

Working with Adolescents who have a Chronic Disease: Information for Educators and Counsellors

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Adolescence is an important developmental period during which individuals typically gain life experiences and make a number of major decisions that will influence their subsequent career development (Young et al., 2011). However, research evidence suggests that career development does not progress in a typical way for adolescents with a chronic disease (Isralsky, Goldberg, & Shwachman, 1979; Maslow, Haydon, McRee, Ford, & Halpern, 2011). Medical advances in diagnosis and treatment have increased the length of survival among those living with a chronic disease, meaning that these individuals now have a life expectancy that will allow them to pursue longer-term career paths. In light of this situation, it is useful for counsellors and educators to become informed about the characteristics and career development needs of adolescents with a chronic disease, and how to work with this population.

Characteristics and Needs

Adolescence tends to be a difficult and stressful time for most individuals in the general population (Santrock, 2009). Therefore, it is not surprising that adolescents with a chronic disease find this developmental period especially challenging. When caring for a child who has a chronic disease, parents may perceive their child to be more vulnerable. This may, in turn, influence the normal development trajectory of autonomy, as

adolescents attempt to enter the workforce or pursue higher education (Holmbeck et al., 2002; Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010; Mullins et al., 2007; Pinquart & Pfeiffer, 2015).

Due to the nature of some chronic diseases, some adolescents with a chronic disease may have limited employment opportunities available to them (Williams, Burker, & Kazukauskas, 2011; Brake, 2013). For example, jobs requiring physical labor could potentially be hazardous to an individual with cystic fibrosis who has a chest infection or whose lung function has decreased (Brake, 2013). In addition, the way an adolescent with a chronic disease will transition through the career development process may depend on their age and the type of chronic disease they have (Stern et al., 1991).

Many adolescents with a chronic disease may have to deal with added challenges and skills that most healthy adolescents do not have to face (Young et al., 2001; Calsbeek et al., 2006). For example, these youth may be confronted with hospitalization or the need to adhere to diet or medication (Calsbeek et al., 2006). These additional challenges could influence school performance, in regards to education level and absenteeism, and the ability to attend work (Calsbeek et al., 2006; Williams et al., 2011). Compared to healthy adolescents, adolescents with a chronic disease may also encounter higher rates of developmental (e.g. difficulties with learning, attention, and communication), emotional (e.g. anxiety and depression), and behavioral (e.g. acting out, fighting, bullying, or arguing) co-morbidities, which could also affect school performance (Blackman & Conaway, 2013; Gortmaker, Walker, Weitzman, & Sobol, 1990; Blackman, Gurka, Gurka, & Oliver, 2011).

At the end of adolescence, individuals with a chronic disease may face the additional burden of transitioning from pediatric to adult health care services. This tends to be a challenging transition for many adolescents with a chronic disease, due to the loss of familiar surroundings and relationships (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014). Keeping these characteristics and needs in mind, it is evident that this population could benefit from professional support and specialized counselling during this developmental period.

Recommendations

The literature reveals several important recommendations for educators and counsellors working with adolescents with a chronic disease. A top priority is to develop an understanding of the nature and severity of the chronic disease (Isralsky et al., 1979; Mungle, Burker, & Yankaskas, 2002; Jackson, 2013). Knowledge of disease may help adolescents with a chronic disease make realistic career choices that are consistent with the limitations of their disease (Isralsky et al., 1979; Mungle et al., 2002). It is important to recognize, evaluate, and treat emotional, developmental, and behavioral co-morbidities, as this could help reduce the severity of a chronic disease and could help adolescents gain control over their disease (Blackman et al., 2011; Blackman & Conaway, 2013).

Given the demands of some chronic diseases, it may also be beneficial to assist with the enhancement of coping strategies and disease mastery (Hogg, Braithwaite, Bailey, Kotsimbos, & Wilson, 2007; Huff, McClanahan, & Omar, 2008; Targett et al., 2013). Acquiring coping strategies and disease mastery could

positively impact workforce participation, while improving employment options and quality of life (Hogg et al., 2007; Targett et al., 2013). In addition, it is important to provide adolescents with a chronic disease with early vocational and employment guidance, as earlier preparation may help these adolescents balance their desire for employment with their health care needs (Isralsky et al., 1979; Demars, Uluer, & Sawicki, 2011).

Because adolescents with a chronic disease may have overprotective parents, it could be beneficial to encourage parents to allow their child to assume more responsibility and autonomy (Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006). This would allow the child to develop skills needed to cope with the challenges of transitioning into adulthood (Stam et al., 2006). As adolescents with a chronic disease make the transition into adulthood, a transition plan could be useful in alleviating stress associated with this change (Barnes, 2014). Adolescents with a chronic disease may also need to be prepared for the transition from pediatric to adult care services (Barnes, 2014; Fegran et al., 2014). By helping adolescents with a chronic disease understand this process, they may find it easier to adjust to the differences found in adult care facilities (Barnes, 2014).

