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Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbor support

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ABSTRACT

Parental mental health-related quality of life affects the ability of a family to cope with and adapt to the presence of a disability in a family member, such as their child. Therefore, understanding variables that influence parental mental health-related quality of life in families of children with autism spectrum disorder is important. The purpose of this study was to examine the pathways to parental mental health-related quality of life, focusing on the variables of parental stress, children's performance, medical support, and neighbor support. These variables were hypothesized to be interrelated with one another and directly or indirectly associated with parental mental health-related quality of life. Samples of this study were 429 parents of children with autism spectrum disorder aged 6–17 years in the United States. These parents were selected from the respondents interviewed over the telephone by the 2007 National Survey of Children's Health. The item indicators selected from the survey were used to construct latent variables for the investigated variables. Structural equation modeling was used to analyze the data. Results showed that parental stress, children's performance, medical support, and neighbor support played important roles in the pathways. Implications and limitations are discussed.

1. Introduction

Parental mental health-related quality of life (HRQOL) is important because it has influences on the ability of a family to cope with and adapt to the presence of chronic illness or a disability in a family member, especially a child (Chen & Clark, 2010; Kuhlthaua et al., 2014; Lee, Hwang, Chen, & Chien, 2009). Raising a child with autism spectrum disorder (ASD) can be a demanding and challenging task, involving challenges to obtain diagnosis, seek appropriate intervention and educational services, and pay for treatment (Ekas, Lickenbrock, & Whitman, 2010; Tomanik, Harris, & Hawkins, 2004). Parents of children with ASD consistently report elevated levels of parenting stress (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Meadan, Halle, & Ebata, 2010; Rao & Beidel, 2009). However, when parents of children with ASD have strong mental HRQOL, they are better prepared to cope with the diagnosis of ASD and are more supportive of their child (Feetham, 2011; Chuang, Tseng, Lu, Shieh, & Cermak, 2014). Therefore, understanding

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what factors influence parental mental HRQOL and how they interrelate for families of children with ASD is important, as this provides implications for programs and services to support these children and their families (Kuhlthaua et al., 2014). The purposes of this study were to examine the pathways to parental mental HRQOL, focusing on the factors of parental stress, children performance, medical support, and neighbor support. The theoretical frameworks for this study were based on Transactional Model of Stress and Coping (Lazarus, 1999; Lazarus & Folkman, 1984) and Human Ecology Theory (Bronfenbrenner, 1979). The former indicates that individuals' perceptions of their own stress will have an impact on their HRQOL. The latter indicates that human development is affected by various environmental systems. The environmental systems in this study include family, school, health care provider, and neighbor. These environmental systems will have direct and indirect effects on children and parents. Specific factors and pathways in the conceptual model for this study are based on the aforementioned theories and a review of the literature as described in the following passage.

Quality of life (QOL) reflects an individual's personal interpretation of the environment and its impact on his or her well-being (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). It is a subjective and multidimensional concept (Claes, Hove, Loon, Vandevelde, & Schalock, 2010). Katschnig (2006) indicated that "neither a commonly accepted definition nor a gold standard for measuring QOL exists" (p. 139). Frank-Stromborg (1988) indicated that QOL includes life satisfaction, happiness, mental well-being, adjustment, functional status, and health status. However, an individual's perception of QOL impacts his or her interaction with both the internal and external factors within the family system and, overtime, influences the functions of the family unit (Schalock, 1994). HRQOL is a subset relating only to the health domain of QOL (Torrance, 1987). Definitions of HRQOL also vary. Wilson and Cleary (1995) indicated that most conceptualizations of HRQOL include the dimensions of physical functioning, social functioning, role functioning, mental health, and general health perceptions. They developed a HRQOL model for measurement of patient outcome. These measures include biological and physiological variables, symptom status, functional status, general health perceptions, and overall quality of life. These variables are not independent but interact with one another. In addition, characteristics of the individual (e.g., personality, motivation, preferences, values) and characteristics of the environment (e.g., psychological supports, social and economic supports) all affect these measures. Ware and Sherbourne (1992) developed the Medical Outcomes Study (MOS) measures based on two overarching dimensions of health (mental and physical) to measure HRQOL. Variables of physical HRQOL are categorized into subscales of physical functioning, pain, role limitations due to physical health, and general health; while variables of mental HRQOL are categorized into subscales of role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, psychological well-being, and cognitive functioning (Lee, Lopata et al., 2009). HRQOL is usually used to measure patients' perception about their HRQOL. However, parents rather than children with ASD are investigated in this study, their biological or physical health may result from mental health and stress due to their tense interaction. This study especially focuses on parental mental HRQOL and conceptualizes it as including only parental relationships and mental and emotional health.

One way to examine the factors affecting parental mental HRQOL is to investigate parental stress (Benson, 2006; Hastings et al., 2005; McStay, Trembath, & Dissanayake, 2014). Lee, Lopata et al. (2009) evaluated the impact of psychosocial variables on the HRQOL of 89 parents of children with high-functioning ASD. Psychosocial variables examined included stress, resources, and coping. They found that only stress was a significant predictor of mental HRQOL, after controlling for five demographic variables (e.g., age, education, income, number of children in family, and severity of child with disability). Johnson, Frenn, Feetham, and Simpson (2011) examined the relationships among parenting stress, family functioning, and HRQOL of parents of a child with ASD and found that dealing with personal and family life was the most stressful for parents of a child with ASD. They found that the stress had a negative impact on mental health outcomes. Many studies also have documented the negative impact of stress on psychological outcomes among parents of children with ASD, such as depression, anxiety, and adjustment among parents of children with ASD (e.g., Ozturk, Riccadonna, & Venuti, 2014; Reed & Osborne, 2012; Sanders & Morgan, 1997; Wolf, Noh, Fisman, & Speechley, 1989).

Another way to examine the factors associated with parental mental HRQOL is to investigate the impact of the child's symptom severity and behavior problems (Lee, Lopata et al., 2009; Reed & Osborne, 2012; Tung et al., 2014). Benson (2006) studied the impact of child symptom severity on the depression of parents of children with ASD. The findings indicated that both child symptom severity and parental stress predicted depression and that the effect of child symptom severity on parental depression was partially mediated by stress. Osborne and Reed (2009) examined the relationship between parenting stress and behavior problems of children with ASD, and found that the severity of the autism was the best predictor of parenting stress when the child was younger, while child behavior problems were the best predictors of parenting stress when the child became older. Herring et al. (2006) studied the relationships between behavior and emotional problems in toddlers with ASD and parental outcomes. The study indicated that behavior and emotional problems had a significant impact on parental mental health, maternal stress, and family functioning. Tung et al. (2014) indicated that the child's severity of autism and behavior problems had low to moderate associations with caregiver's HRQOL. These studies show that the severity of the ASD and behavior problems predict parental stress, mental health, and family functioning, while parental stress mediates the effect of the severity of the autism and behavior problems on parental mental health and family functioning. That is, child symptom severity and behavior problems also indirectly affect parental mental health and family function through parental stress. Since child behavior problems rather than the severity of the autism are more related to parent stress as the child becomes older (Dumas, Wolf, Fisman, & Culligan, 1991; Lecavalier, Leone, & Wiltz, 2006; Reed & Osborne, 2012), we might contend that the performance of a child with ASD in middle childhood and adolescence also would affect parental stress and mental health and family functioning in the same way. Child performance