CI questions were not included in the packets so participants did not know the content of the interview questions ahead of time. Twelve of the adolescents from the larger study were included in this project and only those who responded to the CDI-SF questions were interviewed.

Setting

Cognitive interviews in these twelve youth were conducted in person at the participant's home or by phone. Interviews were scheduled by the participants or their parents to insure the most convenient time. Parents or caregivers or family members were encouraged to be present during the interviews

Sample

Twelve youth ages 12-21 who met the eligibility criteria of the larger prospective long-term UWCORR study of pain and fatigue in children with disabilities were interviewed at time points five and six. Participants in this study were nearly equally divided between boys (n=5) and girls (n=7). Of the 12 youth interviewed disabilities were as follows: traumatic brain injury (n=6), neuromuscular disease (n=3), spinal cord injury (n=1) and other (n=2).

Eligibility criteria for the larger study from which these data were extracted included: (a) child diagnosed with a chronic condition associated with pain and/or fatigue such as spina bifida (SB), cerebral palsy (CP), neuromuscular disease (NMD), spinal cord injury (SCI), traumatic brain injury (TBI) or limb deficiency (LD) (congenital or amputation), (b) child between ages of 8-20 years old, (c) child able to read and understand English, (d) child able to accurately respond to questions about pain and fatigue such as, “In the past week how many days did you have pain?”, and (e) child reported at least some pain and/or fatigue. These twelve youth had been seen within the last three years at a local Northwest pediatric development and rehabilitation program and all but one lived within 70 miles of downtown Portland, Oregon.

Instrumentation

The Child Depression Inventory (CDI) was developed specifically for use with children and adolescents 8 to 16 years of age and is currently one of the most widely used assessments of depression in those populations (Kovac, 1992). In a 1991 study, Weiss and colleagues questioned whether there were developmental differences in the factor structure of the CDI between youth in two age groups 8-12 (children) and 13-16 (adolescent). Youth were separated into these age groups because the developmental space between 12 and 13 represents, for many children, the beginning of pubertal changes and the shift from concrete to formal operation thinking. This study revealed, not surprisingly, that there were developmental differences between responses in the 8-12 and the 13-16 age groups; in particular, children tended to self-report more externalizing behavior than did adolescents (Weiss, Weisz, Politano, Carey, Nelson and Finch, 1991).

The CDI Short Form was used for the larger UWCORR study. The following set of questions from the short form was eliminated because the primary investigators felt the information gathered might be redundant: I do not worry about aches and pains; I worry about aches and pains many times; I worry about aches and pains all the time. This current study used the CDI-SF as the instrument under investigation. The CDI questions were presented in the original pain and fatigue survey under section 6. Quality of Life, a copy of section 6 is included in Appendix A.

The cognitive interviews for this study were conducted by research staff using a list of guiding questions at time point five, approximately 16 months into the larger study, and time point six, approximately 20 months into the larger study. CI questions were designed, in part, to evaluate respondent understanding of three target questions from section 6 Quality of Life in the larger survey. The three target questions under investigation are questions 1, 3, and 6 from section 6 Quality of Life. At study time point five, eight open-ended cognitive interview questions were asked and at time point six, five different open-ended cognitive interview questions were asked. Questions were developed by the researcher in consult with faculty for this study and are included in Appendix B and C.

Data Collection

Immediately following completion of the UWCORR survey participants were asked if they were willing to answer the CI questions. Interviewees were reminded that they did not have to answer any question, there was no right answer to the questions and they could stop the interview at any time. Responses from participants were recorded by hand with clarifying questions asked as needed. Approximate time for the CI was on half hour or less. Data from the interview were later typed into a word document and saved with a password. Original interviews were kept in a locked cabinet.

Data Analysis

As the purpose of this study was to examine understanding of items taken from the UWCORR survey under development, the previously cited literature on the use of CI informs the initial process of analysis of this data. Transcripts of the data were considered individually by three research staff and then as a group to identify common themes (Knafl et al., 2007). Independently, researchers assigned each participant response into one of four categories: (a) response demonstrated understanding of intended meaning of item (b) response demonstrated partial understanding of item (c) response demonstrated lack of understanding of item or (d) response indicated that they did not know the meaning of the item. Subsequently, areas of agreement and disagreement were discussed between researchers and consensus was reached about the categorization of each participant's response.

Human Subjects Considerations

This study used data from the UWCORR Study of Pain and Fatigue in Children and Adolescents. The study received clearance from the institutional review boards of Washington State University, Legacy Health Systems and Seattle Children's Hospital Medical Center (University of Washington).

Parents and youth aged 18 and over were asked to sign a consent form that described the study and the risks and benefits of participation. In addition to parental consent, youth under the age of 18 were asked to sign an assent form that described the study in age appropriate language (one form for youth 8-13 and a second for youth 14-17).

CHAPTER THREE

FINDINGS

Sample Characteristics

The following outlines the demographics and the findings of this study.

Demographics. Cognitive interviews were completed with 12 adolescents (7 female and 5 male) age range from 12-21 years. Disabilities found in this sample were as follows: traumatic brain injury (n=6), neuromuscular disease (n=3), spinal cord injury (n=1) and other (n=2).

