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Asthma Self-Management Goals, Beliefs and Behaviors of Urban African American Adolescents Prior to Transitioning to Adult Health Care

Wanda Gibson-Scipio PhD, APRN, BC[a,*], Dustin Gourdin MA[b], Helene J. Krouse PhD, ANP-BC, FAAN[a]

[a]*Wayne State University College of Nursing, Detroit, MI*
[b]*University of Chicago Department of Sociology, Chicago, IL*

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Adolescence is a unique time of development incorporating a transition from child centered to adult centered health care. This transition period can be particularly challenging for individuals with a chronic disease such as asthma. Inadequate transition planning during adolescence may place an already vulnerable population such as African American adolescents with known health disparities in asthma prevalence, morbidity and mortality at risk for a continuation of poor health outcomes across the lifespan. Central to transition planning for these youth is the core element of developing and prioritizing goals. The purpose of this qualitative study was to explore the asthma self-management goals, beliefs and behaviors of urban African American adolescents prior to transitioning from pediatric to adult health care.

Methods: A focus group composed of 13 African American adolescents with asthma ages 14–18 years from an urban population was conducted. Responses from transcripts and field notes were reviewed using an iterative process to best characterize asthma self-management goals and beliefs that emerged.

Results: Four core themes were identified: 1) medication self-management, 2) social support, 3) independence vs. interdependence, and 4) self-advocacy. Medication self-management included subthemes of rescue medications, controller medications and medication avoidance. The social support theme included three subthemes: peer support, caregiver support and healthcare provider support.

Conclusion: Findings suggest that adolescents with asthma form both short term and long term goals. Their goals indicated a need for guided support to facilitate a successful health care transition.

ASTHMA IS A common chronic disease that often begins in childhood and may persist, resolve or relapse across the lifespan (Gershon, Guan, Victor, Wang, & To, 2012). When children and adolescents are affected by asthma, they fall into the broad category of youth with special health care needs (YSHCN) as they meet the basic criteria of having a chronic medical condition (McPherson et al., 1998). A secondary criteria of being a YSHCN is requiring health services beyond those of other youth with a similar condition; urban African American youth with asthma meet this criteria due to significantly higher prevalence, morbidity, and mortality rates and asthma severity levels compared to white and other racial or ethnic groups except Puerto Ricans (Akinbami et al., 2012; Lara, Akinbami, Flores, & Morgenstern, 2006). In the United States, 21% of non-Hispanic black children are diagnosed with asthma compared to 12% of white children (Akinbami et al., 2012). Morbidity and mortality rates for African American adolescents with asthma in urban environments are markedly

* Corresponding author: Wanda Gibson-Scipio, PhD, APRN, BC.
E-mail address: gibsonsc@wayne.edu.

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high compared to white youth of the same age (Akinbami, Moorman, Garbe, & Sondik, 2009). According to the Centers for Disease Control and Prevention (2003), asthma mortality rates for adolescents are highest among African American youth between the ages of 15 and 24 years.

Adolescence is a period of vulnerability for YSHCN, including those with asthma, because these individuals face multiple developmental changes (cognitive, physical, emotional and social) while also making multiple personal transitions (i.e., high school to college, living independent from parents, possible full time employment) (Bruzzese et al., 2004; Meschke, Peter, & Bartholomae, 2012). They are also faced with transition from pediatric to adult focused health care (Pai & Schwartz, 2011). Although the transition from pediatric to adult focused health care is a national priority supported by consensus statements from leading organizations, this aspect of care continues to be widely neglected (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians–American Society of Internal Medicine, 2002; American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011; Ferris et al., 2013; Reiss, Gibson, & Walker, 2005; U.S. Department of Health et al., 2008).

Investigators (Lotstein, Kuo, Strickland, & Tait, 2010; Richmond, Tran, & Berry, 2011) found African American youth with special health care needs such as asthma were less likely than their white counterparts to discuss the transition in care with a health care provider and/or engage in transition planning. A failure to plan for health care transitions during adolescence when lifelong behaviors are established may contribute to findings such as those noted in a study by Scal, Davern, Ireland, and Park (2008) where approximately 20% of young adults with asthma had no usual source of health care. These findings suggest that poor transition planning during adolescence may place an already vulnerable population with known health disparities in asthma prevalence, morbidity and mortality at greater risk for a continuation of poor health outcomes across the lifespan.

Health care transition planning defines a process of care that prepares youth to increasingly take on the primary responsibilities of their health care while receiving developmentally appropriate guidance and support that maximize their independence in context of their disease, disability, and related cognitive and physical capabilities (Institute of Medicine, 2007). The health care transition planning process should be formalized and begin during adolescence (Betz, Lobo, Nehring, & Bui, 2013; Blum, 2002; Davis, Brown, Taylor, Epstein, & McPheeters, 2014) and address six core elements designed to assist youth and young adults as they transition to adult centered care. These elements include (a) developing and implementing a transition policy, (b) identifying a method of tracking and monitoring transition, (c) developing and prioritizing goals with youth and families to support transition readiness, (d) transition planning, (e) transfer of care, and (f) assessment of transfer completion (Got Transition, 2015). Some elements (a, b, e and f) are the primary responsibility of health care providers and health care systems while others (c and d) are directed at families, affected youth and health care providers.

An understanding of disease self-management goals of adolescents with asthma is essential to assure that the transition needs of youth are appropriately identified and supported so that optimal health outcomes can be achieved (Betz et al., 2013). Self-management goals of youth in transition go beyond adherence to medications. They include an understanding of one's disease process that informs interactions with health care providers, peers and family members; use of community resources such as pharmacies and medical facilities; and health care decision-making and self-advocacy. Discussing goal setting with youth provides a means of actively engaging them in their care and learning what is most important to them. It is also important to discuss goal setting with input from youth as their transition goals may differ from the health care provider's goals. However, goal setting, which is a core element of transition preparation including asthma self-management is less likely to occur among African American adolescents (Lotstein et al., 2010).

Goal setting is related to health behavior. The development of goal directed health behaviors can be targeted during the transition readiness management (AAP et al., 2011). Self-regulation of disease self-management improves health outcomes because the behavior is derived from knowledge and skills as opposed to habit, fear, or tradition (Clark, Gong, & Kaciroti, 2001). Goals "enhance self-regulation through their effects on motivation, learning, self-efficacy, and self-evaluation of progress" (Schunk, 2001, p. 1). Health care providers can benefit from understanding the self--regulated goals of youth with asthma during transition planning. Short-term goals are particularly relevant in health care planning for adolescents as they "help people to succeed by enlisting effort and guiding action in the here and how" (Bandura, 2004, pg.145). Although outcomes of a successful health care transition have not been standardized, in our present study chronic disease self-management was considered a metric of transition readiness. The purpose of this qualitative study was to describe the asthma self-management goals and behaviors of urban African American adolescents with asthma prior to the transition to adult focused health care.

Methods

A descriptive exploratory design utilizing focus group was used for this study. This was the second data collection point held to examine goals related to asthma self-management during adolescence; a previous report described the goals of caregivers (Gibson-Scipio & Krouse, 2013). To our knowledge focus groups have not been formerly used to understand adolescents' goals related to asthma disease self-management prior to transitioning to adult health care. Also to our knowledge this topic has not been explored