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Mental Health and Chronic Disease

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Chapter 8

MENTAL HEALTH AND CHRONIC DISEASE

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ABSTRACT

By 2015, worldwide, 1.2 billion children aged 5-14 years will have some kind of significant chronic disease. Although scientific evidence indicates that children with chronic illness have more mental health issues than their healthy peers, many controversies and gaps in the literature exist. It is imperative that an understanding of the effects of chronic illness upon the mental health status of children and adolescents be undertaken. This chapter uses a biopsychosocial perspective to investigate the connection between chronic illness and mental health. The intent of the chapter is to suggest ways that medical and mental health professionals can provide services to chronically ill children and adolescents that foster positive mental health through the achievement of all developmental tasks with as little psychological stress as possible.

INTRODUCTION

The major tasks of childhood involve achieving healthy development and functioning in the physical, cognitive, emotional, and psychosocial domains. Past research indicates that childhood chronic illness can severely impair psychosocial functioning and impede further development in all domains of functioning [1,2]. Considering the biological, psychological, and social (herein referred to as 'biopsychosocial') concerns and effects in the management of chronic illness and simultaneously fostering positive mental health includes continuous assessment and management of the biopsychosocial factors which all influence one another and are integral to the healthy emotional functioning of children and adolescents.

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This chapter uses a biopsychosocial perspective to investigate the connection between chronic illness and mental health. The intent of the chapter is to suggest ways that medical and mental health professionals can provide services to chronically ill children and adolescents that foster positive mental health through the achievement of all developmental tasks with as little psychological stress as possible. The medical management goal is to minimize the impact of the disease on the physical and emotional development and functioning of children and adolescents while the mental health goal is to achieve balance between disease management and positive mental health. These goals can only be met through the facilitation of interactions that occur in each of the four domains of adaptive functioning.

A focus on the developmental and biopsychosocial domains that all chronic childhood illnesses share will assist in drawing conclusions about mental health that apply regardless of the specific illness. It should be noted, however, that tremendous complexity exists among chronic illnesses including the type, severity, and progression of the illness, the resources of the family and community to support the child or adolescent, and the capacity of the health care provider team.

CHILDHOOD CHRONIC ILLNESS

The causes of chronic illness are discussed extensively in research involving the medical aspects of childhood chronic illness [3-5]. The causes typically include genetic or hereditary dispositions, birth traumas and other conditions present at birth, accidents and injuries, disease and illnesses, and conditions associated with the aging process. Detailed discussion of these causes is beyond the scope of this article. Despite the varied and complex causes of childhood and adolescent chronic illness, there are striking similarities among the effects that chronic illness has on the mental health status of this population.

Common Chronic Illnesses

The most common and disruptive chronic illnesses that have their onset in childhood or adolescence in the United States are respiratory allergies (9%), asthma (4%), eczema and skin allergies (3%), heart disease (2%), epilepsy (0.2%), and diabetes (0.1%) [2]. These chronic illnesses often co-occur with mental illness. For instance, depression and anxiety are associated with heart disease [6], type 2 diabetes [7,8], renal disease [9], obesity [10,11], and asthma [12-14].

Effects of Chronic Illness

By 2015, worldwide, 1.2 billion children aged 5-14 years will have some kind of significant chronic disease [15]. National population-based studies from western countries show that 20% to 30% of adolescents have a chronic illness, defined as one that lasts longer than six months, and 10% to 13% of those adolescents report having a chronic illness that

substantially limits their daily life or requires extended periods of care and supervision. The increasing prevalence of chronic illness across the globe further indicates the need for research that fully explores the relation between mental health and chronic illness.