Descriptive Findings. Participant responses to all questions were included in the data analysis. However, upon examination of the data it became evident that the responses to three particular CDI questions more elegantly illuminated misunderstanding in question content and context in both time point five and time point six than did data from the other CI questions. Therefore, the remainder of this paper will focus on data from the following three questions: (a) Nothing will ever work out for me, I am not sure if things will work out for me, Things will work out for me o.k., (b) I do most things okay, I do many things wrong, I do everything wrong, and, (c) Things bother me all the time, Things bother me many times, Things bother me once in a while.

The CI questions addressed understanding of terms in two different ways. First, in time point five respondents were asked what they were thinking about when they responded to each of the three target questions. Second, in time point six respondents were asked what it means, for example, to have things work out, to have things bother them or to do most things okay. Because the CI questions were different in time points five and six the following findings were organized by time point to assist in distinguishing between the two probe questions.

Time point five. Of the twelve participants who responded when asked what they were thinking about in response to the question about having things work out, 75% (n=9) indicated that they understood the question with responses such as, “I know where I’m headed. I have a path,” and “my future career, my working at a job,” and “possibly being able to walk one day.” Seventeen percent (n=2) indicated they partially understood as evidenced by statements such as, “just about what will happen next,” and “like schedule changes in school and nurses and their hours or doctor’s appointments.” One respondent did not understand the question as evidenced by the response, “nothing.”

Of those who responded (N=11) when asked what they were thinking about in response to the question about doing most things okay, 64% (n=7) showed understanding of the question through responses such as, “Keeping on top of things I need to get done,” and “just about everything I can do. I can’t do everything,” and “I have friends.” Thirty-six percent (n=4) indicated partial understanding of the question as evidenced by responses like, “People don’t tell me when I do things wrong. They kinda let me figure it out on my own,” and “well, I feel that I’m doing much better than I used to.”

Of those who responded (N=11) when asked what they were thinking about in response to the question about things bothering them, 42% (n=5) showed understanding of the question in the following responses, “Just everything that is going on right now,” and “my pain and bad dreams,” and “family, just siblings. And like, not walking bothers me.” Fifty-five percent (n=6) partially understood the question as evidenced by the following, “My sister and flies,” and “when somebody doesn’t share their stuff or things you need,” and “just typical stuff. It’s just normal stuff that bothers me, nothing big.”

Time point six. Of the nine participants who responded when asked what it means to do most things okay, 56% (n=5) understood the question in such a manner, “Daily stuff, activity,” and “getting along with other people and not fighting,” and “um, that I’m doing my best. Or that I’m not great but it’s ok.” Twenty-seven percent (n=3) showed partial understanding by statements like, “Do it ok. Do it all,” and “like when you take the garbage out when its garbage day.” And one did not understand as evidenced by, “I don’t know. I make mistakes. I sometimes make mistakes.”

Of those who responded (N=8) in response to the question about what it means to do everything wrong, 38% (n=3) understood the question to mean, “It sucks. I do a lot of things wrong but then I figure stuff out and work hard and then do it right. No one does everything wrong,” and “just messing everything up. It’s my fault.” And 63% (n=5) partially understood the question as illustrated by the following examples, “Like if a mailman delivered a package to the wrong house,” and “you didn’t try your best,” and “well, no one’s perfect.”

Of those who responded (N=9) when asked what it means to have nothing work out, 33% (n=3) understood the question as evidenced by the following responses, “I’m afraid of that. I don’t know what I’m doing or how I’m going to get a job because of my pain,” and “that I’m living at home for the rest of my life. That my plans for the future don’t work out.” Sixty-seven percent (n=6) partially understood the question given the following responses, “Darn it,” and “I don’t know. I probably wouldn’t sit around wallowing in self pity. I’d probably do something about it,” and “like if my plans will be too hard.”

Of those who responded (N=9) when asked what it means to have things work out, 44% (n=4) understood the question as evidenced by, “Everything will be ok. I can do it myself,” and “I get finished with school ad go on to the military or somewhere where I can get trained to do work.” And 56% (n=5) partially understood the question as indicated by the following responses, “Today’s been a good day,” and “happy, excited,” and “well, like I might go bankrupt but I’m not going to commit suicide. It’s not like things will go to the very edge of unreason.”

Of those who responded (N=9) when asked what it means to have things bother you, 67% (n=6) understood the question to mean, “Picking on me. People lying to me. People disappointing me,” and “kind of like I don’t like it. It’s not in my best interest. Maybe it annoys the person,” and “Sister. Someone picks on a person. Someone gets in my way. I can’t move and I hurt.” And 33% (n=3) partially understood the question as evidenced by the following, “Like having things not work out. Um, or fighting, arguing about silly things,” and “my sister’s ignoring me bothers me.”

CHAPTER FOUR

DISCUSSION, CONCLUSIONS, RECOMMENDATIONS

Discussion

Use of an adolescent development framework to examine the data in this small CI study indicated there were similarities and differences in understanding of emotional health constructs by early, middle and late phase adolescents. The results further indicated that research into how cognitive and psychosocial development affects understanding of health related terms is warranted. This discussion may be useful in settings where adolescents come into contact with healthcare practitioners and when they are screened for mental health issues.

While there was expected variability in understanding among the early, middle and late adolescents there was also considerable discrepancy between what was understood and only partially understood. Results indicated that misunderstandings can not be completely understood using the framework of adolescent development. It is possible that lack of context in the CDI questions indicating a self-reflective response was expected contributed to some of the erroneous responses. It is also possible that asking about the meaning of terms, a common CI practice, is more abstract than asking about what a respondent was thinking about when answering the question. Finally, results indicated that adolescent are often not clear about the meaning of terms used in the CDI.

