



Mental health concerns and childhood chronic physical health conditions: a narrative review

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Background and Objective: Children who have a chronic physical health condition, whether diagnosed at birth or acquired later in life, are at increased risk for mental health issues compared to the general population. The purpose of this paper is to discuss some of the common mental health concerns related to chronic physical health conditions of children and youth and to consider some of the ways to address them.

Methods: This review is based on decades of work as a practicing clinician and investigator in the field of chronic conditions and children's mental health.

Key Content and Findings: The vast majority do well. The ongoing health condition may be viewed as a stressor that places extra challenges on both the child and his or her parents and requires parents and care professionals to help the child become resilient. Physical and mental health affect one another and therefore must both be addressed in an integrated manner. Doing this requires an honest and trusting relationship and partnership with the child and parents as they are key in the care and treatment of the child.

Conclusions: Proactive involvement by the clinician or clinical team in the care of the child in a way that integrates both mental and physical health care is highly effective in helping each child to develop emotionally and to maximize their ability to function at their full potential and become a functioning member of society.

Keywords: Chronic conditions; mental health; functioning; interventions; integrated care

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Introduction

In the past, the mental health of children and adolescents who have significant ongoing physical health conditions has not been a high priority. But today, as a result of advances in medicine that have successfully increased longevity of children with many serious physical health conditions, more children with such conditions survive. With their increased survival there has been more emphasis on maximizing their quality of life and their functioning, and as a result the care of their mental health has become a more major concern. Children with chronic conditions range from those with asthma and diabetes mellitus to those who are medically fragile or technology-dependent for essential body functions. It also includes children with complex

inborn metabolic disorders as well as those with congenital anomalies. Thus, the array of children who are included in this designation is extremely diverse and their care needs vary enormously.

In resource poor areas where there is limited accessibility to medical care, the care and survival of this group of children is a challenge. That care is not always affordable and early mortality may be more the rule than the exception. But even in resource poor areas, children with a wide assortment of relatively stable physical conditions and impairments are likely to be found in considerable numbers and to be at risk for mental health conditions that are secondary to or accompany their primary physical health conditions. Thus, the general discussion that follows applies to all these children and their families.

What is a chronic condition?

At the outset it is important to define some terms. By chronic health condition, we mean any disorder of a body part or system that is, or is expected to be, of long duration (we selected a 1-year period as the minimum) if it causes one or more consequence for a child. We define a consequence to include: (I) the need for extra health care above that usual for age; (II) dependency on compensatory mechanisms such as appliances or medication or personal assistance to function; and/or (III) a direct affect or limitation on some aspect of the child's functioning (1). This definition is generic, or non-categorical, because it does not apply to any specific diagnoses or list of conditions. The rationale for using such a broad definition is that the nature of the specific disease or disorder itself is not a key factor in determining the mental health risk or the types of services that the child and family may need (2). In saying this, we refer here to the full scope of services and care that go beyond the highly specific biological treatments or interventions that the child may need for his or her specific medical condition.

Children with chronic conditions are often referred to children with ongoing health conditions or children and youth with special health care needs. In cases in which multiple organs are involved or when the child is technology-dependent, the children are sometimes referred to as children with complex care needs. In the past some of these children have been described as children with "chronic illness", but many do not consider themselves ill (e.g., children with spina bifida or cerebral palsy) or "handicapped" children, but many do not have disorders that are disabling. All these children are at somewhat heightened risk for mental health conditions, though the evidence is clear that most will be resilient and free of serious mental health issues, even if they have some difficulties along the way.

Of course, many mental health conditions themselves tend to be chronic and therefore meet this definition and many of us believe that they are biological in origin as well. However, given the current state of our knowledge, we make a distinction that is probably artificial and characterize mental health disorders by DSM 5 criteria on the basis of their symptoms (3), rather than on our understanding of the underlying biological basis.

In this discussion we focus on those mental health issues that are secondary to or co-occur with ongoing physical health conditions, although many of the principles that

are discussed apply to significant primary mental health conditions as well. We make this distinction, despite our belief that when science finally unravels their causes, all mental health disorders will be determined to be based on physiological disorders or malfunction.

Current concepts of effects of conditions

As identified by the International Classification of Disease (ICF) (4), chronic conditions themselves affect organs or body systems directly. But, knowing about the extent of damage or disruption to the organ or body system, while key to biomedical management, may tell us little about the individual's experience of it and the ways in which it affects the child's life. Of course, immediate survival with many conditions may be a direct reflection of the availability of medical resources to address the organ or body system problem.