Conclusion

The adverse experiences that characterize the lives of many adolescents with a chronic disease suggest that career development does not progress in a typical way for this population (Isralsky et al., 1979; Maslow et al., 2011). However, educators and counsellors who are informed about the characteristics and needs of these adolescents could work with this population to promote successful career development.

Through the implementation of appropriate interventions, adolescents with a chronic disease may begin to feel more prepared as they make the transition into adulthood.

References

- Barnes, B. (2014). The care and education of student with cystic fibrosis. *International Journal of Academic Research, 6*, 159-164.
- Blackman, J. A. & Conaway, M. R. (2013). Developmental, emotional and behavioral co-morbidities across the chronic health condition spectrum. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 6*, 63-71.
- Blackman, J. A., Gurka, M. J., Gurka, K. K., & Oliver, M. N. (2011). Emotional, developmental and behavioural co-morbidities of children with chronic health conditions. *Journal of Paediatrics and Child Health, 47*, 742-747.
- Brake, M. J., (2013). Education and career planning for people with cystic fibrosis. *IWK Health Centre*. Retrieved from <http://iwk.nshealth.ca>
- Calsbeek, H., Pijken, M., Bekkers, M. J. T. M., Dekker, J., van Berge Henegouwen, G. P. (2006). School and leisure activities in adolescents and young adults with chronic digestive disorders: Impact of burden of disease. *International Journal of Behavioral Medicine, 13*, 121-130.
- Demars, N., Uluer, A., & Sawicki, G. S. (2011). Employment

experiences among adolescents and young adults with cystic fibrosis. *Disability & Rehabilitation*, 33, 922-926.

Fegran, L., Hall, E. O. C., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: A qualitative metasynthesis. *International Journal of Nursing Studies*, 51, 123-135.

Gortmaker, S. L., Walker, D. K., Weitzman, M., & Sobol, A. M. Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. *Pediatrics*, 85, 267-276.

Hogg, M., Braithwaite, M., Bailey, M., Kotsimbos, T., & Wilson, J. W. (2007). Work disability in adults with cystic fibrosis and its relationship to quality of life. *Journal of Cystic Fibrosis*, 6, 223-227.

Holmbeck, G. N., Johnson, S. Z., Willis, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology*, 70, 96-110.

Huff, M. B., McClanahan, K. K., & Omar, H. A. (2008). The effects of chronic illness upon mental health status of children and adolescents. *International Journal on Disability and Human Development*, 7, 273-278.

Hullmann, S. E., Wolfe-Christensen, C., Meyer, W. H., McNall-

- Knapp, R. Y., & Mullins, L. L. (2010) The relationship between parental overprotection and health-related quality of life in pediatric cancer: The mediating role of perceived child vulnerability. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation, 19*, 1373-1380.
- Isralsky, M., Goldberg, R. T., & Shwachman, H. (1979). Vocational development and adjustment of adolescents with cystic fibrosis. *Archives of Physical Medicine And Rehabilitation, 60*, 369-374.
- Jackson, M. (2013). The special educational needs of adolescents living with chronic illness: A literature review. *International Journal of Inclusive Education, 17*, 543-554.
- Maslow, G. R., Haydon, A., McRee, A., Ford, C. A., & Halpern, C. T. (2011). Growing up with a chronic illness: Social success, educational/vocational distress. *Journal Of Adolescent Health, 49*, 206-212.
- Mullins, L. L., Wolfe-Christensen, C., Hoff Pai, A. L., Carpentier, M. Y., Gillaspay, S., Cheek, J., & Page, M. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. *Journal of Pediatric Psychology, 32*, 973-982.
- Mungle, J., Burker, E. J., Yankaskas, J. R. (2002). Vocational rehabilitation counseling for adolescents and adults with cystic fibrosis. *Journal of Applied Rehabilitation Counseling, 33*, 15-21.

- Pinquart, P. & Pfeiffer, J. P. (2015). Solving developmental tasks in adolescents with a chronic physical illness or physical/sensory disability: A meta-analysis. *International Journal of Disability, Development, and Education, 62*, 249-264.
- Santrock, J. W. (2009). *Adolescence* (13th ed.). New York, NY: McGraw-Hill.
- Stam, H., Hartman, E. E., Deurloo, J. A., Groothoff, J., Grootenhuis, M. A. (2006). Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *Journal of Adolescent Health, 39*, 4-13.
- Stern, M., Norman, S. L., & Zevon, M. A. (1991). *Journal of Counseling Psychology, 38*, 431-439.
- Targett, K., Bourke, S., Nash, E., Murphy, E., Ayres, J., & Devereux, G. (2014). Employment in adults with cystic fibrosis. *Occupational Medicine, 64*, 87-94.
- Williams, L. W., Burker, E. J., & Kazukauskas, K. (2011). Cystic fibrosis and achieving vocational success: The key role of the rehabilitation counselor. *Journal of Applied Rehabilitation Counseling, 42*, 12-18.
- Young, R. A., Marshall, S. K., Valach, L., Domene, J. F., Graham, M. D., & Zaidman-Zait, A. (2011). *Transition to adulthood: Action, projects, and counselling*. New York, NY: Springer.

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