

Understanding the Mental Health Needs of Children and Youth with Chronic Conditions

Introduction

Mental health is a critical aspect of children's health and well-being. Children and youth with chronic conditions are at an **increased risk** compared to their peers without such conditions for developing mental health problems, with nearly one in three experiencing co-morbidity (Schwartz et al., 2006). Yet, physical concerns often take precedence over the mental health needs of these children and youth (Petrenchik, King, & Batorowicz, 2011). Few studies have examined the specific types of mental health problems children and adolescents with chronic conditions may have (Hunt, 2009) or the broad range of factors that may contribute to the development of these problems (Brossard-Racine et al., 2012, 2013).

A view of health that recognizes the mental and physical needs of children and youth with chronic conditions is needed in both research and practice. This is particularly important given that the mental health needs of these children and adolescents **often go untreated** (Brossard-Racine et al., 2013; Hunt, 2009).

The **purpose** of this *Facts to Go* is to summarize recent research that has examined the presence of specific types of mental health problems among children and youth with chronic conditions and the factors related to those problems. Implications for service providers, policy makers, and future research will be discussed.

Domains of Mental Health

Recent studies have used the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) to assess specific types of mental health problems among children and adolescents with chronic conditions. This measure is comprised of 25 items, divided into 5 different domains: conduct problems, emotional symptoms, hyperactivity-inattention, peer relationship problems, and pro-social behavior.

Brossard-Racine and colleagues (2012, 2013) used the parent-report SDQ to find that **peer relationship problems is the most common difficulty** faced by children and youth with cerebral palsy.

Specifically, 38% of 76 children, aged 6-12, and 48% of 160 adolescents, aged 12-19 had scores in the clinical range for this domain. **Emotional symptoms** was the second highest problem for adolescents at 22%. This was somewhat less of a problem for school-aged children at 17%. In the younger age group, 24% had clinical levels of hyperactivity/inattention, 22% had pro-social behavior difficulties, and 16% exhibited conduct problems. Rates of these problems were substantially lower in the adolescent group, at 13%, 11%, and 6%, respectively. Still, high rates of mental health difficulties can be seen across both age groups.

Etherington and colleagues (2014) found similar results when four domains of the parent-report SDQ were used with 363 youth aged 11-17 with various chronic conditions (e.g., cerebral palsy, brain injury, autism spectrum disorders, communication disorders, spina bifida). Forty-two percent were in the clinical range for peer problems, 27% for emotional symptoms, 18% for hyperactivity-inattention, and 12% for conduct problems.

These recent findings reflect past studies (Lavigne & Faier-Routman, 1992) that suggest, on average, **social functioning** (i.e., social difficulties/daily adjustment) and **internalizing problems** may be greater issues than externalizing problems for children and youth with chronic conditions.

Factors Related to Children's Mental Health

The reasons for the increased vulnerability of children and youth with chronic conditions to mental health problems are complex. The development of such disorders entails a **complex interplay of risk factors**, which may be intrapersonal (e.g., intellectual ability), familial (e.g., parental mental health), interpersonal (e.g., social support), or environmental (e.g., poverty). The number of risk factors a child is simultaneously exposed to can also increase their vulnerability to mental health problems (Furstenberg et al., 1999). Children with chronic conditions are also **more likely to experience such life adversities** as marginalization, victimization, and negative social environments (Davis & Watson, 2001; Petrenchik, et al., 2011).

Brossard-Racine and colleagues (2012, 2013) recently examined the role of **biomedical and environmental factors** as well as **factors related to activity and participation** in mental health difficulties among children and adolescents with cerebral palsy. Higher IQ scores and gross motor functioning were positively correlated with pro-social behavior.

Hyperactivity/inattention was associated with poor socialization skills and parental stress. Conduct problems were also significantly related to elevated levels of **parental stress**.

Familial Factors

Familial factors most certainly **play a primary role** in the mental health of children with chronic conditions. Mothers of these children report experiencing many stressors, such as social isolation, disruptions to family and work life, and financial difficulties related to caring for their child (McKeever & Miller, 2004). Indeed, perceived stress has been found to be strongly related to mental health problems for both mothers and fathers of children and youth with chronic conditions (Hung, Wu, Chiang, Wu, & Yeh, 2010). In turn, mental health problems in parents may affect the mental health of their children. Etherington and colleagues (2014) recently found that the presence of a self-reported maternal mental health condition was associated with clinical signs of hyperactivity/inattention in youth with chronic conditions over a period of one year. Additionally, low maternal education was associated with the development of peer problems for girls with chronic conditions over one year.

