

Background: Adolescents Coping with Chronic Illness

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Adolescents Coping with Chronic Illness

Chronic illness refers to a disorder characterized by periods of exacerbation that can impair physical or mental functioning, which is long lasting, and is persistent in nature¹. Children and adolescents who suffer from chronic illness differ from adults with chronic illness in an important way, in that they are simultaneously experiencing a period of rapid growth and development. Therefore, not only must they cope with their medical condition, they must learn to cope with it in the context of this growth and development. Learning to manage this effectively can prove challenging, often resulting in psychological consequences, for both the child and his or her family.

Developmental level relates to how a chronic illness impacts a child or adolescent², as well as how one copes with the illness. Adolescence in particular is a unique period of development characterized by a sense of independence. Intimate social relationships with peers provide the adolescent with a primary source of support. As socialization increases, self-image and appearance become extremely important. Decision making related to future plans, as well as a desire for privacy are also key characteristics of adolescent development. The presence of a chronic illness can threaten these typical developmental aspects and result in psychological maladjustments. However, this psychological impact of illness is often overshadowed by the more physical symptoms. While one report suggests that 20-30% of children

¹ Goodman, 2001

² Malhotra & Singh, 2002

with chronic illness have psychological maladjustments³, Boice⁴ reports that fewer than 20% receive the appropriate support and health services.

Chronic illnesses manifested in childhood and adolescence include but are not limited to asthma, diabetes, cancer, congenital heart problems, cerebral palsy, epilepsy, and sickle cell anemia. While a chronically ill child or adolescent is not necessarily always sick, the presence of the underlying condition can significantly impact emotional and behavioral functioning. For instance, Martini⁵ reports the rate of depression in asthmatic adolescents at 15%.

While this drastic period of development undoubtedly causes chronically ill adolescents to be more vulnerable to emotional and behavioral problems, it does not automatically imply a mental health issue. Boice⁶ describes five factors that seem to impact the psychological effect of chronic illness on an adolescent including the following: type and degree of physical impairment; visibility of the illness; uncertainty about course of illness; irregular and unpredictable effects of illness; and high cost of treatment or great pain. These factors are relevant to how an adolescent copes with his or her condition. For instance, an adolescent may experience a seemingly mild impairment as extremely traumatic, due to the degree of importance placed on appearance and self-image during this period of development. Also, cognitive

³ Malhotra & Singh, 2002

⁴ Boice, 1998

⁵ Martini, 2010

⁶ Boice, 1998

advances present in adolescence, which allow a greater understanding of the illness, can lead to stress and anxiety, especially when the course of the illness is uncertain.

Interestingly, studies show that disease variables are poor predictors of adjustment⁷.

Malhotra and Singh⁸ suggest factors that may be responsible for psychological consequences in adolescents with chronic illnesses. The first factor proposes that individual factors within a child determine if psychological symptoms will result. While the authors mention temperament as a factor, they propose that low distractibility contributes to the greatest degree to psychopathology, in that these children take longer to recover from a state of distress⁹. That is, they focus on the distress for an extended period after the stressful situation concludes. Distress within a parent or caregiver is also thought to contribute to the mental health state of the adolescent¹⁰.

One of the most significant psychological risks for chronically ill adolescents is depression, for the obvious reasons related to the importance of image and the peer group. However, it is often difficult to distinguish between depression as being comorbid with the chronic illness, which means that depression exists simultaneously yet independently of the chronic illness, or being a result of the illness. The Diagnostic and Statistical Manual of Mental Disorders, 4th edition, has a classification of mood

⁷ Malhotra & Singh, 2002

⁸ Malhotra & Singh, 2002

⁹ Malhotra & Singh, 2002

¹⁰ Malhotra & Singh, 2002

disorder due to a general medical condition. With this diagnosis, the mood disturbance is a direct physiological consequence of the medical condition¹¹, meaning that the depression is directly related to the general medical condition, rather than a separate entity, and would not be present without it. For instance, this depression may be a reaction to limits placed on their independence by parents, a lack of acceptance by peers, or poor self-esteem. It is important for treatment purposes to distinguish between these diagnoses.

Another relevant dimension of psychological risk is anxiety. The uncertainty that often accompanies a diagnosis of a chronic illness, especially related to medical interventions and outcomes, can lead to stress¹². As adolescents have the cognitive ability to think about and raise questions related to their condition, they may begin to embody a constant state of worry (i.e., stress) leading to anxious feelings. Once again, it is important to distinguish between anxiety as a separate, comorbid condition to the medical condition, or as a result of the medical condition.

In treating a child or adolescent with a chronic illness, one should focus on psychological consequences, as well as physical symptoms. Understanding how mental health issues impact adolescents with chronic illness is essential in helping them cope with their condition.

¹¹ American Psychiatric Association, 2000

¹² Martini, 2010

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