In time point five the CI questions asked about what respondents were thinking when they answered the three target questions. In time point six the CI questions asked what the respondent felt the meaning of each of the three target questions were. The following are examples from the CI interviews outlining the difference between the responses to the CI questions that targeted what the respondent was thinking about when answering the questions and what the respondent felt the meaning of the questions were. In addition, the conceptual framework of adolescent development was used in an attempt to uncover similarities and differences in responses between early, middle and late adolescents. The following sections are organized by the core terms: bother, okay and work out. Each section is further divided into examples of what respondents were thinking about and what they thought about the meaning of the questions.

Bother. A late phase adolescent made the following statement when asked what she was thinking when she responded to the question about being bothered by things, “Just everything that is going on right now is hard,” this response indicated, to all three raters, that she understood the question. The response was also indicative of abstract thinking as “everything that is going on” is a global, almost existential concept. In addition, the word “now” in her response acknowledged both the present and the future; the future is a sophisticated perspective in keeping with the developmental milestones of a late phase adolescent. This same young woman responded to the probe about what it means to have things bother a person in the following manner, “Um, people blocking access. Having things advertised as accessible but they aren’t. For people like me they aren’t accessible.” Again, this response indicated to all three raters that she understood the term bother in its broader sense and understood the context of what it means to have things bother a person and how bothersome things might affect a person’s life.

As an example of partial understanding of the question, as agreed upon by all three raters, a middle phase young man stated that he was thinking, “My sister and flies. Both are the worst.” It was clear from his comment that he understood what bothersome things are. Still, his response was more concrete than might be expected for someone in the middle phase of development when the ability for abstract thought begins to develop more fully. It is possible that, without context indicating what was meant by being bothered, his response simply reflects his cognitive ability and his partial understanding of what it means to have things bother him in relation to depressive symptoms. This same young man showed an understanding of the question, documented by all three raters, when he reported that being bothered meant, “Sister. Someone picks on me. Someone gets in my way. I can’t move and I hurt.” This response was an exemplar of fully understanding the question but it was also understanding by default as he gave such a broad response as if to capture all the possible elements of what it means to have things bother a person.

Okay. As an example of understanding the question, agreed upon by two out of three raters, a middle phase young man when asked what he was thinking when he responded to the question about things working out okay stated, “The play station, computer, video games. Like drawing maybe, too.” While it was clear he understood what he can do well, it was less clear if he understood that the question was attempting to uncover possible distress about being capable. In the following comment this same middle phase young man showed partial understanding of the meaning of the question as agreed by two of three raters, with one believing that he did not understand the question at all, “Like when you take the garbage out when it’s garbage day.” Further, this young man showed only partial understanding, all three raters agreed, of what it means to do everything wrong, “Like if a mailman delivered a package to the wrong house. A doctor gave a patient the wrong medicine and he got killed,” again, his responses showed understanding of what it means to have things go wrong but there was no context in terms of his own ability. In comparison, another middle phase young man who reported, “Just messing everything up. It’s my fault,” all three raters agreed he showed understanding of the question. If we look closely at the differences in content of both responses we can see the concreteness in the first response and the abstractness of the second in spite of the fact that both young men are in their middle adolescence. The variability in this particular young man's responses may be a result of his not understanding the terms used in the context of the questions which may be a result of his developmental abilities are lagging behind in comparison to the same age peer.

Work out. All three raters agreed that this late phase adolescent understood the probe about what she was thinking when she responded to the question in this manner, "I was thinking about cause I'm a senior and graduating I was thinking about college. I may not get into the college I want but I'll end up at the one I need to be." Her response was an example of future oriented thinking which is common hallmark among late phase adolescents. However, when she responded to the question about what it meant to have things work out, all three raters agreed, she only partially understood as evidenced by her response, "Well, like I might go bankrupt but I'm not going to commit suicide. It's not like things will go to the very edge of unreason." Her response to the meaning probe about having nothing work out, all three raters again agreed, she had a similar level of partial understanding, "I don't know. I probably wouldn't sit around wallowing in self pity. I'd probably do something about it." The inconsistency of her understanding was an interesting finding and can not necessarily be understood through the lens of adolescent development and may indicated a more complex misunderstanding of the intent of the CDI questions.

In contrast, the following examples illustrated how cognitive development may have affected understanding of the terms used in the CDI. Two out of three raters agreed that this early phase adolescent partially understood the question while one believed he had completely understood as shown in this comment, "I guess I wasn't thinking about anything. Just about what will happen next." All three raters agreed that he only partially understood the question about what it means to have things work out when he responded in the following manner, "Today's been a good day." Finally, in his response to the probe about what it means to have nothing work out he stated, "Darn it," all three raters agreed he only partially understood the intent of these questions. It is possible that his relative immaturity have influenced his responses as he is so firmly in the here and now which is a notable perspective for an early phase adolescent.