Assuming the condition is not immediately life threatening, individuals with the same underlying condition or diagnosis may experience its impact very differently because of variation in the ways the diagnosis alters their personal functioning. Functioning can be greatly affected by individual reactions to and determination to overcome the effects on body components. While the underlying biological causes of specific physical illness are the same across societies, function and participation (discussed below) are highly variable across individuals and communities and each person may experience a condition's effect on daily life very differently. One may experience enormous impairment while another does not. In general, function is most impacted by other aspects of the individual's biology and personality, as well as by access to appropriate medical care and compensatory mechanisms and by social factors. These in turn are dependent on resources (financial and human) and access to a broad range of services and treatments as well as by cultural norms and expectations. It is known that some characteristics of individuals, such as greater resilience and higher levels of emotional support and cognitive functioning are associated with somewhat more ability to find ways to function despite physical limitations.

Beyond individual capacity to function the ICF identifies participation as another important domain. Participation is the extent to which the individual is able to participate and be included in his or her community and society. Participation is dramatically affected by the built environment and by the social attitudes, stigma, and cultural beliefs of the people in the community in which a child lives. Depending on

the nature of the functional impairment different external factors may play the key role in whether or not a child is able to participate in a wide range of activities. For example, physical environmental adaptations such as curb cuts, ramps and single-story construction or elevator access may make a major difference for a child in a wheelchair.

Social and cultural acceptance of deviation from typicality is often specific to individual communities and the same condition may be stigmatizing in one setting, but not in another. Functioning and participation are the components that are most important in assessing the impact on the child overall and often affect the way children see themselves.

Social attitudes such as familiarity with a condition or fear of contagion may alter willingness to be inclusive. Stigma, that is disgrace associated with a particular condition or attribute, is a major reason why children with a chronic condition may be excluded from participation by others or by the child's own sense of rejection and accompanying discomfort. Some notions of stigma are specific to a particular set of religious ideas or cultural beliefs, and others are more widely held. For instance, in some societies a seizure disorder is considered a very stigmatizing condition, while in others it is considered a special endowment (5). A similar dichotomy exists in the view of sexual and gender ambiguity, which in some cultures is associated with high prestige and in other's with great embarrassment. For example, *"In many tribes, two spirit people filled special religious roles as healers, shamans, and ceremonial leaders."* (6).

It is clear from considering these factors, that how a family reacts to the diagnosis of a condition is critical to the child's own perception of themselves and self-esteem. But beyond that, it is important to consider how the immediate community, faith group, school setting and others with whom the child interacts respond to the reality of that child's chronic condition. Until the past few decades exclusion from school settings was more the rule than the exception. However, much progress has been made on this front and in many countries, there are provisions for accepting children with chronic conditions and functional impairments in schools. For example, in the United States the Individuals with Disabilities Education Act was first passed in 1975 (7) and has been renewed and updated multiple times since then. This type of legislation and the accompanying enhancement of educational experiences considerably improves the life chances of children with serious ongoing conditions and their opportunities for peer relationships, learning of academic and vocational skills and a sense of normalcy.

Epidemiology

The exact number of children who are affected by chronic conditions is unknown and is highly dependent on the definition that is used and on how it is operationalized (8). An estimated 1 in 33 infants has a congenital anomaly according to a recent WHO posting, resulting in 3.2 million children with disabilities related to birth defects every year (9). In the US estimates are that one in five children is affected by a chronic physical condition (10). It has been estimated that somewhere between half and two-thirds of individuals with a chronic condition have more than one disorder and these conditions may result in morbidity that is cumulative and may be more impactful on functioning and participation than each of the conditions individually. Thus, despite the widespread belief that childhood is a time of health, there are considerable numbers of children who do not enjoy good health. As the WHO reports:

"Congenital anomalies, injuries, and non-communicable diseases (chronic respiratory diseases, acquired heart diseases, childhood cancers, diabetes, and obesity) are the emerging priorities in the global child health agenda....The global disease burden due to non-communicable diseases affecting children in childhood and later in life is rapidly increasing, even though many of the risk factors can be prevented." (9).

Previous research suggests that overall children with ongoing physical conditions are at about double the risk for mental health issues as children without chronic conditions (11-13). Therefore, it is important to recognize the risk for mental health issues and to employ a proactive prevention approach to identifying and treating children's mental health issues early. Since the treatment goal for all these children is to improve their functioning and participation in society, achieving that goal requires care for both their physical and mental health conditions, including a conscious effort to ameliorate their risk for secondary morbidities, such as mental health conditions. Doing so requires an integrated approach that involves the family unit as partners in care and addresses both mental and physical health concerns in a seamless way. This can be done by a single clinician who cares for the child or may be done through a team approach, but either way taking a family-centered approach is of utmost importance (14).

