Mental health issues in children and adolescents with chronic illness

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Abstract

Purpose – *The purpose of this paper is to consider mental health issues in children and adolescents with chronic illness or health conditions, including their treatment, and issues related to delivery of services.*

Design/methodology/approach – *A selective review of the literature was conducted to highlight significant mental health issues and their treatment in youth with various types of chronic illness.*

Findings – *A significant portion of youth experience mental health problems related to their chronic health conditions. While evidence-based treatments are available to address these problems, significant barriers exist that impede the delivery of psychological and behavioral interventions for many youth.*

Research limitations/implications – *More controlled studies are needed to demonstrate the effectiveness and cost offset of delivering psychological and behavioral interventions for the population of youth with various types of chronic health conditions, particularly in clinical and community settings.*

Social implications – *Policy reform can ensure that mental health issues are effectively addressed for children with chronic illness. Policy is needed that promotes integrated health care, whereby psychological and behavioral interventions are delivered in health care settings along with medical interventions to reduce barriers to care.*

Originality/value – *Significant numbers of children and adolescents have chronic health conditions and many experience mental health problems related to their conditions. While evidence-based treatments are available to address these problems, significant barriers impede the delivery of psychological and behavioral interventions for many youth. Health care policy promoting integrated health care to deliver psychological and behavioral interventions in health care settings along with medical interventions should reduce barriers to care and improve both physical and mental health outcomes for youth.*

Keywords *Mental health, Health care, Behavioural intervention, Chronic illness, Psychological treatment*

Paper type *Viewpoint*

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Introduction

This paper considers the issue of mental health problems among children and adolescents with chronic illness or chronic health conditions. Chronic health conditions increase the risk for comorbid physical and mental health conditions, complications from mismanagement, increased health care costs, and reduced quality of life. After discussing the prevalence of these conditions, we examine the relationship between mental health issues and management of chronic illness, and psychological treatments and behavioral interventions to address mental health problems and management of chronic health conditions. We then consider access and barriers to psychological and behavioral treatment among the population of youth with chronic health conditions, and discuss implications for research and policy. We focus our selective review on several representative chronic health conditions including obesity, asthma, and diabetes.

Prevalence of chronic health conditions affecting children

A recent study conducted in the USA estimated that 43-54 percent of children and adolescents have some type of chronic health condition (Bethell *et al.*, 2011). The higher rate includes youth who are overweight or obese, an excellent example of a chronic health condition with significant

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related psychological factors. Recent epidemiological research in the USA indicates that approximately one-third of children and adolescents are overweight or obese, with higher rates observed among ethnic minority black and Hispanic youth (Ogden *et al.*, 2014). The prevalence of obesity in children throughout the world has been steadily increasing in recent years. One report indicated that approximately 43 million pre-school aged children worldwide were overweight or obese, and it was estimated that 9.1 percent of pre-school aged children would be overweight or obese by 2020 (de Onis *et al.*, 2010). Studies also indicate that obesity in childhood has a high risk of persisting into adulthood and increases the risks for adverse health conditions such as type 2 diabetes (T2D), cardiovascular disease, and cancer (Torpy *et al.*, 2010).

After obesity, asthma is one of the most common chronic health conditions of childhood. The prevalence of asthma in the USA in 2005 was approximately 9 percent, doubling since the 1980s, with higher rate among ethnic minority youth (Akinbami, 2006). A recent global study of asthma, conducted by the International Study of Asthma and Allergies in Childhood, found that the prevalence for asthma in the 13-14-year-old age group was 14.1 percent, while prevalence in the six- to seven-year-old age group was 11.7 percent (Mallol *et al.*, 2013).

Diabetes, while not as common as obesity and asthma, is a chronic illness affecting many children throughout the world, and the most common endocrine disorder. Studies indicate that the incidence of both type 1 diabetes (T1D) and T2D in children is increasing worldwide, and associated with increased health care costs; management requires complex daily treatments performed by the child and parents. Research has shown significant geographic variability in the incidence of T1D throughout the world, with the greatest incidence in northern European countries (Karvonen *et al.*, 2000). Research findings suggest there are approximately 500,000 children under the age of 15 with T1D worldwide, with the majority from Europe and North America (Patterson *et al.*, 2014).