One middle phase young man showed consistent understanding in all questions in both time points and was an elegant example of cognitive and psychosocial development and of understanding of the intent of questions aimed at uncovering distress. The following examples are representative of only one set of the CDI questions. Raters eventually agreed that he understood all of the questions, though there was some disagreement on two probes, when one rater felt he only partially understood and a second when two raters felt that he only partially understood. When he was asked what he was thinking when he responded to the question about having things work out he stated, "Um. My future career, my working at a job. I have so much pain and most jobs are physical labor and I don't know what I'll do. I already have to help my mom." His response to the probe about what it means to have things work out he reported, "I get finished with school and go onto the military or somewhere where I can get trained to do work. I don't have pain anymore, that would be like having things work out." Further, when he was asked what it means to have nothing work out, he stated, "I'm afraid of that. I don't know what I am doing or how I am going to get a job because of my pain. I can't get help." If we compare his responses to those of the middle phase young man discussed above we see considerable differences in ability to responds to the probes. These responses do indicate this young man is passing through the middle phase of development as he is beginning to look toward the future and is measuring his abilities against those he sees in his environment. In comparison to the early phase young man in the previous paragraph we can see that this young man has firmly placed himself in a more dynamic place and has left the more concrete, here and now place of early adolescence behind.

Thing. The word "thing" was thought by raters to also be problematic as it was imbedded in all three target questions and was not specific about what kinds of things the respondent was meant to consider. Were the things an adolescent was meant to have considered emotional, social, environmental, physical or all of those? Without some context the adolescent may not understand how to respond to what things she does or does not do well, what things do or do not bother her or what kinds of things do or do not work out for her.

From these examples it is fairly clear that the adolescents in this study had varying levels of understanding of the terms used in the CDI. Probes asking about the meaning of terms imbedded in the CDI questions and about what the respondent was thinking when she answered the questions both had the potential to reveal understanding, partial understanding or lack of understanding. Result indicated that adolescents in varying phases of cognitive and psychosocial development were more able to respond with understanding to the more concrete probe about what they were thinking, than to the more abstract probe regarding the meaning of terms within a question. There was uncertainty as to whether the inconsistency in understanding was a result of developmental differences, general misunderstanding of terms or lack of appropriate context in the CDI.

Limitations

This study had some anticipated limitations of qualitative research and cognitive interviewing methodology. In spite of training provided to research staff there is confusion in the literature about how to perform and interpret cognitive interviews. The small sample size in this study revealed recurrent themes and misunderstandings. However, a larger respondent pool might have increased variability in responses and broadened our understanding of reasons for misunderstanding. In addition, some assumptions about the intent of the target questions in the CDI were made. Because the CDI is a well validated and reliable tool developed to screen for depressive symptoms in children and adolescents, it was assumed that the question were intended to reveal various levels of emotional distress. In addition, nearly fifty-percent of the respondents participating in this study had a traumatic brain injury which may have confounded understanding of cognitive ability and its function in adolescent development.

Implications

An adolescent can behave like a different person at every clinical visit; because of this, knowledge about their developmental phase could help influence treatment and assist in understanding outcomes (McDonagh & Kaufman, 2009; Drury, 2009). A clinician who is attuned to the nuances of adolescent development may have a better sense of how to approach an issue that needs to be addressed more aggressively than one who has little experience with this population. Because symptoms of depression can be subtle (Keenan, Hipwell, Feng, Babinski, Hinze, Richall et al., 2008) and can actually look like socially expected behavior and attitudes (Dury & Giedd, 2009; Horowitz & Wakefield, 2009) it is imperative that clinicians develop trusting relationships with their adolescent clients (National Research Council and Institute of Medicine of the National Academies, 2006).

Nurses can be important advocates for the adolescent population as they encounter this group in a variety of settings. Even nurses who are not experts in adolescent development may pick up on subtle changes in behavior or attitude, especially if the young person is well know to them. If the adolescent is not well know to them it is even more important that nurses have an understanding of and compassion for the ever evolving and often disruptive changes in an adolescent's life. It is vitally important that nurses be attuned to signs and symptoms of emotional distress, drug use and trauma or abuse. Because there is a range of cognitive and psychosocial functioning in the adolescent population, education of nurses that incorporates aspects of developmental theory will likely lead to more effective nursing care in this population (McDonagh & Kaufman). Nurses can also help families by directing these adolescents to community services and advanced practice clinicians when problems do arise (Sen & Yurtsever, 2006).

The use of measures to assess for and track outcomes of depression in adolescents is only one part of the complicated picture of working with this population. Continued research that addresses the phases of adolescent development in relation to prevention, treatment and outcomes of mental health issues is warranted and recommended. In particular, qualitative research that allows the adolescent to verbalize her experience is of particular value.

Recommendations

Current understanding of etiology, prevention, and treatment of depression in the adolescent population includes a well developed and articulated understanding of how cognitive, emotional and psychosocial development affects mental health (Fischer, Stein & Heikkinen, 2009; National Research Council and Institute of Medicine of the National Academies 2009). In fact, the World Health Organization, the Society for Adolescent Medicine, the American Medical Association's Adolescent Preventative Services, the National Research Council and Institute of Medicine and the US Preventative Task Force have indicated an ongoing need to educate practitioners in cognitive and psychosocial development and to ensure those same clinicians take the varying degrees of development into consideration when working with adolescence. These recommendations also encourage a multimodal approach when working with this population. Use of more than one approach when gathering information in efforts of prevention, assessment, diagnoses and treatment is of particular importance because how and from whom a clinician gathers information may alter the quality of that information (Bennett et al., 1996; Lothen-Kline, Howard, Hamburger, Worrell & Boekeloo, 2003).