Stages of the condition and responses to them

The time of diagnosis or recognition of a condition is often traumatic for the parents and often for the child

him or herself, especially when it is accompanied by symptoms, hospitalizations, procedures or medications that are experienced as painful or unpleasant. Whether the diagnosis comes after a long period of worry or suddenly and unexpectedly, the labeling of the health problem is likely a shock for the child and family. Most wonder what they did that might have caused the condition or that might have enabled them to avoid it. This reaction is nearly universal, though often not addressed, and it can be helpful to simply state that most families worry about this and see how the family reacts to such a statement. Our experience is that when they are told that such thoughts are common, many families reveal their concerns directly or with visible body language. Some of their concerns would be impossible to guess and address successfully without the families expressing them directly. Occasionally there is unnecessary finger pointing, but most often there is some sense of guilt (unjustified) and magical thinking, regardless of the ages of the parents or child. Younger children often see the pain of tests and illness and separation from their usual lives in terms of punishment, having little conceptual understanding of what is happening. Older children and parents often have a mix of such magical thinking and an intellectual appreciation of the irrationality of their magical thoughts.

In their overall reaction to the level of upset, children are likely to take their cues from their parents and trusted adults. It is helpful when parents can share that they are upset and wish the child were not experiencing the condition, but that they are confident that the health care professionals are going to do what they can to make it better.

Adults and older children tend to go through a fairly predictable sequence of emotional responses that have been well described. These go from initial shock to denial and then to sadness and anger. This is followed by adaptation and reorganization (15). These stages mirror the usual stages of grief. Each of these stages plays an important role in helping individuals to get to the stage of acceptance and a new normal in the final stage of reorganization. As described by Drotar *et al.* in 1975, the first stage is labelled the “shock”, an initial attempt to protect oneself from the reality of the condition and often accompanied by an inability to hear important details about the care plan. As a result, clinicians should recognize that much of what they say at the time of giving or confirming a diagnosis may not be absorbed by the family. One consequence is that information needs to be repeated in the future and often is only absorbed in small next steps. It underscores the fact that informing is a process, not an event. Denial is also protective as long

as it does not interfere with the necessary treatments. It is sometimes the only way to continue to function in the short run. One very adherent mother of a critically ill child with a poor prognosis told me “*I know what is happening, but pretending that it isn't is the only way I can get through my day.*” Sadness and anger are natural emotions that accompany the grief of accepting the change in life's expectations and the reality that the child's life will not be problem free. A sense of acceptance of a new normal accompanies the stage of adaptation. It is only when the child and family move to the final stage of reorganization that child development can proceed in a maximal way. Helping the child and parents to understand that all these feelings are common helps the individuals to normalize the situation.

Each person goes through this sequence at a different rate and it is not unusual for parents to be at different stages from one another or from the child at any given point. In addition, the members of the family may use different coping mechanisms for dealing with these emotions and one member may need to talk excessively, while the other cannot tolerate talking about it. Further, the sequence of reactions is reactivated, although usually more briefly, both by illness exacerbations such as exacerbations of symptoms or rehospitalization. They are also triggered by key developmental milestones and transitions that accentuate the differences between same-aged typical children and the child with a chronic condition.

When these processes occur in a usual way, children, even those with life threatening conditions, can thrive emotionally and can continue on the typical course of emotional development. The vast majority of children with chronic conditions do in fact thrive emotionally. For those who experience mental health conditions the majority experience periods of anxiety and depression or have attention deficit hyperactivity disorder, which not surprisingly are also the most common conditions found in the general childhood population. Other types of mental health disorders occur as well, though far less often.

Mechanisms for mental health problems

It is important to recognize the various mechanisms that may result in mental health issues for children with chronic physical health conditions. Mental health issues may arise directly as a result of the disorder, as in autism spectrum disorder or systemic lupus erythematosus (where there can be direct central nervous system effect of the disorder) or indirectly as in a syndrome (i.e., schizophrenia associated

with Velo-cardio-facial-Syndrome) that puts the individual at heightened risk for a mental health condition (16), or as a result of medication for the condition (i.e., steroid induced psychosis) or of treatments such as chemotherapy or radiation during treatment of a malignancy. Mental health conditions such as anxiety or depression can also be a result of increased stressors or what is referred to as increased allostatic load. This can be due to societal or family rejection and poor self-image, or repeated hospitalizations, especially when they involve long separations from family supports and painful or traumatic treatments and of course to any other adverse childhood experiences.

