



2017

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Recommended Citation

(2017) "Chronic Illness and Functionality: How It Affects Adolescents Academically and Socially and How They Can Cope," *Intuition: The BYU Undergraduate Journal in Psychology*: Vol. 12 : Iss. 2 , Article 8.

Available at: <https://scholarsarchive.byu.edu/intuition/vol12/iss2/8>

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Chronic Illness and Functionality: How It Affects Adolescents Academically and Socially and How They Can Cope

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Abstract

This paper explores the prevalence of chronic illness in adolescents, and its effects on academic and social functionality. When diagnosed with a chronic condition, adolescents must often make lifestyle changes that can put substantial pressures on some, or even all, areas of life. Many adolescents report needing help to make the changes necessary to manage their illness. Chronic illness affects millions of adolescents worldwide, and these individuals need understanding, support, and guidance to succeed. The aim of this paper is to review the literature examining psychosocial aspects of chronic illness in adolescents and to examine healthy coping styles, accessibility to assistance, and the beneficial effects of external support for adolescents with chronic illness.

Chronic Illness and Functionality: How It Affects Adolescents Academically and Socially and How They Can Cope

The prevalence of chronic illness has grown exponentially in the last decades: about 50% of citizens in America have one chronic illness, 26% have two or more, and 13% have a disability (Bauer, Briss, Goodman, & Bowman, 2014). Sadly, that population also includes adolescents. Studies have found that the number of people 17 years of age and younger that have one or more chronic health condition associated with body function, activity, or participation has risen to approximately 43% (Compas, Jaser, Dunn, & Rodriguez, 2012). These conditions could be a myriad of things such as “autism spectrum disorders, developmental delay, asthma, diabetes, epilepsy or seizure disorder, or brain injury” or could be defined as any condition that lasts six months or more (Denny, de Silva, Fleming, Clark, Merry, Ameratunga, & Fortune, 2014; Kim, Amtmann, Salem, Park, & Askew, 2014, p. 96). Technological advances over the years have increased treatment opportunities and therapy options, beneficially aiding the lives of so many that are afflicted with chronic conditions. These advances have also led to improvement in surgical procedures, which have helped and will continue to help those with health concerns. However, the intense and invasive nature of these procedures run the risk of permanent damage and can lead to impairment which increases the number of people with chronic pain or disability. Currently, 26% of adolescents report recurrent pain while a third of those have severe pain that disables them (Wojtowicz & Banez, 2015). In this review, a chronic condition or illness will refer to all kinds of chronic disease, chronic disability, and chronic pain. Adolescents struggling with a chronic condition may find it difficult to adjust their lifestyle or manage their own well-being in the face of such a burden.

The burden of chronic illness may seem even larger to those in relatively early stages of life. When diagnosed, adolescents are often required to make lifestyle changes that can put significant pressure on areas of life that may have been easy, manageable, even non-existent, prior to the diagnosis (Casier, Goubert, Gebhardt, De Baets, Van Aken, Matthys, & Crombez, 2012). In addition, financial stability can often be a concern as most chronic illnesses involve prolonged medical attention, medication, therapy, and possibly special equipment. The strain on physical health is an obvious effect as well; however,

adolescents with chronic conditions are also more susceptible to emotional health issues, most commonly anxiety and depression, than adolescents without a chronic illness (Denny et al., 2014). Research has shown that having a chronic illness in adolescence leads to increased risk of mental illnesses; behavioral, cognitive, and impairment issues; and general functioning difficulties, such as difficulties with physical and social ability (Casier et al., 2013). Research that examines the functioning of chronically ill adolescents claims that many teens need help in one or more of the following categories: socialization, school, family, daily activities, and mood regulation (Denny et al., 2014). These results and insights suggest that it is more the impact or burden of the chronic illness, rather than the illness itself, that causes lower quality of life for those diagnosed (Denny et al., 2014; Kim et al., 2014). These adolescents' lives often revolve around their experiences of pain, fatigue, and emotional distress that adversely affect their well-being and functioning (Kim et al., 2014). The complexities and difficulties that come from and are exacerbated by their conditions are causes for distress, isolation, confusion, and hopelessness—all of which are detrimental to a person's growth and development.