Assessing for changes in status and tracking outcomes is of significant importance for adolescents with physical disabilities as they often have life long relationships with healthcare practitioners and are particularly vulnerable as they transition through phases of development (Child and Adolescent Health Care Initiative, 2007; Hostler et al, 1989; Kennedy, 2008). This population experiences a host of physical and psychological symptoms that can have an adverse affect on quality of life; assessment tools, in particular self-report instruments, designed for their cognitive and psychosocial development are necessary to provide quality care (Hawley, 2003; Hostler et al., 1989; Jemta, Dahl, Nordahl & Fugl-Meyer, 2007; Ju, Lee, Lo, Wang, Chu & Lin, 2006; Kim, 2003). Interest in instrument development and refinement should continue as an avenue of research especially for tracking and assessing clinically significant symptoms like depression (Hunter, Cameron, & Norrie, 2007; Spranger, 2008) with special attention devoted to discovering and understanding treatment outcome measures and their relationship to quality of life (Arvidsson, 2008; Christodoulou, Junghaenel, Dewalt, Rothrock, & Stone, 2008; Eiser, 2001).

The results of the current study indicated that there were differences in how adolescents interpreted terms from a commonly used assessment tool suggesting additional information might be necessary to discover more accurately the level of depression an adolescent is experiencing. As suicide is the third leading cause of death in the adolescent population and has long been linked with untreated depression the importance of having assessment tools in place that are sensitive to adolescent development is not to be taken lightly (Dury & Giedd, 2009; Klein, Shankman, Lewinsohn & Sheely, 2009).

Summary

Cognitive interviews assist researchers in deepening our understanding of what the respondent believes she is answering; it helps to illuminate what kinds of questions do and do not work in specific populations. While the CDI was developed specifically for use in the child population, this study revealed some important inconsistencies with terms used in the questions. In particular the CDI questions do not give any context for the questions and allowed adolescents to interpret words such as “bother” and “things” with a wide range of meanings.

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Appendix A

Section 6. Quality of Life

Was anyone present for the QoL Section? ___ Yes ___No

USE KEY 3.5a-3.5j

Kids sometimes have different feelings and ideas. Next are groups of three feelings and ideas. From each group of sentences, I want you to pick the one sentence that describes you **best** for the ***past two weeks***.

There is no right answer or wrong answer.

1. ☐ I am sad once in a while.
   ☐ I am sad many times.
   ☐ I am sad all the time.

2. ☐ Nothing will ever work out for me.
   ☐ I am not sure if things will work out for me.
   ☐ Things will work out for me O.K.

3. ☐ I do most things O.K.
   ☐ I do many things wrong.
   ☐ I do everything wrong.

4. ☐ I hate myself.
   ☐ I do not like myself.
   ☐ I like myself.

5. ☐ I feel like crying every day.
   ☐ I feel like crying many days.
   ☐ I feel like crying once in a while.

6. ☐ Things bother me all the time.
   ☐ Things bother me many times.
   ☐ Things bother me once in a while.

7. ☐ I look O.K.
   ☐ There are some bad things about my looks.
   ☐ I look ugly.

8. ☐ I do not feel alone.
   ☐ I feel alone many times.
   ☐ I feel alone all the time.

9. ☐ I have plenty of friends.
☐ I have some friends but I wish I had more.
☐ I do not have any friends.

10. ☐ Nobody really loves me.
☐ I am not sure if anybody loves me.
☐ I am sure that somebody loves me.

Appendix B

Cognitive Interview Guide: Time Point Five

The QOL questions ask about different feelings and ideas you had about your life in the past two weeks… (Re-read the questions to remind the child of which questions)

1. What period of time were you thinking of?
2. Do you think you would have answered these questions the same way a year ago?
3. Which is the most difficult question for you to answer and why?
4. Which is the easiest for you to answer and why?
5. Which set of questions do you think is the most important and why?
6. When I asked you if you think/feel that: nothing will ever work out for me/ I am not sure if things will work out for me/ things will work out for me ok (you said…) what were you thinking about?
7. When I asked you if you think/feel that: I do most things ok/I do many things wrong/ I do everything wrong (you said…) were you thinking of ‘doing’ anything specific?
8. When I asked you if you think/feel that: things bother me all the time/ things bother me many times/things bother me once in a while (you said…) what were you thinking about?

