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Measuring Transition Readiness: A Correlational Study of Perceptions of Parent and Adolescents and Young Adults with Sickle Cell Disease[1]

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Abstract Adolescents and young adults (AYAs) often transfer from pediatric to adult care without adequate preparation, resulting in increased morbidity and mortality. The purpose of this descriptive research study of parent/AYA dyads was to measure perceptions of transition readiness. Factors that were found to be associated with perceptions of increased readiness to transition included AYA age, the amount of responsibility AYAs assume for their healthcare and the degree of parent involvement. More attention should be focused on these aspects of care to improve transition from pediatric to adult care for AYAs with sickle cell disease.

Background

SICKLE CELL DISEASE (SCD) is a group of genetic disorders characterized by presence of hemoglobin S (HbS) that leads to multisystem morbidity and an increased risk of early death (Quinn, Roger, McCavit, & Buchanan, 2010). It is the most common hemoglobinopathy, affecting approximately 80,000–100,000 individuals in the United States (Ashley-Koch, Yang, & Olney, 2000; Newland, 2008). SCD is a chronic disease associated with lifelong vaso-occlusive episodes and end organ damage. In 1973, the average life span of a patient with SCD was 14 years of age (Claster & Vinchinsky, 2003). Today, early identification of affected infants through newborn screening combined with early introduction of comprehensive supportive care, enables individuals with SCD to live longer, well into adulthood. Approximately 90% of individuals with SCD now reach 21 years of age, and the majority live into their forties (Quinn et al., 2010). Consequently, more and more SCD individuals require adult care services necessitating systematic processes to transition adolescents and young adults (AYAs) from pediatric to adult care.

Transition is defined as 'the purposeful planned movement of adolescents and young adults from child-centered to adult-oriented health care systems" (Blum et al., 1993,

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p.570). Transition readiness is defined as the specific decisions made and the actions taken for building the capacity of the AYAs, parents, and the providers to prepare for, begin, continue, and finish the process of transition (van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011). Researchers have documented that transition is often abrupt, resulting in AYAs leaving pediatric care without adequate preparation (McPherson, Thaniel, & Minniti, 2009; Wojciechowski, Hurtig, & Dorn, 2002). Poor transition in AYAs with chronic illnesses has been associated with potentially serious health-related consequences such as lack of continuity of care, disengagement from services and increased morbidity and mortality with subsequent additional health care costs (Huang et al., 2011; Watson, 2000). Unnecessary parental-dependency by the transitioning patient, developmental difficulties and psychosocial delay are also concerns (Coleman & Newton, 2005; Huang et al., 2011; McPheeters et al., 2014).

Poor transitions to adult care also affect health care systems. An increasing number of acute care encounters, re-hospitalizations and deaths have been reported shortly after transfer to adult care in SCD patients 18 years and older (Brousseu, Owens, Mosso, Panepinto, & Steiner, 2010; Hemker, Brousseau, Yan, Hoffman, & Panepinto, 2011; Quinn et al., 2010). Poor preparation can manifest as missed follow-up appointments with the new adult provider or a return to the pediatric provider or the emergency room for health care (Bryant & Walsh, 2009). Lack of AYAs' healthcare responsibility has been found to be a barrier to transfer (Freyer & Kibrick-Lazear, 2006). Anxieties about leaving pediatric care, difficulty finding an adult doctor, handling financial issues and parental overprotection have also been identified as barriers to transition (de Montalembert & Guitton, 2014; Mennito, Hletko, Ebeling, Amann, & Roberts, 2014).

Successful transition to adult care in SCD is linked to better outcomes and improvements in self-care regimens (Lenoci, Telfair, Cecil, & Edwards, 2002), resulting in substantial reductions in morbidity and mortality (Hauser & Dorn, 1999; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004; Wojciechowski et al., 2002) and overall managed care costs (Coleman & Newton, 2005). Assessment of transition readiness can guide individualized interventions that promote appropriate patient education and skill development (Cooley, 2004; Ellingford, 2006). Ensuring that AYAs are ready to transition from pediatric to adult care must be a coordinated, gradual process (Soanes & Timmons, 2004; Tuchman, Slap, & Britto, 2008). Transition should start and proceed at different times based on the readiness of each AYA patient and his/her family (Bell et al., 2008; Tuchman et al., 2008).

Findings from different studies support that self-care management (SCM) is essential to transition readiness and is a key component of effective chronic illness care (Cerns, McCraken, & Claire, 2013) and critical to improved quality of life and health status (DeBaun & Telfair, 2012; Jenerette & Murdaugh, 2008; Ryan & Sawin, 2009; van Staa et al., 2011). SCM support includes processes that develop patient problem-solving skills and improve self-efficacy, and support application of knowledge in real-life situations important to AYA patients. Aspects of SCM such as independence, educational and vocational choices, insurance and fiscal independence must be addressed in transitioning AYAs to adult care (Betz, Redclay, & Tan, 2003; Edwards, Telfair, Cecil, & Lenoci, 2001; Sawicki, Katryne, Xiaoping, Demars, & Huang, 2009).

Transition readiness has been associated with factors such as age, AYA responsibility for healthcare, parent involvement and disease severity (Rutishauser, Akre, & Suris, 2011; While et al., 2004). Parent involvement is often reported to be less for older AYA (Federicks et al., 2010) and those who have more responsibility for healthcare behaviors (Gilleland, Amaral, Mee, & Blount, 2012). Transition readiness was found to be positively associated with age, with older adolescents demonstrating higher transition readiness (van Staa et al., 2011). Although age is associated with transition readiness, it is not necessarily an indicator of the AYAs' ability to self-manage (Gilleland et al., 2012).

There are conflicting reports on the role of disease severity in transition readiness. Research found no evidence of a relationship between amount of participation in transition and measures of disease severity or quality of life (Craig, Phty, Towns, & Bibby, 2007; Fernandes et al., 2014; Rutishauser et al., 2011). In contrast, van Staa et al. (2011) found that a higher general health score and a higher quality of life score were associated with higher transition readiness among AYAs with chronic illness. Andemariam et al. (2014) documented that demographic factors, such as gender, race and type of insurance, did not influence transition outcome; however, AYAs with milder disease severity (SC and Sβ + genotypes) were at higher risk for an unsuccessful transition than patients with severe disease.

There is a lack of research regarding evaluation of intervention programs to help AYA with SCD transition from pediatric to adult care and the characteristics of successful transitions and medical practices that promote successful transitions have yet to be fully identified (Huang et al., 2011). The current criteria or reason for AYA transition in many institutions is based on chronologic age or pregnancy, not maturity or patient and family readiness (Bryant & Walsh, 2009; Por et al., 2004; Sobota, Neufeld, Sprinz, & Heeney, 2011). A survey of sickle cell centers showed that most now have formal transition programs, however, 70% reported that they performed transition readiness assessments just before transfer (Sobota et al., 2011). In a systematic review of AYA transition in sickle cell disease, Jordan, Swerdlow, and Coates (2013) reported no optimal model of transition management. To promote an effective transition, pediatric providers need to assess patient and family readiness and offer education tailored to meet individual patient and family needs (Lebensburger, Bemrich-Stola, & Howard, 2012). This descriptive, correlational study was conducted to better define individualized