Moreover, chronic illness can have a profound effect on a person's social and academic functioning—two key aspects of life for adolescents. This review will first explore the effects chronic illness has on academic functioning and will examine social functioning, how adolescents can cope, and why it is important to receive support from others.

Functioning with Chronic Illness

The symptoms and effects of chronic illness can greatly impair adolescents' functioning in several areas of their lives. For this report, functioning encompasses both performance and competence in a certain area (Pinquart & Teubert, 2012). There may be many contributing factors to an adolescent's quality of life, or the level of comfort, satisfaction, happiness, and general well-being a person experiences; nonetheless, studies have concluded that for chronically ill patients, the higher level of sleep problems, fatigue, pain, or other symptoms reported, the lower the functioning in school and social activities, support from peers, and overall satisfaction with their life (Kim et al., 2014). As most adolescents with chronic problems deal

with at least one of these factors—if not more or all of them—it is clear why a chronic diagnosis can greatly disrupt someone’s life.

In a study involving adolescents with chronic conditions, Pinquart and Teubert (2012) found five reasons why patients may function more poorly than their healthy peers. First, some chronic conditions limit adolescents’ choices of and participation in activities, contact with peers, and school attendance; second, their conditions could impair them academically or socially because of cognitive problems, pain, or reduced motivation and energy; third, side effects of medication or therapy may hurt or reduce their capabilities; fourth, reactions from others can influence lifestyle, such as overprotective parents or peer rejection and bullying; and fifth, behavioral issues that can come from chronic conditions, such as depression or aggression, can negatively impact functionality. When an adolescent with a chronic condition cannot function properly, or as well as he or she would like, he or she can fall into even further isolation with higher negativity regarding self-image. This review will focus on two main aspects of an adolescent’s functioning—academics and sociability—and why functionality in those areas is necessary.

Effects on Academic Functioning

When students function well academically, they show behaviors that ultimately lead to academic success such as mastery of subjects, high test scores, and writing ability. These behaviors could be anything that contributes to motivation, working hard, and performing well in educational endeavors (Pinquart & Teubert, 2012). Academics play a major role in lifestyle, especially for adolescents who are in the middle of their educational career. Those in their adolescent years are often faced with decisions about their education and future as they are heading into that time of life, and functioning well academically is crucial. However, as Forrest, Bevans, Riley, Crespo, and Louis (2011) point out, the quality of school hinges on more than grades: school is also a factor in a student’s feelings of adequacy, control, and level of belonging, which all contributes to motivation, engagement in learning, and, ultimately, success. Both performing well and being able to function academically are important in an adolescent’s life; these expectations can cause problems for those who are not able to function as well due to chronic illness. Apart from lifestyle and educational success, studies have also shown

that there is a direct association between the ability to accomplish schoolwork and adolescents' self-esteem (Myers, Willse, & Villalba, 2011). This association is important to understand, especially for students with a chronic illness that may not be able to perform well in school, as underperforming or excessive struggling with education will contribute to the feelings of despair and impairment that these students already feel.

Studies have shown that there is an identified link between chronic health problems in adolescents and lower educational attainment overall. In 2015, Champaloux and Young conducted a study illustrating this link. They found that those who reported a chronic illness had significantly lower odds of completing high school or getting their General Education Development (GED) equivalent by age 21 compared to those who did not have a chronic illness, and this also applied to the odds of going on to get a job. The results pointed to low functionality due to their symptoms such as depression, fatigue, treatments, concentration difficulties, emotional turmoil, or pain, among others. A huge part of this rests on school attendance, as research has pointed to the idea that cognitive ability and actual grade point average (GPA) may be less important for functionality than being able to be in class (Champaloux & Young, 2015). This suggests an important factor in education that parents, teachers, and physicians should be more aware of and strive for.

