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Brief Report: Adolescents' Reasons for Participating in a Health Care Transition Intervention Study

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Purpose: This study investigated the reasons adolescents with spina bifida consented or assented to participate in a randomized controlled prospective health care transition intervention study.

Methods: Sixty-five adolescents with spina bifida (SB), ages 14 to 18 years, who had previously participated in the Transition Preparation Training Program (TPT) study were recruited for the current study. A total of 26 consents/assents were obtained; a total of 25 questionnaires were returned (11 treatment; 14 control). Study findings were from a sample of 25 adolescents, aged 14 to 20 years who had participated in a randomized controlled prospective study entitled the Transition Preparation Training Program (TPT). Content analysis was used to code and analyze data.

Results: Study findings revealed adolescents indicated several reasons for choosing to participate in the research study. Major reasons cited for their participation were related to the desire to learn more about their condition and for altruistic purposes. Numerous reasons were offered by respondents as to why adolescents declined to participate in the research study; feelings of discomfort and issues of privacy were cited. Sixty-four percent of the respondents indicated the offer of a research incentive did not affect their decision to participate in the TPT study. Other findings are reported as to the use of research incentives and future recruitment recommendations.

Conclusions: Youth shared a number of reasons and insights about recruitment strategies that may be helpful for future research efforts, especially those studies involving adolescents with special health care needs who participate in health care transition research.

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BEGINNING NEARLY THREE decades ago, researchers recognized the importance of a better understanding of the comprehensive needs of children and adolescents with chronic conditions to improve their long-term biopsychosocial outcomes and quality of life. In 1989, Surgeon General C. Everett Koop urged concerted effort in addressing

these needs during the landmark United States Surgeon's (US) General Conference, Growing Up and Getting Medical Care: Youth with Special Health Care Needs (Koop, 1989). Since that time, due to improvements in health care and technology, the life expectancy and prevalence rate of U.S. children and adolescents with special health care needs has increased. Currently, 90% of children diagnosed with a special health care need survive into their 20s (Scal & Ireland, 2005). According to the findings of the 2009–2010

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National Survey of Children with Special Health Care Needs (NS-CSHCN), the prevalence rate of CSHCN, from birth to 17 years is estimated to be 15.1% (11.2 million). The NS-CSHCN prevalence rate is highest in the groups of early, middle and older adolescents (12–17 years) at 18.4% as compared to other younger age groups, due in part to acquired conditions diagnosed during adolescence (U.S. Department of Health et al., 2013). Other findings reported in the NS-CSHCN demonstrate that living with special health care needs has demonstrable adverse outcomes. Approximately a quarter of parents (27.1%) report their children's condition has a pervasive impact upon their children's daily living. Other consequential NSCSHCN findings are as follows: 15.5% are absent from school 11 more days during the school year; approximately 60% report their children have difficulties with daily living functions (i.e. bathing, dressing), activity levels (i.e. ambulation), as well as have behavioral and emotional challenges.

Researchers have taken on the challenge and imperative to better understand the impact and consequences of living with a special health care need upon children, adolescents and their families to serve as the basis for development of service models and intervention approaches that improve not only their health status but their quality of life as well (Gans & Brindis, 1995). Concomitantly, researchers have grappled with the ethical, practice and practical issues concerning the involvement of children and adolescents with SHCN in research studies. The importance of conducting studies with children and adolescents with SHCN using methodology that elicit responses from them directly rather than from adult proxies such as their parents, health care providers and other caregivers has become increasingly obvious yet difficult to fully realize. Illustrative of this viewpoint were recently published findings of a systematic review of ASHCNs' perspectives pertaining to health care transition, wherein approximately 25% of studies were ultimately excluded from the review as adolescents responses were merged with parents, caregivers and providers or that parents served as the proxy respondent for their children (Betz, Smith, & Macias, 2010; Betz, Smith, Macias, & Deavenport-Saman, in press). Of the studies included in this review, authors concluded that more research involving adolescents as respondents using more rigorous designs and methods was needed (Betz et al., 2010, in press).

The purpose of this study was multifold: (a) to investigate adolescents' reasons for participating in a randomized controlled prospective study entitled the Transition Preparation Training Program (TPT); (b) to understand their perceptions as to adolescents' reasons to agree or decline participation in research studies; (c) to elicit their recruitment suggestions for future studies; and (d) to learn if the offer of an incentive affected their decision to participate in the TPT study.

Background

The literature pertaining to issues regarding research practice involving children and adolescents have focused primarily on their understanding of the consent/assent process. Researchers

have studied the extent to which adolescents are included in the consent/assent process itself (i.e. explanation of the study), the extent to which their decision to participate is recognized and accommodated during the consent/assent process, the decision-making influence of authority figures (i.e. parents, physicians) to provide study consent/assent and the current practices involving children and youth in the informed consent/assent process (Brody, Annett, Scherer, Turner, & Dalen, 2009; Broome, Kodish, Geller, & Sminoff, 2003; Fogas, Oesterheld, & Shader, 2001). Currently, scant research is available to inform researchers as to evidence-based approaches to use in recruiting samples of adolescents, especially those who represent rare populations that are difficult to access (Villarruel, Jemmott, Jemmott, & Eakin, 2006).

As the following narrative review indicates, the range of chronic conditions of adolescent samples in this field of study has been limited to HIV positive adolescents (Stanford et al., 2003; Villarruel et al., 2006); small samples of adolescents with varied chronic conditions (i.e. sickle cell disease, diabetes, cancer) and those without chronic conditions (Broome & Richards, 2003; Jones & Broome, 2001); asthma (Brody, Annett, Scherer, Perryman, & Cofrin, 2005) and those with attention deficit hyperactivity disorder (Fogas et al., 2001).

This review begins with the findings of studies examining adolescents' reasons for choosing to participate in research studies. Next, summary findings of studies examining the influence of parents and other factors on adolescent's decisions to participate in research studies are presented. This review concludes with the opinions of experts who have conducted research with adolescents.

Although not assessed directly, 106 Latino adolescents who participated in an HIV risk reduction randomized clinical trial, were queried as to the reasons that facilitated and/or inhibited their participation in the intervention program. The reasons for continuing program participation identified by adolescents were the urging of peers and family; participation incentives; commitment to participate; and the altruistic desire to assist others. The participation barriers identified by adolescents were competing time demands (i.e. homework) and lack of peer and family encouragement (Villarruel et al., 2006).

HIV positive and HIV negative ethnically diverse adolescents, ages 12 to 18, ($n = 438$) who participated in the REACH (Reaching for Excellence in Adolescent Care and Health) study were surveyed to rate the importance of 13 research recruitment and retention factors. Their responses were the same for both recruitment and retention: quality health care, caring staff, health education, privacy/confidentiality and altruism (Stanford et al., 2003).

Three focus groups composed of 15 African American adolescents (ages 13 to 17 years) with sickle cell disease ($n = 5$), diabetes ($n = 3$) and without a chronic condition ($n = 7$) were queried as to reasons for participating in research. The two major themes were, strategies pertaining to recruitment and those pertaining to retention emerged from their input. Recruitment factors included incentives, study logistics, learning about their condition and intervention appeal.

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