Appendix C

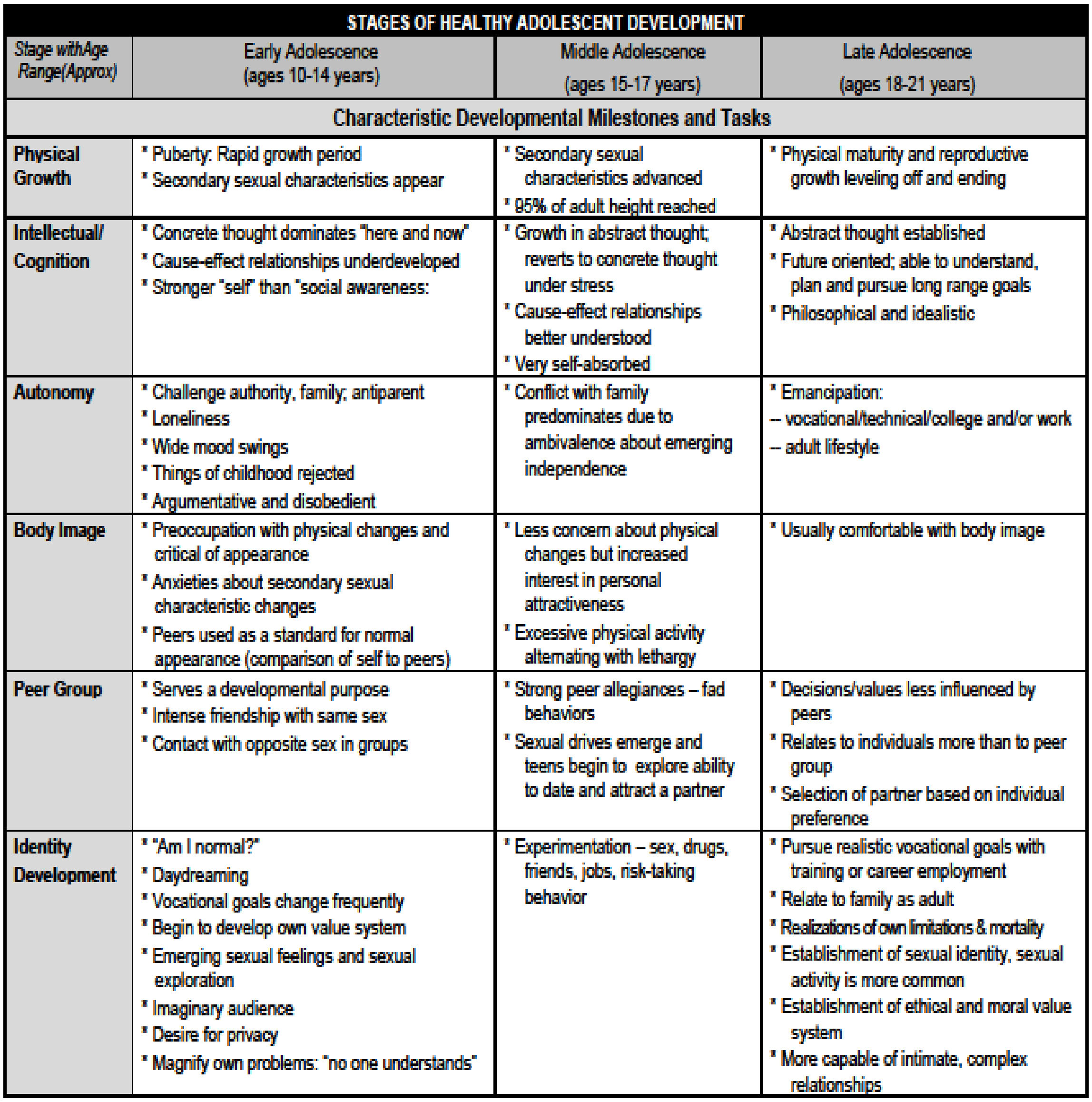
Cognitive Interview Guide: Time point six

The following questions are about three sets of questions you answered in the QOL section 6. I'd like to know what you were thinking about when you answered them.

1. What does it mean to do most things okay?
2. What does it mean to do everything wrong?
3. What does it mean to have nothing ever work?
4. What does it mean to have things work out?
5. What does it mean to have things bother you?

Appendix D

Adolescent Development Chart



STAGES OF HEALTHY ADOLESCENT DEVELOPMENT			
Stage withAge Range(Approx)	Early Adolescence (ages 10-14 years)	Middle Adolescence (ages 15-17 years)	Late Adolescence (ages 18-21 years)
Characteristic Developmental Milestones and Tasks			
Physical Growth	• Puberty: Rapid growth period • Secondary sexual characteristics appear	• Secondary sexual characteristics advanced • 95% of adult height reached	• Physical maturity and reproductive growth leveling off and ending
Intellectual/ Cognition	• Concrete thought dominates "here and now" • Cause-effect relationships underdeveloped • Stronger "self" than "social awareness:	• Growth in abstract thought; reverts to concrete thought under stress • Cause-effect relationships better understood • Very self-absorbed	• Abstract thought established • Future oriented; able to understand, plan and pursue long range goals • Philosophical and idealistic
Autonomy	• Challenge authority, family; antiparent • Loneliness • Wide mood swings • Things of childhood rejected • Argumentative and disobedient	• Conflict with family predominates due to ambivalence about emerging independence	• Emancipation: – vocational/technical/college and/or work – adult lifestyle
Body Image	• Preoccupation with physical changes and critical of appearance • Anxieties about secondary sexual characteristic changes • Peers used as a standard for normal appearance (comparison of self to peers)	• Less concern about physical changes but increased interest in personal attractiveness • Excessive physical activity alternating with lethargy	• Usually comfortable with body image
Peer Group	• Serves a developmental purpose • Intense friendship with same sex • Contact with opposite sex in groups	• Strong peer allegiances – fad behaviors • Sexual drives emerge and teens begin to explore ability to date and attract a partner	• Decisions/values less influenced by peers • Relates to individuals more than to peer group • Selection of partner based on individual preference
Identity Development	• "Am I normal?" • Daydreaming • Vocational goals change frequently • Begin to develop own value system • Emerging sexual feelings and sexual exploration • Imaginary audience • Desire for privacy • Magnify own problems: "no one understands"	• Experimentation – sex, drugs, friends, jobs, risk-taking behavior	• Pursue realistic vocational goals with training or career employment • Relate to family as adult • Realizations of own limitations & mortality • Establishment of sexual identity, sexual activity is more common • Establishment of ethical and moral value system • More capable of intimate, complex relationships

http://www.oregon.gov/DHS/ph/ah/growth/adoldevstages.pdf

CHILDREN'S HOSPITAL AND REGIONAL MEDICAL CENTER
WASHINGTON STATE UNIVERSITY
AND THE UNIVERSITY OF WASHINGTON

CONSENT FORM FOR PARENTS AND PARTICIPANTS 18 YEARS AND OLDER
ASSENT FORM FOR PARTICIPANTS (Ages 14-17 YEARS)