Attendance issues and effects on academics. Chronic illnesses can often cause students to miss school more frequently and for longer time periods than students without a chronic illness. Absences can cause two major problems, according to Boonen and Petry (2011): first, missing class can disrupt cognitive development, as school plays a huge role in that—especially for those who experience cognitive difficulties because of their illness and/or treatment, which can lead to weaker academic functioning; second, the problem involves reducing normalcy for the student, which is important for psychosocial well-being. Positive school experiences can give students a feeling of adequacy and control, boost self-esteem, promote good relationships with peers, and reduce emotional trauma from their illness (Boonen & Petry, 2012). Staying in school is also important because students do not have to face returning after being out, especially for an extended period of time. Chronically ill students can be more susceptible to

succumbing to phobias, anxiety, problems with body image, self-esteem, separation, peer rejection, and may face harder transitions because of learned feelings of helplessness and despair (Boonen & Petry, 2011; Emerson, Distelberg, Morrell, Williams-Read, Tapanes, & Montgomery, 2015). These negative emotions can further impact their academic functioning, and may adversely affect their return to school, or keep them from wanting to return at all, exacerbating the problem and catching students in a negative cycle.

For those students who cannot return to school, homebound instruction may be a possible avenue. Boonen and Petry (2011) conducted a study involving homebound instruction for students with a chronic illness that could not make it to school. They set up a homebound education program with teachers coming to the students' home with teaching material that was completed and collected. Both parents and students gave very positive feedback regarding the system. However, previous studies have found that both parents and students have been largely dissatisfied and had serious problems with homebound instruction programs (Boonen & Petry, 2011). The researchers made sure students in their study were given extra hours of help from both paid teachers and volunteer tutors. This may be a good point for further research to determine how much support is needed for a student with a chronic illness to succeed academically when completing education from home because they currently aren't getting it.

For those students who have chronic health problems and are able to make it to school the majority of the time, the literature stresses staff education and support (Grier & Bradley-Klug, 2011; Kucera & Sullivan, 2011; Wyckoff, Hanchon, & Gregg, 2015). Schools should have compassionate staff that are willing and able to aid a student struggling due to illness. Both Grier and Bradley-Klug (2011) and Kucera and Sullivan (2011) discuss the need for strong support from school psychologists—making sure they are easily accessible to students and promoted in a way that students don't feel ashamed, embarrassed, or stigmatized for getting help. School nurses should also be equipped to handle and help students with a chronic condition that are struggling academically or in extracurricular activities and teachers should be sensitive, considerate, and willing to work with those students who are chronically ill (Kucera & Sullivan, 2011;

Wyckoff et al., 2015). It is vital that students with a chronic illness receive the support that they need so they are able to function academically, as education can have lasting consequences for years to come.

Effects on Social Functioning

Social functioning can cover a wide range of behaviors and skills, but it is defined as the general quality of someone's ability to make friends, hold conversations, and have social experiences (Pinquart & Teubert, 2012). As adolescents with chronic illness often struggle with symptoms, treatments, and side effects, it is crucial to note how valuable social functioning and support can be for them. However, the idea of a social support network can be a direct contrast to automatic tendencies if adolescents react to their chronic illness problems by feeling isolated and withdrawn. Emerson et al. (2015) found that those with a chronic illness diagnosis often feel excessively different, stigmatized, and less socially competent than their peers. In a study examining how adolescents with chronic illnesses are received and how that may affect their future social functioning, teachers reported that students with chronic illness were less disruptive and aggressive by nature; however, those students received less best-friend nominations and did not have as many reciprocated friendships as their peers without chronic illness (Noll, Kiska, Reiter-Purtill, Gerhardt, & Vannatta, 2010). Interestingly, reports from teachers and peers illustrated that they believed those with chronic illness had no social competence problems, but the patients themselves and their parents believed that they struggled with social functioning. This self-image of inadequate or dissatisfactory social functioning may further feelings of isolation and difference.