Children with chronic illnesses have an increased risk of emotional and behavioral problems [16]. This risk has been documented in epidemiological studies [1], as well as in studies of clinic samples [17]. The assessment and treatment of emotional and behavioral problems is recognized as an essential part of treating children and adolescents with chronic illness [17]. Even though children and adolescents with chronic illness may be in regular contact with general and specialty healthcare providers, the children may not have access to needed mental health support services, and many children and adolescents do not report mental health issues to medical providers [1]. Glazebrook and colleagues [17], for example, suggest that pediatricians detect only approximately 25% of psychosocial problems among their chronically ill patients.

Developmental Issues and Mental Health

Regardless of the specific developmental stage, children and adolescents must adapt to the nature and limitations of the chronic illness with its physical and emotional sequelae, as well as comply with recommended medical treatments to attain adult functionality. In addition, children and adolescents must fulfill normative tasks of individual growth and development. Incomplete adaptation to the chronic illness, non-adherence to medical advice, and/or failure to accomplish normative developmental tasks can result in significant emotional disorders, psychosocial impairment, and developmental delay [1]. Whereas adequate adaptive functioning in the psychosocial domain promotes mental health as well as effective management of the chronic illness, inadequate adaptive functioning within this domain can become a precursor to future mental health difficulties and/or play a significant role in assessing and managing current mental health concerns.

The response to living with a chronic illness depends on several factors, including but not limited to personality characteristics, the specific illness, and the family. Extremely important to the complex set of sequelae is the particular developmental stage in which the child or adolescent is operating that requires energy. Infants and toddlers, for example, are beginning to develop trust and an overall sense of security. They generally have very little understanding of their illness. Children in this stage of development experience pain, restricted emotion, and separation from parents as challenges to developing trust and security.

Preschool children are beginning to develop a sense of independence. They may understand what it means to get sick but they may not understand the cause and effect nature of illness. Being in the hospital or adjusting to a medication schedule, for example, can challenge the child's developing independence.

Early school-aged children are developing a sense of mastery over their environment. They can describe reasons for illness, but these reasons may not be entirely logical. Children this age often have "magical thinking." They may believe they caused the illness by thinking bad thoughts, by hitting their brother, or by not eating their vegetables. Children also begin to sense that they are different from their peers.

Older school-aged children are beginning to focus on peer relationships. They are now more capable of understanding their illness and its treatment but they should not be expected

to respond as adults do. They may feel left out when they miss school or activities with their peers as developing and maintaining peer relationships is one of the most important psychosocial developmental tasks that will continue into adolescence.

Adolescents begin to develop their own identity separate from their families. Self-image becomes extremely important during the teenage years. The perception of the peer group is of paramount importance and is an issue when the adolescent's appearance is altered by illness or medication.

MENTAL HEALTH ISSUES

As stated previously, children and adolescents with chronic illness have the same developmental needs as other same age peers. In many ways, the accomplishment of developmental tasks is made more difficult by an extra set of demands and hardships associated with the chronic illness [18].

Typical developmental tasks may interact with issues related to chronic illness, producing increased demands and stress upon children and adolescents. If the additional stress is not managed effectively, then the risk for mental health problems increases. Although many chronically ill children and adolescents do not experience mental health problems secondary to development-related stress, several epidemiologic studies have found indications of approximately a two-fold increase in mental health problems among this group of children [1,19].

Although chronically ill children and adolescents can develop any type of mental health problem, the following discussion illustrates some of the areas in which the chronically ill may be most vulnerable.

Body Image Issues

One of the major developmental tasks of childhood and adolescence is the establishment of an individual identity while major changes are also occurring physically. Chronic illness may intensify concerns about personal and sexual identities with fears or distortions related to the illness. Research during the last two decades has demonstrated variability in body size preference and in body image dissatisfaction among children and adolescents based on age, pubertal status, presence or absence of a chronic illness or disability, gender, ethnicity, body mass index (BMI) or weight, and family relationships [20]. Specific body image concerns among chronically ill children or adolescents have not been investigated.