Studies have also shown an increasing incidence of T2D among youth (Chen *et al.*, 2012). Results from epidemiologic studies have shown the incidence of T2D in children and adolescents to have a range of 1-51/1,000, depending upon ethnic group (Fagot-Campagna *et al.*, 2000). Results from the US SEARCH study showed the lowest rates of T2D among non-Hispanic white youth and the highest rates among Native American Indians (Dabelea *et al.*, 2007). The recent increase in incidence of T2D in youth is most likely driven by the increasing rate of obesity, poor nutrition, decreased physical activity and increased sedentary behavior of children.

Evidence indicates that the prevalence of pediatric chronic health conditions in the USA has increased dramatically in the past four decades, particularly with regard to obesity and asthma, but also including developmental conditions such as attention deficit hyperactivity disorder and autism spectrum disorders (Perrin *et al.*, 2007). Research has shown in three nationally representative cohorts of children in the USA from 1988-2006 that the prevalence of chronic health conditions has increased substantially, from 12.8 percent in 1994 to 25.1 percent in 2000 and 26.6 percent in 2006 (Van Cleave *et al.*, 2010). The third cohort studied had the highest prevalence of having a chronic health condition during any part of the six-year study period, with 51.5 percent of youth affected. Higher rates were observed among male, Hispanic, and black youth. The rise in chronic conditions among youth, particularly for obesity, asthma, mental health conditions, and neurodevelopmental disorders, has also created a challenge in terms of how best to care for them (Perrin *et al.*, 2014).

Mental health issues among youth with chronic health conditions

A substantial research base over the past 30 years has demonstrated that children with chronic health conditions are at increased risk for mental health problems, as shown by meta-analytic studies (Lavigne and Faier-Routman, 1992), epidemiological studies (Cadman *et al.*, 1987), and studies of clinical samples (Glazebrook *et al.*, 2003). For example, in a study conducted in Norway, both boys and girls with a chronic physical illness had more than twice the risk of having significant emotional and behavioral problems than physically healthy children (Hysing *et al.*, 2007). Another study suggests that girls with chronic illness are more at risk for emotional problems (Suris *et al.*, 1996). Research has shown that poor asthma control was

associated with lower quality of life in children, mediated by poor nighttime sleep quality and daytime sleepiness (Li *et al.*, 2016).

Among youth with T1D, research has shown they have a greater risk of depression, anxiety, psychological distress, and eating disorders compared to their healthy peers (Grey *et al.*, 2002; Hood *et al.*, 2006; Reynolds and Helgeson, 2011; Young *et al.*, 2013). A recent study of 629 youth with T1D in Germany found that youth had a greater risk (OR = 1.61) for mental health problems than youth in the general population, and that the quality of life of these youth who reported mental health problems was more severely impaired (Stahl-Pehe *et al.*, 2014). A study conducted in the Netherlands found elevated depressive symptoms in youth with T1D, with girls reporting more depression than boys (De Wit and Snoek, 2011). As shown in a recent meta-analysis, depression is associated with poorer treatment adherence, and to a lesser extent, poorer glycemic control (Kongkaew *et al.*, 2014). A recent prospective study showed that greater depressive symptoms predicted less frequent blood glucose monitoring, poorer quality of life, and poorer glycemic control over time (Hilliard *et al.*, 2013).

Depression and anxiety are very important because both have been associated with poor diabetes management and glycemic control (Herzer and Hood, 2010; Hood *et al.*, 2006; Lawrence *et al.*, 2006; McGrady and Hood, 2010). Increased symptoms of depression and anxiety have also been linked with poor control of asthma in children and adolescents in studies conducted in the Netherlands and USA (Letitre *et al.*, 2014; Peters and Fritz, 2011).

Compared with research in T1D, relatively fewer studies have addressed mental health problems in youth with T2D. Findings from the SEARCH study indicated that youth with T2D, especially boys, were more likely (OR = 3.5) to report depressed mood than youth with T1D (Lawrence *et al.*, 2006). In this study, 20 percent of girls and 18 percent of boys with T2D reported symptoms of moderate to severe depression. Furthermore, depressed mood was associated with poor glycemic control and more frequent emergency department visits. The TODAY Study Group reported that 15 percent of youth with T2D reported significant depression, with older girls reporting more depression; depressed mood associated with lower quality of life (Anderson *et al.*, 2011). Another report from the TODAY Study Group showed that 20 percent of youth reported subclinical and 6 percent reported clinically significant binge eating; binge eating was associated with greater obesity, more depression, and lower quality of life (TODAY Study Group, 2011). Lower quality of life in youth with T2D has also been reported (Varni *et al.*, 2003).