In a similar study, Denny et al. (2014) discovered a correlation between students who have a chronic condition and their emotional well-being; however, it was only among those who reported that their condition had an effect on their ability to participate in activities and socialize. Of course, this effect could be directly derived from mental/emotional disorders, avoiding or being unable to attend social activities and/or situations, or lack of school attendance or involvement in extracurricular activities all due to the impact of the chronic illness. As previously mentioned, the nature of these illnesses often causes diagnosed adolescents to withdraw from those and the

world around them. As they are more susceptible to depression and anxiety, among other mental illnesses, this isolation can be even further exacerbated, and the isolation can cause further depression, withdrawing, and other harmful behaviors. The ability to participate and be an active participant in life—in whatever form that takes from person to person—is a huge part of positive self-imagery, feelings of adequacy, and sense of self.

This may also be a result of parenting: studies have indicated that parents are more willing to send their child to school when health is stabilizing or improving, but they are less likely to do so for social activities even when social functioning increases (Emerson et al., 2016). Because of the impact of the illness or repercussions of it, such as mental illness or physical limitations, social functioning can be minimal or reduced.

Psychologists have studied whether social support is greater among those who have the same chronic condition. Helms, Dellon, and Prinstein (2015) found that among adolescents with cystic fibrosis, 43% had at least one friend that also had cystic fibrosis. The friendships with common conditions, however, were rated as having lesser quality than friendships with someone who did not have a similar chronic condition. Regardless, all expressed the need for social support. Further research may help discover exactly what causes social dysfunction based on certain illnesses and symptoms, and what can be done to manage and/or overcome these issues so that adolescents with chronic health conditions can receive the support and love they need.

Coping With Chronic Illness

Acceptance is a huge part of living a successful life with a chronic illness. This involves how individuals evaluate their illness and lives, recognizing the need to adapt as needed, and having the ability to tolerate and handle the unpredictability and adverse nature of these diseases (Casier et al., 2013). Thus, being able to accept a chronic illness diagnosis is a major factor in well-being and coping. To be the most effective, acceptance and coping needs to happen on an internal and external level.

Coping on a Personal Level.

Myers et al., (2011) did a study regarding wellness factors and how they influence self-esteem in adolescents. In the study, they used the

Indivisible Self Model of Wellness that was broken down into different sections of the self: creative, coping, social, essential, and physical. They found that the Coping Self was the only factor that consistently related to all four parts of self-esteem (general, social, home, and school). Defined, the 'Coping Self' refers to the way individuals regulate their responses to life events and the means used to rise above negative outcomes or effects (Myers et al., 2011). The authors called for more research to examine what aspects of the Coping Self contribute to self-esteem and why.

It is also important to note the other factors of self, mentioned in the study discussed above: creative, social, essential, and physical. As discussed earlier in this review, a chronic illness can greatly influence or undermine an adolescent's sense of social self and/or physical self (Denny et al., 2015). Emotional or mental disorders derived from chronic conditions have the potential to negatively affect the creative sense of self (thinking, emotions, control, positive humor) and the essential sense of self—spirituality, identity, and self-care (Myers et al., 2011). Should the chronic illness affect one or more—or perhaps all—of these factors of the self, it is easy to see why adolescents may struggle with every aspect of life when diagnosed.

However, one should never assume there is no hope. Lansing and Berg (2014) argue that self-regulation is a way to manage difficult chronic conditions. They explain that “as adolescents set goals to manage their chronic illness, they must regulate their cognitions (thoughts about pain), emotions (embarrassment with managing disease around friends), and behaviors (checking blood glucose), toward the goal of achieving health” (p. 1092). This means adolescents must be able to recognize and be cognitively aware of problems, emotions, and behaviors, then be able to organize a response that is beneficial to them. This includes goal setting, maintaining social connections, and establishing meaningful activities (Allison, Baune, Roeger, Coppin, Bastiampillai, & Reed, 2013). However, the study notes that adolescents with poor coping and self-efficacy struggle with self-regulation practices. Learning to accept and cope with a chronic condition is a personal expedition, but outside support can be beneficial—even crucial—in aiding adolescents with coping.

