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Factsheet 19

Mental health issues in children and young adults with CHARGE syndrome

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'Mental health' can be a challenging thing to define. For some, it would be the absence of 'mental illness', while for others it would mean functioning at a high degree of wellness. A major problem for parents of children with CHARGE is how to make sense of their child's behaviour and understand the various psychiatric diagnoses which are often given.

Unusual and sometimes challenging behaviour is common in individuals with CHARGE (Hartshorne and Cypher, 2004). This is not surprising given the rate of psychiatric illness in the intellectually and developmentally disabled population (Wachtel, 2011). There are two probable reasons for this (Harris, 2006):

- The neurobiological factors that cause the disability may also be a factor in the development of a psychiatric disorder.
- The psychosocial stressors the person with disability experiences might predispose them to psychiatric illness.

Harris (2006) lists a number of problems that increase the vulnerability of individuals with intellectual and developmental disabilities for psychiatric illness: capacity to cope with social or cognitive demands, problem solving difficulties, poor conflict resolution skills, poor social judgment, and communication problems. He also notes the lack of willingness on the part of some professionals to provide treatment.

Psychiatric diagnoses in CHARGE

Wachtel *et al.* (2007) asked parents what psychiatric diagnoses, if any, their child with CHARGE had been given. Of 87 responses, 32 listed at least one diagnosis.

The most common diagnostic category was anxiety disorders identified in 17 children with a further 15 children diagnosed with Obsessive Compulsive Disorder (OCD). The next most common was Pervasive Developmental Disorder (PDD) with 14 children, including 8 with autism. There were 11 diagnosed with ADHD/ADD.

Eighteen of the children had only one diagnosis, but one had five including Autism, Aspergers, PDD, ADHD and Oppositional Defiant Disorder (ODD). It is interesting to note that Autism, Aspergers and PDD all fall into the same diagnostic category and would rarely be diagnosed in the same individual.

Difficulties in diagnosis

Mental illness is diagnosed by a system of categories based on behavioural symptoms. When individuals, such as those with CHARGE, demonstrate behaviour which is consistent with those encompassing the definition, it is tempting to give them the diagnosis. For example, without going into detail, Autistic Disorder is diagnosed by the presence of three characteristics: problems with social interaction, impairments in communication, and repetitive and stereotyped patterns of behaviour (American Psychiatric Association, 2004).

Children with CHARGE have problems with social interaction. However, this difficulty may not be due to their lack of interest or ability to be a friend, but to the difficulties inherent in having disabilities. Hartshorne *et al.* (2005), found that compared with individuals who have autism, children with CHARGE were more interested in social contact and relating. But they may be socially excluded by their peers.

Children with CHARGE often have communication challenges. This can be due to sensory impairments and sensory integration difficulties. The Autism diagnosis is based on children who have intact sensory systems. Repetitive and stereotyped behaviours are quite common in children with CHARGE, as they are in children with vision impairment generally.

The OCD behaviours we see in CHARGE are very similar in nature to repetitive and stereotyped behaviours, and so their expression may be due to OCD rather than Autism. If one wants to classify a child with CHARGE as Autistic, there is reason to do so based solely on the behavioural symptoms – but such a diagnosis may then mask what these symptoms represent in the child.

Making the correct diagnosis

On the other hand, it is certainly appropriate in certain cases to apply a psychiatric diagnosis, including Autism, to someone with CHARGE. Whether one should do so or not depends on what happens next. Does the diagnosis lead to appropriate treatment planning or to unhelpful interventions?

Myrbakk and Tetzchner (2008) looked at psychiatric disorders in individuals with mild-to-moderate versus severe-to-profound cognitive impairment, and with or without behaviour problems. While psychiatric illness was more common in those with behaviour problems, it is interesting that depression was associated with aggression, tantrums, and screaming in the group with severe to profound intellectual impairment, and associated with tantrums and self-injury in the mild to moderate group.

These kinds of findings are important because one might be tempted to assume that aggression and tantrums, for example, were due to Oppositional Defiant Disorder, while in particular populations they may be related to something else.

With CHARGE it is important to understand what particular behaviours may mean, because all behaviour is communication, and many individuals with CHARGE have behaviour as a major form of communication. We do not know if aggression and tantrums expressed by someone with CHARGE mean depression, or ODD, or even pain. But we must use psychiatric diagnoses very carefully so that we do not misunderstand the nature of the symptomatic behaviour.

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