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Experiences with and Outcomes of Two Interventions to Maximize Engagement of Chronically Ill Adolescents During Hospital Consultations: A Mixed Methods Study

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Improving patient-provider communication during hospital consultations is advocated to enhance self-management planning and transition readiness of adolescents with chronic conditions. This longitudinal mixed methods study evaluates the implementation and the outcomes of independent split-visit consultations and individual transition plans by 22 hospital teams participating in the Dutch Action Program 'On Your Own Feet Ahead!'. The interventions raised awareness in adolescents and professionals, improved adolescents' display of independent behaviors and led to more discussions about non-medical issues. Successful implementation required a team-based approach and clear explanation to parents and adolescents. Pediatric nurses played a pivotal role in improving transitional care.
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EMERGING ADULTHOOD, THE developmental stage between late adolescence and adulthood, covers the period in which young people start to take primary responsibility for tasks associated with adult life (Arnett, 2000). For adolescents with chronic conditions, this is a challenging time in which they must assume increasingly independent responsibility for the management of the condition, in parallel with the transfer from pediatric to adult care settings (Garvey et al., 2013). Both processes require changes in the relationship between the patient and the healthcare provider. Pediatric and adult medical care systems place different demands and expectations on their patients, and adolescents must learn to become effective partners in their own healthcare communication (Viner, 2008). Effective communication is a critical component of independent self-care skills in emerging adults (AAP et al., 2011) as it may help build positive, trusting relations between professionals and their patients. Good communication is also correlated with better clinical outcomes such as treatment adherence (Dimatteo, 2004; Zolnierek & Dimatteo, 2009).

Staff attitude, communication, and youth involvement are also essential elements for young people's perception of adolescent-friendly healthcare (Ambresin, Bennett, Patton, Sanci, & Sawyer, 2013). In their judgment of quality, aspects of trust and respect are rated as most important and adolescents prefer communication directly to them rather than to their parents (Britto et al., 2004). Despite good interactional competence or perceived self-efficacy, adolescents often remain inactive during consultations where parents are present (Pyörälä, 2004; van Staa, Jedeloo, van der Stege and On Your Own Feet Research Group, 2011; van Staa, Jedeloo, van

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Meeteren and Latour, 2011; van Staa and On Your Own Feet Research Group, 2011; Wassmer et al., 2004). Still, as they gradually grow out of the pediatric environment, they welcome being treated more age-appropriately and as equal partners in care (Dovey-Pearce, Hurrell, May, Walker & Doherty, 2005; van Staa, Jedeloo, van der Stege et al., 2011; van Staa, Jedeloo, van Meeteren et al., 2011; van Staa and On Your Own Feet Research Group, 2011). Healthcare professionals and parents have an important role here, but both seem to have mixed feelings about active adolescent involvement (Coyne, 2008). This is particularly marked when it comes to confidentiality and the right to decide who is present during consultations.

Current guidance about developmentally appropriate care emphasizes the benefits of offering confidential consultations to adolescents without parents present, in which psychosocial assessments can be undertaken (Berlan & Bravender, 2009; Committee on Adolescence AAP, 2008; Ford, English & Sigman, 2004). First, young people have the right to have their developing autonomy recognized. In many countries, this is embedded in health laws. In the Netherlands, the Dutch Medical Treatment Act (WGBO; 1995) states that young people aged 16 or over have the right to make their own treatment decisions autonomously, and those between 12 and 15 years are entitled to take decisions with their parents. Second, adolescents place high value on confidentiality and seeing healthcare providers alone (English & Ford, 2007; Rutishauser, Esslinger, Bond & Sennhauser, 2003). When explicit assurances of confidentiality are provided to adolescents, they are more likely to seek healthcare, disclose sensitive matters, and return for future visits (Ford, Millstein, Halpern-Felsher & Irwin, 1997), whereas concerns over confidentiality decreases willingness to seek care for sensitive issues and may inhibit communication (Carlisle, Shickle, Cork & McDonagh, 2006).

Although confidential care with associated psychosocial assessment is important for all adolescents, it is particularly relevant for those with chronic conditions, who generally have poorer psychosocial outcomes and lower social participation rates than healthy peers (Sawyer, Drew, Yeo & Britto, 2007). Still, there is a gap between chronically ill adolescents' expectations and the opportunities given to them to be seen alone in consultations (Rutishauser et al., 2003; Shaw, Southwood & McDonagh, 2007b). Only a minority of adolescents reported to have had confidential consultations with their healthcare providers (Duncan, Jekel, O'Connell, Sanci & Sawyer, 2014; Surís, Akre & Rutishauser, 2009; van Staa, Jedeloo, van der Stege et al., 2011; van Staa, Jedeloo, van Meeteren et al., 2011; van Staa and On Your Own Feet Research Group, 2011); this is in part explained by parents having mixed feelings about confidentiality (Duncan et al., 2014; Gilbert, Rickert & Aalsma, 2014; Sasse, Aroni, Sawyer & Duncan, 2013) and in part by healthcare providers not being aware of legal minor consent guidelines or being concerned about parental reaction to such confidential discussions (Berlan & Bravender, 2009).

Information provision, transition planning and development of self-management skills are important in preparing for transition to adult care. The need for a service model that supports young people to develop self-management skills and become an autonomous individual is widely recognized (Modi et al., 2012). It should address not only medical management, but also psychosocial functioning and social participation, which are considered integral components of comprehensive adolescent care (Martinez, Carter & Legato, 2011; Sawyer et al., 2007). The use of comprehensive individual transition plans that regularly monitor the development of autonomy in various life domains has been advocated (Ferris et al., 2015; Reiss & Gibson, 2002). Most patients in transition do not have such plans (Sawicki, Kelemen & Weitzman, 2014), however, and their practical application has been rarely evaluated (Gravelle, Paone, Davidson & Chilvers, 2015; Robertson, McDonagh, Southwood & Shaw, 2006). In contrast to transition readiness assessments (Moynihan, Saewyc, Whitehouse, Paone & McPherson, 2015; Sawicki et al., 2011; Wood et al., 2014), which serve primarily as a measurement for healthcare providers, such individual transition plans provide guidelines for action for patients, parents and professionals. To date, few approaches for preparing adolescents for transitioning to self-management and transfer to adult care have been empirically tested (Annunziato et al., 2014). Patient-provider communication content and quality, a critical element of transition readiness, has particularly been under-studied (Monaghan, Hilliard, Sweenie & Riekert, 2013). Intervention opportunities include developmentally-appropriate styles of clinic visits (including independent consultations) and promoting skills for self-management (Gravelle et al., 2015; Monaghan et al., 2013). The implementation and effects of two such interventions (independent consultations and individual transition plans) in a nation-wide quality improvement program in the Netherlands is the focus of this study.

The aim of this study is twofold: (1) to examine the implementation of, and the experiences with, two transitional care interventions by Dutch hospital-based teams participating in the 'On Your Own Feet Ahead!' Quality Improvement program (2009–2012); and (2) to evaluate the short-term and long-term outcomes of the adolescents and young adults involved.

Methods

Setting: The 'On Your Own Feet Ahead!' Quality Improvement Program

In the Netherlands, transitional care is usually provided on an ad hoc basis - essential elements such as transition protocols, coordinators, and individual transition plans, are largely lacking (van Staa, Eysink Smeets-van de Burgt, van der Stege & Hilberink, 2010). Professionals, parents and adolescents themselves all agreed that improvement was highly necessary (van Staa, Jedeloo, van Meeteren, &

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