It is known that there is a higher incidence of child neglect (17) and abuse among children with underlying conditions (18). Parenting and care of children who are atypical in any way may require personal resources that may exceed those of some individuals or families. When parents are unable to meet these needs and become frustrated, children with chronic conditions may be vulnerable to abuse and neglect. This is particularly the case when there is excess fatigue and social stigma and isolation, so that support for caregivers is inadequate. This highlights an important relationship between the health and well-being of parents and children (14).

It is worth noting that parents of children with serious ongoing conditions are also at somewhat heightened mental health risk. Both their mental health and physical health can be at risk as result of their child's health condition. The latter may occur because of physical strain, such as having to lift or move a large child who needs assistance to move, or from extra work to cover costs of care and chronic emotional strain. Parental mental health issues in turn may increase the mental health vulnerability of the child, as parental mental health is an important buffer for children who are experiencing increased vulnerability.

While the presence of mental health risk among children with chronic conditions has long been recognized, the recent subspecialty literature is rediscovering the higher rates of anxiety and depression on a condition-by-condition basis (19,20). This is occurring long after it had been demonstrated among children and youth with ongoing health conditions on a population basis (2,11,12).

The interrelationship between physical and mental health among children and youth with chronic conditions

We have already discussed the fact that poor physical health

puts individuals at risk for mental health problems. But this is a two-way relationship. It is quite clear that mental health problems may present with physical complaints such as somatization as a manifestation of anxiety. This may complicate diagnosis and management of chronic health conditions, especially when they coexist (21). In addition, mental health conditions may also significantly affect the outcomes of physical health conditions. For example, it has been known for many years that failure to address mental health issues leads to higher rates of rejection of kidney transplants (22), worse control of diabetes mellitus (23), and more asthma exacerbations (24) as well as a whole range of other morbidities. Therefore, the implications of mental health problems among children and youth with chronic conditions is not just important for the purposes of recognizing their mental health risk so it can be addressed. But it is actually key to their overall physical as well as mental health outcomes. In particular it has been demonstrated that patients with depression are more than three times less likely to be adherent to medical treatment (25). Moreover, the evidence is strong that intervening and treating their mental health issues can actually change the physical health outcomes for the better. The importance of this was highlighted in a meta-analysis of behavioral treatments of mental health conditions for children with chronic conditions by Kahana *et al.* (26), and in a review of psychosocial interventions (27).

Assessment of the child's mental health

The ways in which mental health conditions of children with chronic conditions are manifest depends on the age of the child. As with other children, those who are younger will mostly be recognized as having emotional distress based on their acting out or withdrawn behavior, while older children and adolescents often experience internalizing as well as externalizing (and obviously disturbed behavioral) symptoms. In particular their internalizing disorders may be well hidden, unless they are specifically assessed. Optimally the mood and behavior of children with chronic conditions will be noted and changes will prompt evaluation. Additionally, children should be screened by the clinician who is following them on a regular basis as their primary care physician or medical home, if one is available. In many places, however, children with ongoing conditions are followed closely by subspecialists, who may be unaware of mental health screening recommendations. This may be especially the case in areas where children with ongoing health conditions are treated primarily by subspecialists

who mostly take care of adults. Failure to do screening at regular intervals results in lost opportunities to head off problems in the early stages. When a concern is raised or screening is failed, it is usually necessary to get detailed information directly from the child as well as the parents about the child's baseline behavior and emotions. Parents or other caregivers know the child best and are often able to help provide critical information about the child's mood and behavior over time.

One of the critical issues is that some instruments that are used to screen and or diagnose these conditions may include symptoms that can either be caused by mental health issues or may be manifestations of their underlying conditions and/or their medications. For example, being anxious and having shaking may be a symptom of too much albuterol for asthma or of hypoglycemia or hyperthyroidism, rather than of anxiety (28,29). This can significantly affect the ability to identify these issues and may lead to either under or over diagnosing mental health issues. Another concern is that many of the most commonly used screening tools have not been validated with children who are cognitively impaired or have life experiences that are very atypical.

Key issues in the management of children with serious ongoing health conditions and their families

A key issue in the management of these children and their families is gaining their trust. This requires open communication and honesty, which is highly recommended by a body of evidence, but is not always culturally acceptable. Honesty includes the difficult task of sharing uncertainty, which is common in caring for children with serious conditions. It is also a feature that families find among the most challenging (30). We know, for example, that conditions that fluctuate unpredictably are more difficult to deal with, than those that are more significantly, but stably, impairing.

Communications with the child should also be honest and be adapted to the child's developmentally-appropriate ability to understand what they are experiencing and why. Simple explanations about trying to help the child, relieve symptoms, or treat the condition go a long way toward enabling the child to participate constructively in care. Providing the child simple choices (i.e., which arm would you like me to try first for your IV?) allows the child to experience some sense of control and of mastery. It is also important to provide anticipatory preparations for

hospitalizations, procedures or new experiences and the necessary scaffolding to make the experience as successful as possible.