University of Washington Center for Outcomes Research in Rehabilitation (UWCORR): Survey of Pain and Fatigue in Individuals with Disabilities

Children's Hospital and Regional Medical Center
Seattle, Washington
Institutional Review Board
JAN 25 2008
APPROVED

Investigators:

1. Dagmar Amtmann, Ph.D., Research Assistant Professor, UW Department of Rehabilitation Medicine. Telephone: (206) 685-4181
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4. Joyce Engel, Ph.D., Professor, UW Department of Rehabilitation Medicine. Telephone: (206) 598-0005
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21. Dominique Ryder, BA, Research Study Assistant, UW Department of Rehabilitation Medicine, (206) 221-2414
22. Nina Lang, BA, Research Study Assistant, UW Department of Rehabilitation Medicine, (206) 221-2414
23. Gia Accuardi, RN, Research Study Assistant, Intercollegiate College of Nursing, Washington State University, (360)546-9788

Investigator's Statement About the Research Study:

When we say "you" in this consent form, we mean you or your child; "we" means the doctors and other study staff.

You are being asked to take part in a research study. Taking part in research is voluntary. Please take time to make your decision, and discuss it with family and friends.

This form provides a summary of the information the researchers will discuss with you. If you take part in this research study, you will keep a copy of this form. Be sure to ask any questions you have about the research study.

You are being asked to take part in this research because you or your child has a disability.

Why is this research study being done?

This study is looking at whether youths with physical disabilities experience pain and/or tiredness and how pain and/or tiredness affects their lives. We want to ask youths who are 8-20 year old with disabilities about any pain and/or tiredness they experience. We will be talking to youths with different types of physical disabilities such as spina bifida, cerebral palsy, spinal cord injuries, neuromuscular disease, and/or limb deficiencies (congenital or amputated). We hope that this study will help us understand more about pain and tiredness in youths with disabilities and ways to help reduce that pain and tiredness.

Are there benefits to taking part in the study?

You will not directly benefit from participation in this study. However, we will provide you with study results to help you better understand how your individual pain and/or tiredness relates to the degree of pain and tiredness in a population with similar chronic medical conditions.

What is involved in the study?

Youth: You will be asked to answer the same questions 6 times over the next two years. You will be asked questions about your pain and/or tiredness. For example, we will ask about how pain and/or tiredness affects things you do such as school, free time, and sleep. We will also ask you how you deal with pain and/or tiredness. We will also ask you about your feelings and moods. Some of the questions are personal and sensitive. They include questions about feeling alone, sad or unable to stop your pain. You do not have to answer any questions. You can stop the interview at any time. Each interview may take up to 120 minutes. You will have the interview either in-person or over the telephone. With you/your parents' permission, the interview will be audio-recorded. The recordings will be reviewed by the researchers to gain full understanding of your experiences. We will be asking you these same questions every 4 months (± 2 weeks) until we have 6 interviews with you. Your answers will help us learn more about the pain and/or tiredness experiences of youth with physical disabilities from your perspective.

Parent/Guardian: You will be interviewed once at the beginning of the study. You will also be asked about your child's moods and how they behave. You will also be asked about the impact of your child's moods and behavior on your family. Two examples of the most sensitive questions you will be asked are "How would you rate your family's ability to get along with one another?" and "During the past 4 weeks did your child's emotional well-being or behavior limit the amount of time you have for your own personal needs?" You will be asked these questions either over the phone, in-person, or through the mail. The survey may take up to 120 minutes to complete.

What are the risks of taking part in this research study?

You might become tired after talking for a long time. Also, you might feel embarrassed by some of the questions. Talking about pain and tiredness might make you feel sad or angry. You can skip any question or stop the interview at any time. Information that you share will be kept confidential and will not be shared with your parent/guardian unless you are at risk for suicide or other serious risk of harm.

Will my child or I be paid to take part in the study?

Youths: In order to thank you for the interviews we will give you $25 for each interview. If you participate in all 6 interviews, you will receive $50 for the last interview instead of the $25 given for the previous interviews. In addition, if you do the in-person interviews at a University of Washington location, we will pay you for parking if it applies.

Parents/Guardians: You will not receive payment for your participation, but if you do the in-person interviews at a University of Washington location, we will pay you for parking if it applies

What are my rights and my child's rights as a research participant?

This study is completely voluntary. You do not have to take part in the study if you do not want to. If you do take part, you can stop at any time. You can also decline to answer any individual question on the survey by telling the interviewer. Your decision will not influence the care you receive from Madigan Army Medical Center, Children's Hospital and Regional Medical Center, or the University of Washington Medical Center.

What about confidentiality?