Adolescents report greater body image dissatisfaction than do younger children [21]. In addition, dissatisfaction with one's body image and the desire for thinness, with its perceived approval from others, increases as children approach puberty [22]. Girls report greater dissatisfaction than boys [23,24] and a greater desire for thinness [21]. Body mass index, at risk for overweight, or being overweight have positive associations with body image dissatisfaction among youth, according to some studies [25,26].

Children and adolescents with chronic illness may struggle with body image, especially if there is a visible difference or limitation in activity. This is especially apparent for

adolescents who are concerned with membership in a particular peer group. For those adolescents who may take medication on a long-term basis to manage their illness, adherence with the drug regimen may be erratic. If the medication has undesirable side effects, such as weight gain or an increase in acne, adolescents may be acutely aware of body image issues.

Chronically ill children and adolescents may attempt to manage poor body images through the development of an eating disorder: a group of disorders that has a disturbance in eating behavior that endanger physical and mental health. Eating disorders include the following:

- Anorexia Nervosa—a condition in which a person purposely limits food intake and refuses to maintain a weight within a healthy range for height and age. People with Anorexia Nervosa may also binge and purge.
- Bulimia Nervosa—a condition that involves cycles of bingeing and behaviors that follow to prevent weight gain and can include such behaviors as vomiting, using laxatives, diuretics, or involvement in excessive exercise.
- Binge Eating Disorder—a condition in which a person binge eats but does not attempt to control weight through unhealthy purging behaviors. As many as one third of obese people may have this eating disorder but have gone undiagnosed.
- Eating Disorder NOS (not otherwise specified)—a term used with individuals who have disordered eating behaviors, dissatisfaction with body weight or shape, and harmful weight control behaviors that do not meet full criteria for one of the more severe eating disorders above.

Development of Independence

Chronic illness frequently interferes with the attainment of independence and autonomy. Parents may be less willing to grant autonomy to children and adolescents who have a chronic illness. While children and adolescents try to function autonomously, parents or caregivers may be reluctant for this to happen because they fear that the specific child or adolescent will not manage the chronic illness effectively. Because chronic illness may delay the onset of puberty with its immense increase in growth and development, parents may be even more likely to remain protective as children and adolescents may not appear to be capable of autonomous functioning. In addition, children and adolescents may become physically dependent upon the family for companionship, friendship, and social support if there is not a strong connection to the peer group.

Relationships with Peers

Chronic illness and the assessment, treatment, and management of that illness often interferes with time spent in the school setting, which is children's and adolescents' primary social environment. Self-esteem issues related to acceptance of self and concerns about acceptance by others are intensified in chronic illness. In addition, if they have limited access to the school setting or other social environments because they are ill, then their ability to establish and maintain peer relationships is impaired.

Given the central role that peer relationships play in the psychological development of children and adolescents, and because peer rejection and isolation have been associated with subsequent adjustment problems, chronically ill children and adolescents are at an increased risk for difficult psychological development. Meijer et al [27] and his colleagues report that the level of psychological adjustment among chronically ill children and adolescents is variable. This variability may be due, in part, to the presence of protective factors, such as the use of adequate coping strategies.

Promoting Positive Mental Health

Promoting positive mental health among children and adolescents with chronic illness means promoting adaptation and/or competence in living with that illness. Promoting competence requires the development and maintenance of sufficient capabilities to meet cumulative and persistent demands. It may also mean reducing demands or removing barriers to successful adaptation, such as minimizing hospital visits while encouraging family involvement, increasing opportunities for peer interaction, and maximizing independence in living.

There are four strategies to consider when promoting positive mental health: (1) encourage typical life experiences, (2) increase coping skills, (3) increase use of social support, and (4) empower families.