As with diabetes and asthma, obesity in children and adolescents is associated with a greater risk for adverse health outcomes including both medical and psychological problems (Pulgarón and Delamater, 2014). Research indicates that obese youth have increased rates of internalizing and externalizing disorders, problems related to body image, reduced quality of life, low self-esteem, social isolation, and discrimination (Pulgarón and Delamater, 2014; Schwimmer *et al.*, 2003). Studies with obese clinical samples of youth indicate severely impaired quality of life (Morrison *et al.*, 2015; Schwimmer *et al.*, 2003; Zeller and Modi, 2006). One study reported that poor quality of life of obese youth was associated with depression as well as parent distress and peer victimization (Janicke *et al.*, 2007).

A recent review of the literature concluded that obesity in youth was associated with lower quality of life, and associated with a number of factors including bullying, poor self-image, lower socioeconomic status, and unhealthy lifestyle behaviors (Buttitta *et al.*, 2014). However, in the general population, research indicates that while poor physical quality of life is associated with overweight and obesity, psychosocial quality of life was not as affected compared with clinical samples of overweight youth (Swallen *et al.*, 2005). Depressed mood has been associated with both greater risk of obesity and higher body mass index (Goodman and Whitaker, 2002). A prospective study of obese adolescents revealed that as young adults, women had an increased risk of social and economic difficulties (Gortmaker *et al.*, 1993).

Psychological and behavioral interventions for youth with chronic illness

Given that rates of mental health problems are increased for children with chronic illness and these problems impact adversely on regimen adherence and health outcomes, it is important to

consider what the evidence base is for psychological interventions in this patient population. Psychological and psychosocial interventions addressing mental health issues are particularly useful in chronic illness as many conditions can affect mental health, which in turn may adversely affect disease management. Chronic health conditions such as obesity, diabetes, and asthma may adversely affect self-esteem, mood, social skills, coping abilities, and regimen adherence. Interventions that address the emotional components of living with chronic health conditions may be beneficial in improving not only disease management, but also mental health and long-term psychosocial adjustment.

Although there is a considerable research literature on psychosocial and behavioral interventions for disease management, there are relatively fewer studies directly addressing mental health problems in youth with chronic physical illness or chronic health conditions. A recent systematic review examined psychological interventions for mental health disorders in children with chronic illness and found only ten studies that met criteria for inclusion in the review (Bennett *et al.*, 2015). This review concluded there was evidence for some positive outcomes of cognitive behavior therapy for the treatment of mental health problems in youth with chronic illness, but there were only two randomized trials conducted that addressed depression. While there is some support for cognitive behavioral therapy to improve symptoms of anxiety and depression in youth with chronic physical illness, the authors concluded that the current evidence base is weak and there is a need for more research using randomized designs in fully powered trials.

Nevertheless, there is a considerable literature showing some improvements in psychological functioning and quality of life in children with chronic health conditions such as obesity. For example, an interdisciplinary family-based intervention for obese youth led to reduced depression and improved quality of life (Fenner *et al.*, 2016). In a randomized controlled trial conducted in the Netherlands, an interdisciplinary group program for obese adolescents resulted in improvements in quality of life (Hofsteenge *et al.*, 2013). In an uncontrolled report, severely obese youth participating in an interdisciplinary inpatient program had improvements in weight and quality of life (Knopfli *et al.*, 2008). However, a recent meta-analysis of the effects of interdisciplinary interventions on quality of life in obese youth identified just 11 controlled studies; these authors concluded there were only trends towards improvements in quality of life and thus there was insufficient evidence that such programs improve quality of life (Ligthart *et al.*, 2015).

In the field of pediatric diabetes there is a considerable research base demonstrating the beneficial effects of psychological and family-based behavioral interventions to improve regimen adherence and glycemic control (Delamater *et al.*, 2014). In addition, there are a number of studies that have demonstrated the beneficial effects of psychosocial interventions (e.g. coping skills training and motivational intervention) for improved quality of life outcomes in youth with T1D (Channon *et al.*, 2007; de Wit *et al.*, 2008; Grey *et al.*, 2000). There is also evidence that stress management and problem-solving training delivered in small groups of youths has reduced diabetes-related stress (Boardway *et al.*, 1993; Hains *et al.*, 2000), improved social interaction (Méndez and Beléndez, 1997), as well as increased glucose monitoring and improved glycemic control (Cook *et al.*, 2002). These findings suggest that broader intervention approaches targeting stress management and coping skills may generalize to other aspects on life besides managing chronic health conditions.