All of the answers given to us will be kept private, within the limits of the law. No names or other ways of identifying you will be used in any way. All information about you will be kept locked, and only the researchers will have access to it. We will not put your name on any of the interview forms. Study forms will have numbers only, instead of names. We will not share any information you give us with your doctor or family unless you are at risk for suicide or other serious risk of harm. Information collected in this study may be combined with information from other research sites around the country as part of a project funded by the National Institutes of Health (NIH). This information will be analyzed by researchers at the University of Washington and other places. Researchers from other places will not have access to your name or any identifying information. After 7 years, we will destroy all information we have that could identify you.

If you would like to be informed about future studies regarding pain and/or tiredness in youths, we have provided a place at the bottom of this form for you to let us know that. Phone and address information you have provided to the researchers will be used for this future contact. We will also use this information for scheduling your interviews for this study. We will also ask you for the address and phone number of a family or friend. This information will also be used to reach you for future studies or in case we cannot reach you with the phone and address information you have provided. You can be in this study even if you do not want to participate or be contacted about future studies.

A research study assistant may have access to the audio recordings of your interview for the purpose of transcription. After transcription the tapes will be destroyed. Transcripts will be identified only by their study codes and will be stored with other study data in a locked file cabinet and on secure servers. All information that could identify you will be destroyed no later than 2013.

Whom do I call if I have questions or problems?

If you have any questions about this study, you may call Dr. Amtmann at 206-685-4181or the research staff at 206-221-2414 or 1-800-504-0564. If you have any questions about you or your parent/guardian's rights as a research participant you may call the appropriate Institutional Review Board (IRB) below. The IRB is a committee that is responsible for protecting the rights of children and families involved in research.

- Children's Hospital and Regional Medical Center IRB at (206) 987-7804
- University of Washington IRB at (206) 543-0098
- Madigan Army Medical Center's IRB at (253) 968-3524
- Oregon Health Sciences IRB at (503) 494-7887

______________________________ ____________

Signature of Research Investigator/Associate **Date**

Subject Statement:

The study described above has been explained to me. I voluntarily agree to participate in this research study. I had a chance to ask questions. I understand that future questions I have about the research or about research subjects' rights will be answered by the persons listed above.

☐ Yes, you may contact me about future studies on pain and/or tiredness in persons with disabilities. I will provide information for researchers to keep in contact with me if necessary.

☐ No, please do not contact me about future studies. Please do not use my name or my parent/guardian's name for future contact.

☐ Please have the principal investigator, Dr. Amtmann, send me a letter with study results as they become available.

______________________________ ______________________________

Name of Participant (Ages 14 and older) **Signature of Participant (Ages 14 and older)** **Date**

______________________________ ______________________________

Name of Parent/Guardian (PLEASE PRINT) **Signature of Parent/Guardian** **Date**

(Note: Parent/Guardian consent NOT required for participants 18 years or older)

Permission to Audio Record Youth Interview

☐ Yes, you may audio-record my/my child's interview.

☐ No, please do not audio-record my/my child's interview.

Copy to: Participant/Parent
Researcher's File

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23. Gia Accuardi, RN, Intercollegiate College of Nursing, Washington State University. Telephone: (360)546-9788

What is research?

We are asking you to be in a research study. Research is a way to test new ideas. Research helps us learn new things. Being in research is your choice. You can say Yes or No. Whatever you decide is OK. We will still take good care of you.

Why are we doing this research?

We want to find out how to best ask children about what happens with them when they hurt or feel tired. Asking questions the right way will help doctors and nurses to take better care of children with disabilities in the future. With your help grown-ups will be able to ask children questions that are easy to understand. Better questions will lead to better answers and will help us find treatments for pain and tiredness.

What will happen in the research?

If you decide to say yes, we will talk with you six times over the next two years. Each time, we will ask you many different questions. We will ask about your disability and your life. We will also ask about pain and tiredness. Even if you do not have pain or tiredness, we still want to ask you questions. If it is okay with you, we will tape-record your interviews so that we can look back on them and better understand what you tell us. Your tape-recordings will be kept private and no one but us will listen to them.

What are the good things that can happen from this research?

What we learn in this research will not help you now. When we finish the research, we hope we will know more about pain and tiredness in children. This may help children with disabilities later on.

What are the bad things that can happen from this research?

Each time we get together to ask you questions it will take quite long, almost an hour and a half. You can ask for a break any time you feel like it. You can also say that you want to stop at any time. It will be no problem. You may not like some questions and you do not have to answer those questions Just say you want to skip the question.

What else should you know about the research?

Being in this research study is up to you. You can say Yes or No. Either way is OK. Whatever you choose, we will still take good care of you.

You can say Yes now and change your mind later on. You can stop being in the research study at any time. If you want to stop, just tell someone in the research study.

What you tell us is private. We will ask your parent not to be in the room while you answer the questions. If you tell us that you are thinking about hurting yourself, we will have to tell your parent/guardian.

Please take as much time as you want to make your choice. You may ask us any questions at any time. If you have questions later on, you may also call the study staff at (206) 221-2414 or 1-800-504-0564.

Signature of Researcher ______________________________ Date ______________

Child's Statement

The researchers have told me about the research. I had a chance to ask questions. I know I can ask questions at any time. I want to be in this research study.

Signature of child ______________________________ Date ______________

Signature of parent ______________________________ Date______________

Permission to Audio Record Youth Interview

☐ Yes, you may tape record my interview.

☐ No, please do not tape record my interview.

Copies to: Child and Parent