Conclusion and Implications

Children and youth with chronic conditions experience greater rates of mental, emotional, and behavioral difficulties than their peers (Schwartz et al., 2006). There are many child-based, familial, interpersonal, and environmental factors that may contribute to this increased likelihood (Petrenchik et al., 2011). These individuals also **underutilize mental health services** (Brossard-Racine et al., 2013; Hunt, 2009). The mental health of children and youth with chronic conditions may therefore be a key area to be addressed by researchers, service providers, and policy makers. Recent research has identified **aspects of children's and their families' lives that could be targeted for service**. For example, programs might work to enhance youths' gross motor functioning and socialization skills (Brossard-Racine et al., 2012, 2013) as well as coping skills, self-esteem, and participation in activities (Petrenchik et al., 2011). **Support services for families** are also important, as parents of children with chronic conditions often face many challenges that can impact their mental health (Bourke-Taylor, Howie, & Law, 2009).

Future longitudinal research on the multiple factors related to mental health can further inform services and policies aimed at promoting resilience in these children and youth. Studies are needed that examine the roles that these factors play throughout childhood in the

development of mental health problems for children and youth with chronic conditions (McDougall, 2011). In addition, **the potential reciprocal nature of relationships**, such as those between parental mental health and children's mental health should be studied.

Finally, strategies to increase access to and use of mental health services for children with chronic conditions and their families are needed. Another future direction for research might be to **determine barriers to treatment** for these individuals and what might encourage them to utilize available services (Hunt, 2009). Partnerships between researchers, service providers, and policy makers can **facilitate the development of pediatric services** that take into account both the physical and mental health needs of children and youth with chronic conditions.

References

- Bourke-Taylor, H., Howie, L., & Law, M. (2009). Impact of caring for a school-aged child with a disability: Understanding mothers' perspectives. *Australian Occupational Therapy Journal, 57*, 127-136.
- Brossard-Racine, M., Hall, N., Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2012). Behavioural problems in school-aged children with cerebral palsy. *European Journal of Paediatric Neurology, 16*, 35-41.
- Brossard-Racine, M., Waknin, J., Shikako-Thomas, K., Shevell, M., Pulin, C., Lach, L., Law, M., Schmitz, N., the QUALA Group, & Majnemer, A. (2013). Behavioural difficulties in adolescents with cerebral palsy. *Journal of Child Neurology, 28*, 27-33.
- Davis, J. M., & Watson, N. (2001). Where are the children's experiences? Analysing social and cultural exclusion in 'special' and 'mainstream' schools. *Disability & Society, 16*, 671-687.
- Emerson, E., & Hatton, C. (2005). *The socio-economic circumstances of families supporting a child at risk of disability in Britain in 2002*. University Lancaster, Institute for Health Research.
- Etherington, N., McDougall, J., Dewit, D., & Wright, V. (2014). Maternal Factors and the Emotional and Behavioral Outcomes of Adolescents with Chronic Conditions. Unpublished manuscript.
- Furstenberg, F.F., Cook, T.D., Eccles, J., Elder, G.H., Jr., & Sameroff, A. (1999). *Managing to make it: Urban families and adolescent success*. Chicago: University of Chicago Press.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38*, 581-586.
- Hung, J., Wu, Y., Chaing, Y., Wu, W., & Yeh, C. (2010). Mental health of parents having children with physical disabilities. *Chang Gung Medical Journal, 33*, 82-90.
- Hunt, S. M. (2009). Patterns of psychosocial functioning and mental health service utilization in children and adolescents with chronic health conditions or physical disabilities. *All Graduate Theses and Dissertations*. Paper 360.
- Lavigne, J., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: a meta-analytic review. *Journal of Pediatric Psychology, 17*, 133-57.
- McDougall, J. (2011). *Social support and health in youth: Examining relationships*. Germany: Lambert Academic Publishing.
- McKeever, P., & Miller, K. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine, 59*, 1177-1191.
- Petrenchik, T.M., King, G.A., & Batorowicz, B. (2011). Children and youth with disabilities: Enhancing mental health through positive experiences of doing and belonging. In S. Bazyk (Ed.), *Mental health promotion, prevention, and intervention in children and youth: A guiding framework for occupational therapy* (pp. 189-205). Bethesda, MD: The American Occupational Therapy Association.
- Schwartz, C., Gardland, O., Waddell, C., & Harrison, E. (2006). *Mental health and developmental disabilities in children*. Vancouver: Simon Fraser University.

For more information about the study, contact:

Thames Valley  Children's Centre

Nicole Etherington, PhD(C)
Project Coordinator
Research Program
nicole.etherington@tvcc.on.ca

Janette McDougall, PhD
Researcher
Research Program
janette.mcdougall@tvcc.on.ca