Cognitive behavioral therapy, which includes strategies used in coping skills training and stress management, has been used to improve a number of mental health problems in pediatric populations including anxiety disorders (Heimberg, 2002), depression, eating disorders, self-esteem, and social competence. This suggests that applying these interventions would be beneficial youth with T1D among whom depression (McGrady and Hood, 2010) and anxiety (Herzer and Hood, 2010) have been shown to be associated with poor disease management. Similarly, given the high rate of eating disorders among youth with T1D and the relationship of eating disorders to poor disease management and health outcomes (Neumark-Sztainer *et al.*, 2002; Rydall *et al.*, 1997), research addressing the effects cognitive behavioral therapy in youth with eating disorders would be helpful. However, intervention studies specifically addressing mental health problems such as depression, anxiety, or eating disorders among youth with T1D have not yet been reported. The same is true for many other chronic health conditions.

Psychological and behavioral health services in medical settings

Access to mental health services

Mental health problems affect about 20-25 percent of children and adolescents in the USA (Costello *et al.*, 1988; Kessler *et al.*, 2005). However, research indicates that less than half of youth with a mental health disorder do not receive treatment (Costello *et al.*, 2014). Another study suggested 80 percent of children and adolescents who were in need of mental health services did not receive any, and that this unmet need was greater among Latino than white children, and greater among uninsured than publicly insured children (Kataoka *et al.*, 2002). Most children with psychosocial problems are treated in primary care and not referred to mental health professionals (Rushton *et al.*, 2002).

This situation is also apparent among the population of young people with chronic health conditions. For example, in a survey of Dutch youth with T1D, among those with elevated depression symptoms only 28 percent reported receiving psychological services (de Wit and Snoek, 2011). A recent international survey of physicians caring for pediatric patients with T1D revealed that while 43 percent reported that mental health professionals participated in routine clinical care as part of interdisciplinary teams, 30 percent of treatment teams did not have access to mental health professionals (de Wit *et al.*, 2014). Unmet health care needs of young patients predict worse adult outcomes in terms of physical as well as mental health (Hargreaves *et al.*, 2015).

Mental health referral has clearly been a weak link in the comprehensive care of children with chronic health conditions for decades (Sabbeth and Stein, 1990). In a large study or primary care referral of children, among the 16 percent who were identified with psychosocial problems and referred to a mental health provider, only 61 percent of referred families reported their child saw a mental health professional (Rushton *et al.*, 2002). This indicates both low identification of mental health problems and relatively low success at referral.

Barriers to mental health treatment

Significant attitudinal, stigma-related, and structural barriers exist to children receiving mental health services (Campo *et al.*, 2015). Many parents report barriers such as not perceiving mental health problems as serious, believing they can handle their children's mental health problems on their own, or not believing in the effectiveness of mental health treatments (Owens *et al.*, 2002). Stigma related to mental health treatment is another barrier reported by many (Corrigan *et al.*, 2014).

Structural barriers are also common. Many parents report financial barriers, inconvenience and distance, and long waiting times to receive mental health services (Hargreaves *et al.*, 2015; Owens *et al.*, 2002; Rowan *et al.*, 2013). Many mental health providers do not take certain types of health insurance and is another barrier resulting in limited access to mental health services. For example, psychiatrists in the USA have low acceptance rates of Medicaid and most types of health insurance (Bishop *et al.*, 2014). Research indicates that there is an insufficient infrastructure for mental health services for children and adolescents in the USA. Results from a national survey showed that only 63 percent of counties in the USA had at least one mental health facility providing outpatient treatment for children and adolescents, and fewer than half of rural counties had such capacity (Cummings *et al.*, 2013).

Integrated behavioral health care

Addressing barriers such as inadequate insurance coverage and low reimbursement for mental health services will help improve access to mental health treatment, but attention must also be paid to reducing stigma and inappropriate attitudinal barriers related to mental health treatment (Campo *et al.*, 2015). Integration of mental health services in medical settings is an important strategy for addressing these issues, and is especially salient in the case of children and adolescents with chronic illness or other health conditions. Collaborative care based on the chronic disease model has been successfully applied in pediatric primary care (Campo *et al.*, 2015) including improvements in pediatric behavioral problems and depression (Kolko *et al.*, 2014; Richardson *et al.*, 2014).