Another factor that is extremely important is to adopt a strength based, rather than a deficit model in providing care. This involves aggressively taking note of and pointing out strengths, assets and mastery, as well as the deficits that clinicians are always focused on remediating. Doing this applies both to the child and to the caregivers, whose hard and often frustrating roles can be overlooked or taken for granted. Additionally, the family should be encouraged to minimize the areas of daily life that are disrupted or in which the child with the condition is treated specially. For example, many parents instinctively overprotect or spoil children with chronic conditions, giving them special treats or treatment compared to siblings, or imposing fewer rules or expectations for doing chores. Yet we know that limit setting, having rules and enforcing them and doing chores all help children to feel protected and valued and to enhance their self-esteem. Expecting the child with the chronic condition to participate as fully as possible is important for his or her sense of security and of mastery and helps to optimize development and functioning. Part of a strength-based model is treating the child as normally as is possible and only giving special rules or treatment when it is medically necessary.

Treatment of mental health conditions in the context of physical illness

One of the challenges of treating mental health conditions in the context of ongoing health problems is the sense that the family and child often have of yet another problem or complication. This can make referral for treatment even more challenging than with the population at large. One major strategy for avoiding this issue is to integrate mental health professionals as a routine part of the health care team for the child with a serious ongoing condition from the beginning. Making the care of mental health part of the regular package of specialty services enhances both the chance of regular screening and early detection and the availability of preventive interventions and therapeutic treatment on an as needed basis. It also makes the receipt of services by children and families much more acceptable and convenient as opposed to requiring them to go to yet another appointment or venue. There is evidence that psycho-social interventions that provide integrated comprehensive care are effective (26,27) and that families

appreciate the support that they provide (14).

Of note is that there is little correlation between the severity of the physical and mental health conditions in the presence of strong family support (31). Mental health conditions are more likely to be buffered by the level of support and protective factors or exacerbated by other types of stresses and burdens (2,13,14,24).

Another factor to consider is the efficacy of mental health treatments for children and youth with chronic physical health conditions and mental health issues. A recent review underscores the lack of well-done studies to confirm that treatments are as effective in the presence of a physical health condition as for other children and youth, though there is no inherent reason that they should not be (32). In addition, sometimes pharmacological treatments for the primary condition and for the mental health problem may interact and clinicians should always check these potential drug interactions.

Role of the family and their risk

Although not the main focus of this paper, it is important to recognize that there are significant impacts of a child's serious illness on parents and that their mental health needs also need to be addressed. Inherently, having a child with special health care needs extends the role of parents to care for and protect their child and in many instances, this results in a blurring between their roles as parents and roles as caregivers (33). It is also important to note that parents of children with chronic conditions may also experience anxiety and depression that may also interfere with the emotional health of the children and increase their mental health risk and risk for poor adherence to therapeutic recommendations. The physical and mental well-being of children is significantly affected by the health of parents and this is even more apparent in among children with chronic conditions, who are often more dependent on their parents' capacity to meet many extra demands of parenting. Much evidence underscores that caring for the caregivers as well as the child is key to helping the index child to thrive. Further, when their physical and mental health needs are not addressed the outcomes of all are compromised. Parents need support and help and permission to invest their time and effort in themselves and their other children as well as in the child with a physical health concern.

It should be noted that while some parents amaze clinicians by their strength and commitment to extreme care needs of their child with a chronic condition, others may

find the stress too great. In some cases, this may result in their relationship being strained to the point of separation, abandonment, or divorce. The extent to which this occurs has been extremely contraversial and many families report that these stresses have increased their family's cohesiveness and strength. It is worth underscoring that when the parents are not together, whether at the outset or subsequently, it behooves the health professionals to try to involve both parents and to keep them both informed. In instances of shared custody or visitation this extra effort may be lifesaving.

Siblings of children with chronic health conditions may experience a range of emotional reactions, from jealousy and resentment for all the special attention the child with the chronic condition is given, to pride and enhanced self-esteem as a result of their role in helping with the care and supervision of the child with the health condition. They too may experience mental health risks and parents should be encouraged to monitor and attend to their needs as well.

Closing thoughts

Integrating mental and physical health care is a challenge, but it is key to improving the long-term prognosis and quality of life of children with chronic conditions. It behooves all those who are involved in the care of children with chronic physical health conditions to take an integrated family-centered approach and partner with families in caring for children's physical and mental health in order to optimize their care and their future health and well-being.

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