Outside Support Aids in Coping.

Adolescence marks a transitional phase in people's lives in

which they become more independent and tend to rely more on their peers than family, though parents continue to make an important contribution in their life; when parents make their adolescents feel valuable and competent, adolescents tend to have better psychological functioning (Oris, Seiffge-Krenke, Moons, Goubert, Rassart, Goossens, & Luyckx, 2016). This is also true of those with chronic illness. In the same study by Oris et al. (2016), they found that negative parental support attributed to depression and loneliness—issues adolescents with chronic conditions already face (Emerson et al., 2016). Thus, parental support, and family support in general, has shown to be a huge factor in whether adolescents with a chronic problem function positively. Studies have shown that social support—especially from family—is the strongest predictor of positive mental health (Myers et al., 2011; Oris et al., 2015). The authors do call for more research, however, to explore what about family support is so critical and what it can offer separate from non-family members.

Peer support has also been said to be important in coping. Those who had access to strong social support clusters reported better psychological functioning than those who were not part of such a group (Myers et al., 2011). These findings suggest that therapists should focus on all aspects of support, whether it be from parents, family, or peers. Regardless of who it is, it is important that adolescents have access to and feel that they have the support they need, as positive, consistent, and reliable support can help them function and cope better than they would be able to on their own.

Conclusion

Chronic illness greatly affects an adolescent's academic and social functioning. This can contribute to many problems in life presently and in the future. School attendance issues related to chronic illness can have major negative effects on adolescents' academic performances, and symptoms or side effects from the illness can influence learning (Boonen & Petry, 2012; Emerson et al., 2016). Studies have found a link between the ability to accomplish schoolwork and adolescents' self-esteem, thus it is important adolescents are still able to perform well in school (Myers et al., 2011). Apart from academics, adolescents with chronic illness can be limited in their social functioning, whether because of stigma, self-image, mental illness, or

because they don't have the physical ability to be with others (Denny et al, 2014; Emerson et al. 2016; Noll et al., 2010).

Despite all these obstacles, there are things that can help adolescents with chronic illness, both on an external and internal level. Research suggests that implementing programs in schools that are directly for those with chronic conditions confer significant benefits (Boonen & Petry, 2011; Champaloux & Young, 2015). These programs may include accessibility centers where students can have access to tutors and find resources to help them combat their symptoms and perform academically. Knowledgeable and compassionate staff should be available to aid students academically, physically, and emotionally (Grier & Bradley-Klug, 2011; Kucera & Sullivan, 2011; Wyckoff, Hanchon, & Gregg, 2015). On either a school or community level, there should be social support groups put in place for diagnosed adolescents to attend and find help, as well as easy access to licensed therapists and/or psychologists (Grier & Bradley-Klug, 2011; Kucera & Sullivan, 2011). More research is needed to explore positive staff experiences and what contributes to them, as well as homebound instruction programs, including how to make them more effective and widespread. Further benefit can come from researching what part of the impact of chronic illness directly affects an adolescent's social functioning, and in what scenarios that may be helped in. Of course, more research is always needed in the physical aspect of these illnesses, whether by finding cures or ways that can ease symptoms and lead to a better quality of life. Psychologists should also research those who report coping well with chronic illness, and what parts of their lives may be attributed to that so that others may follow suit.

Further knowledge and aid for adolescents with a chronic illness will also benefit future generations who receive a chronic illness diagnosis. If the proper programs are put in place now, they will be there for those who need it in the future. Also, the adolescents who receive the help that is needed to cope with their illnesses will be able to help those that come after them, passing it down to create a line of well-adjusted people. Catering to this group of struggling adolescents will help them to feel less isolated, create a place where they will get the aid and positivity they need, and will create a more empathetic and safer world to live in, benefitting everyone.

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