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Parent Experiences Raising Young People with Type 1 Diabetes and Celiac Disease



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Authors of this qualitative descriptive study interviewed 30 parents concerning their experiences raising a child or adolescent with type 1 diabetes (T1D) and celiac disease (CD). Analysis revealed six themes: (a) health complications of T1D, (b) challenges of daily disease management, (c) financial concerns, (d) the young person's emotional/mental health, (e) experiences with healthcare providers, and (f) experiences with people outside the family and at school. Results suggest nurses need to be sensitive to challenges young people living with T1D and CD and their parents face, conduct ongoing assessments, and provide time during interactions to adequately address concerns.

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MORE THAN 25% of individuals in the United States have two or more concurrent chronic conditions, but the prevalence of multiple chronic conditions is greater among older adults than in children (U.S. Department of Health & Human Services, 2010). For both older and younger individuals, however, managing more than one chronic condition can result in negative health consequences, increased financial burden, and challenges to care management (Vogeli et al., 2007). Indeed, the daily management of more than one chronic illnesses is complex and involves multiple components, including closely following treatment recommendations, monitoring health decisions, and managing how the illness impacts psychological, social, and physical functioning (Bayliss, Steiner, Fernald, Crane, & Main, 2003).

Consequently, for parents caring for a young person with more than one chronic illness, life can be emotionally, psychosocially, and financially challenging. Additionally, caring for a young person with two chronic illnesses may be especially burdensome because each disease has specific management requirements that may affect health outcomes of the other disease. Unfortunately, there is little information in the literature related to caring for a young person with two chronic diseases. Therefore, this study sought to address a gap in the research literature by describing parent experiences raising a child/adolescent with two chronic diseases: type 1 diabetes (T1D) and celiac disease (CD).

The association between T1D and CD has been recognized for more than 40 years due to shared common gene alleles (Visakorpi, 1969; Walker-Smith & Grigor, 1969). However, past research related to T1D and CD has focused primarily on the prevalence, association, and risk of individuals having both conditions (Bhadada et al., 2011; D'Annunzio et al., 2009;

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Mojibian et al., 2009; Samasca, Iancu, Butnariu, Andreica, & Dejica, 2011; Simell et al., 2010; Uibo et al., 2011; Warncke et al., 2010), with little attention being directed towards parents' perceptions of their experiences. Because the experiences and challenges of raising young person with both conditions are poorly understood, it is important to study these parent's perceptions.

Literature Review

Type 1 Diabetes

T1D is a chronic lifelong disease in which individuals have high levels of blood glucose due to lack of insulin production (PubMed Health, 2013). About .25% of youth have T1D, and every year more than 13,000 young people are newly diagnosed (Centers for Disease Control and Prevention [CDC] [CDC], 2011). The primary treatments include daily insulin administration, regimented eating schedules, and strict carbohydrate intake monitoring (American Diabetes Association, 2014; CDC; Chase & Eisenbarth, 2011).

Recent studies have documented parent experiences raising youth with T1D (Freeborn, Loucks, Dyches, Roper, & Mandlco, 2013; Hilliard, Monaghan, Cogen, & Streisand, 2011; Lindström, Åman, & Norberg, 2010; Monaghan, Hilliard, Cogen, & Streisand, 2009; Popp, Robinson, Britner, & Blank, 2014; Sullivan-Bolyai et al., 2014). For example, parents raising youth with T1D experience grief and loneliness, need emotional support, are fearful of allowing the young person to go anywhere alone, feel overwhelmed with daily responsibilities, and are concerned about long-term complications (Bowes, Lowes, Warner, & Gregory, 2009; Freeborn et al., 2013; Marshall, Carter, Toss, & Brotherton, 2009; Popp et al., 2014). Parents also deal with complex management requirements, feel stressed and frustrated by responsibilities, and worry about interpreting and managing blood glucose levels correctly (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). In addition, parents of youth with T1D are faced with constant threats of hypo- or hyperglycemia, may be more overprotective than parents of healthy youth (Graue, Wentzel-Larsen, Hanestad, & Sovik, 2005; Mullins et al., 2004), and are not prepared to deal with an unexpected diagnosis causing sudden life changes (Lowes, Gregory, & Lyne, 2005). Finally, parents know it is important for young people with T1D to independently manage their disease; however, it is difficult to relinquish management responsibilities to the young person (Ivey, Wright, & Dashiff, 2009; Sparud-Lundin, Ohrn, & Danielson, 2010; Sullivan-Bolyai et al., 2014; Tuchman, Slap, & Britto, 2008; Wennick, Lundqvist, & Hallstrom, 2009).

Celiac Disease

CD is an autoimmune condition often associated with T1D (Bhadada et al., 2011). It is a disorder of gastrointestinal

malabsorption affecting approximately 1% of the population (Gainer, 2011). For people with CD, consuming gluten-containing foods triggers an immune-mediated response stimulating antibody production that attack intestinal villi, causing inflammation and damage to the small intestine, and leading to malabsorption and malnutrition (Gainer, 2011; Ruiz, 2011; Westerberg et al., 2006). The only treatment for CD is strict adherence to a gluten-free diet which can interfere with work and social life. Such adherence can be expensive and difficult to maintain (Gainer, 2011; Garcia-Manzanares & Lucendo, 2011). Eating away from home is also concerning because of cross-contamination when foods are prepared in kitchens not gluten-free (Gainer, 2011).

There is a gap in the literature specifically examining parental experiences raising a youth with CD. One quantitative study discovered quality of life was lower in the social dimension for parents raising children with CD compared to parents raising children without CD (de Lorenzo, Xikota, Wayhs, Nassar, & de Souza Pires, 2012). We could find no qualitative studies examining only parents' experiences raising a youth with CD, but found a study by Sverker, Ostlund, Hallert, and Hensing (2007) who interviewed close relatives (e.g., parents, spouses, and cohabitants) of persons with CD. All relatives experienced anxiety and guilt, noted issues related to deviating from the gluten-free diet and managing daily life, and witnessed the person with CD in stressful social situations; however, parent experiences were not analyzed separately from other close relatives. Indeed, it is important to discover parent experiences separately from close relatives as their perceptions of raising a child/adolescent with CD may be different than a close relative who does not live with the young person 24 hours a day, 7 days a week.

Two studies examined perceptions and challenges of teenagers with CD (Olsson, Hörnell, Ivarsson, & Sydnér, 2008; Olsson, Lyon, Hornell, Ivarsson, & Snyder, 2009). Teenagers described various dilemmas related to limited accessibility of gluten-free food (Olsson et al., 2008) and experienced the stigma of needing special meals, leading to feelings of inequality, embarrassment, anger, alienation, guilt, and discrimination (Olsson et al., 2009).

The Dual Diagnosis of T1D and CD

As noted earlier, the association between T1D and CD has been recognized for more than 40 years (Visakorpi, 1969; Walker-Smith & Grigor, 1969), although the presence of CD often occurs without clinical symptoms (Mahmud et al., 2005; Samasca et al., 2011; Smyth et al., 2008). Interestingly, T1D and CD are often diagnosed about the same median age (4.5 years for T1D and 4.3 years for CD) in children with conferred genetic risk for both diseases (Simell et al., 2010). A diagnosis of CD and the presence of antibodies suggestive of CD occur more frequently in patients with T1D than in the general population, with the incidence ranging from 9.2% (Samasca et al., 2011), to 11.1% (Bhadada et al., 2011).

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