Psychologists are increasingly seen as essential members of the health care team in patient-centered medical homes (McDaniel and deGruy, 2014). The integration of behavioral health specialists in the care of youth with chronic health conditions reduces the stigma often associated with mental health treatment (Kolko and Perrin, 2014). The results of a recent meta-analysis of 31 randomized controlled trials demonstrated that improved mental health outcomes for children and adolescents (depression, anxiety, behavioral problems) occurred with integrated behavioral health care compared to pediatric primary care alone (Asarnow *et al.*, 2015). In an example of integrated pediatric primary care, telephone child psychiatry consultations promoted referrals by pediatricians for appropriate counseling and psychological therapies in the community rather than prescribing psychotropic medications as a first strategy (Straus and Sarvet, 2014).

There are several recent examples of integrated behavioral health care in the treatment of youth with T1D. For example, a randomized controlled trial demonstrated that monitoring and discussing quality of life issues with adolescent patients led to improved psychosocial functioning over time (de Wit *et al.*, 2008). A family-centered program integrated with routine clinic appointments led to improvements in glycemic control and parental involvement over a 12-month follow-up (Murphy *et al.*, 2007). In a large multi-site randomized trial, a family teamwork intervention delivered during routine clinic visits led to improved glycemic control for young adolescents (Nansel *et al.*, 2012).

Implications for research and policy

It is clear that integrated behavioral health care represents a strategy that can overcome common barriers related to access of mental health care for pediatric patients. However, more research is needed to demonstrate the effectiveness of integrated health care delivery in community settings rather than academic research settings. More evidence is also needed to show the cost offset associated with behavioral interventions for youth with chronic health conditions. An excellent example of cost offset was shown in a randomized study of multi-systemic therapy for youth with poorly controlled T1D. Young patients receiving this intervention showed improved frequency of blood glucose monitoring, improved glycemic control, reduced hospitalizations, and reduced medical costs (Ellis *et al.*, 2008). More work of this kind is required for other chronic illnesses affecting children and youth.

The idea that pediatricians should collaborate with psychologists and other mental health professionals in inter-professional health care of children and adolescents is not new (Stancin and Perrin, 2014). For example, successful collaboration has been demonstrated in the care of children with cancer (Kazak and Noll, 2015). Training models are being developed to better prepare the emerging work force of psychologists with regard to collaborative inter-professional care of young people with chronic health conditions (McDaniel *et al.*, 2014). There is a need for more research and training of health care professionals in the integrated treatment of pediatric obesity (Dietz *et al.*, 2015).

Integrating mental and behavioral health care with primary care and specialty pediatric care will require significant policy work. In the USA, mental health carve-outs imply that physical and mental health are different and should be paid for by separate health insurance systems. Health insurance for poor children in the USA is provided by Medicaid, but Medicaid is administered by states, and states vary considerably in how psychological services for poor children are managed. In most states, Medicaid does not recognize psychologists as independent health care providers, so poor children with chronic illness and mental health problems cannot typically be seen by doctoral level providers such as psychologists and instead would be seen by less well-trained therapists in a separate community mental health center distinct physically from medical care.

While there are some examples of successful integrated pediatric health care programs in the research literature, more real-world examples should be implemented. However, this will require substantial changes to the existing models of reimbursement as well as the culture of health care. European countries with single payer models of health care offer advantages toward integrated health care, but challenges remain to adequately fund behavioral and psychological services to meet the mental health needs of children and adolescents with chronic health conditions.

Conclusions

Significant numbers of children and adolescents have chronic health conditions and many experience mental health problems related to their conditions. While evidence-based treatments are available to address these problems, significant barriers impede the delivery of psychological and behavioral interventions for many youth. More controlled studies are needed to demonstrate the effectiveness and cost offset of delivering psychological and behavioral interventions for the youth with chronic health conditions, particularly in clinical and community settings. Policy reform should ensure that mental health issues are effectively addressed for children with chronic illness. Health care policy promoting integrated health care to deliver psychological and behavioral interventions in health care settings along with medical interventions should reduce barriers to care and improve both physical and mental health outcomes for youth.

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