Encouragement of Typical Life Experiences

Children and adolescents with chronic illness have the same developmental needs as other same-age peers. Activities that challenge them to develop social skills, master new approaches to social situations, build self-esteem, and form separate and healthy identities away from caregivers while engaging with others (e.g., peers, family members, other adults) promote successful accomplishment of developmental tasks as well as positive mental health. As children and adolescents with chronic illness become fully integrated into family, school, and community activities, engaging in typical life experiences will become more routine and expected. Until then, however, it is often left up to the medical and mental health treatment teams to encourage parents and other caregivers to allow active participation in diverse life experiences by children with chronic illness.

Increase Coping Skills

Teaching children and adolescents with chronic illness and their family members how to cope with the demands of the illness is frequently a strategy used to promote mental health. Coping is behavior directed at restoring a balance between excess demands placed on children and adolescents secondary to achieving developmental tasks and managing the chronic illness with, often, inadequate resources.

If children or adolescents and their families manage to balance these needs, then the number and use of coping skills is adequate. There are times, however, when parents,

caregivers, friends, or extended kinship networks are unable or unprepared to deal with the intense emotional response of chronically ill children and adolescents. Depending upon the type and severity of the chronic illness, just understanding and managing the illness can take so much time and emotional energy that the psychological aspects of the developing person are neglected [28]. The neglect of these psychological aspects may result in depression, anxiety, or other disorders requiring early treatment in order to prevent long-term negative sequelae.

Increase Use of Social Supports

Of all the resources for promoting positive mental health, none has received more attention than social support [29]. There have been many conceptualizations of social support, most of which incorporate the support that is given as well as the person who gives it. Three broad categories of support are listed below:

- emotional support that provides information that one is loved and valued, that children or adolescents matter to and are connected with others;
- informational support that helps chronically ill children and adolescents solve problems and find other tangible services and resources and can give feedback about how they are doing in managing the illness; and
- instrumental support or tangible support during times of extreme stress.

Social supports can be from formal or informal sources. Formal supports include assistance that can be accessed through the school system or the hospital setting. Informal support networks refer to family, friends, relatives, neighbors, churches, clubs, and organizations with whom a person voluntarily interacts. A combination of formal and informal supports is necessary for the optimal management of a chronic illness.

Empowerment of Families

The notion of empowerment of families of chronically ill children and adolescents is becoming associated with service delivery across many medical and mental health settings or professions [30]. Rather than parents or caregivers doing everything for chronically ill children or adolescents, thus maintaining dependency, a process is begun whereby the children or adolescents with a chronic illness discover and build on their own strengths, leading to a greater sense of mastery and control over their lives. They have confidence in their own ability to acquire and use resources to meet needs, to solve problems, and to make decisions. Empowered families of chronically ill children and adolescents are not helpless and dependent, nor are they totally independent. Rather, the goal of empowerment is inter-dependence among self, family, informal support, and formal service providers.

CONCLUSIONS

Growing up is a stressful developmental process even for physically healthy children and adolescents. Chronic illness further complicates the developmental process. The chronic illness, treatment requirements, hospitalization, and surgery, when necessary, all intensify concerns about physical appearance, interfere with the process of gaining independence, and disrupt changing relationships with parents and peers. In addition, developmental issues complicate the transition of children and adolescents toward taking responsibility for managing their illness and learning to comply with the medical and mental health treatment plans.

The prevalence of chronically ill children and adolescents with mental health issues, worldwide, is increasing as larger numbers of such children live until and beyond adolescence. In addition, the prevalence of certain chronic illnesses in adolescence, such as diabetes (types 1 and 2) and asthma, has increased, as have survival rates from cancer.

Although scientific evidence indicates that children with chronic illness have more mental health issues than their healthy peers, many controversies and gaps in the literature exist. A full understanding of the relation between chronic illness and mental health is yet to be available. Second, the specific types of mental health issues associated with specific chronic illnesses continue to be delineated. Third, there is inconsistency and a paucity of data regarding the connection between mental health and social issues among specific clinical groups of chronically ill children and adolescents. As research continues to illustrate the relation between chronic illness and mental health, appropriate services will be more available to meet the needs of children and adolescents.

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