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Psychosocial Implications of DSD Treatment for Parents

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Abstract

Purpose of the review—Historically, studies of caregivers of children with DSD have been limited.

Recent findings—Recent data reveal that parents of young children with DSD report increased stress, anxiety, depression and decreased quality of life (QoL) in ways that are similar to parents of children with other types of chronic illnesses. Also similar to other chronic illnesses of childhood, parents of children with DSD exhibit overprotective parenting and perceive their child as being vulnerable. These emotions and behaviors exhibited by parents are concerning as they may limit an affected child's emotional and social development over time. Perhaps more unique to the situation of DSD is the perceived, or real, child-focused stigma experienced by parents of children with DSD.

Summary—Interventions to improve parents' psychosocial adaptation to their child's medical condition, including coaching in how to discuss their child's condition in a manner that makes them feel safe and supported, are needed to optimize outcomes for families.

Keywords

intersex; parenting; caregiver; stigma; chronic illness

Introduction

An extensive literature highlights the reciprocal relationships that exist between chronic illnesses in children with family functioning and parents' psychosocial status. Day-to-day care of a chronically ill child affects family finances and dynamics, as well as caregivers' levels of anxiety, stress, depression and quality of life (QoL). Additionally, caring for a child with a chronic illness influences parenting capacities. Importantly, family finances, parenting capacities and psychosocial functioning of caregivers influence health outcomes of children with chronic illnesses [1]. In studies that include both parents, mothers typically report a greater impact of their child's illness on their mental health and it is presumed that this is because mothers typically assume the "burden of care" for their affected child [2].

Disorders of sex development (DSD) refer to a group of conditions in which discordance exists between genetic, gonadal, hormonal and/or anatomical sex. Some types of DSD are

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associated with ambiguous external genitalia at birth while others are not. Some, but not all, types of DSD are life-threatening without appropriate medical treatment. Additionally, some types of DSD are associated with decreased fertility potential [3]. Thus, parents may find different aspects of their child's DSD diagnosis and associated treatment options distressing. Furthermore, because the presentations of DSD and natural histories associated with this group of conditions vary between diagnoses, parents can have a range of reactions to their child's health and development. Despite the desire of many parents of children with DSD to receive mental health support [4], only recently have researchers prioritized studies to better understand how raising a child with DSD impacts caregivers' psychosocial status [5]. A summary of what is known about parents' reactions to their child's diagnosis and treatment options is offered here, along with suggestions for applying this information to improve adaptation for parents and their affected children.

Anxiety, depression, stress and QoL in parents of young children with DSD

Similar to parents of children affected by other chronic illnesses, mothers of children with DSD report greater stress than fathers [6]. Stress levels for both mothers and fathers of children with DSD are similar to those reported by parents of children with cancer soon after learning of their child's diagnosis [7]. Mothers report more stress if their young child with atypical appearing genitalia has not yet received genitoplasty [8], and both mothers and fathers report reduced stress 6 months after their young child with ambiguous genitalia received surgery to "normalize" their appearance [9]. This does not necessarily mean that genital surgery is the optimal treatment for ameliorating stress in parents of young children with atypical genitalia; however, it illustrates the need for parents to receive help to deal with their negative reactions to their child's genital phenotype.

Increased stress relates to higher levels of anxiety and greater depression in parents of children with DSD [10], and these factors are associated with decreased mental health QoL for these caregivers [7]. Currently, researchers are attempting to understand how to best support caregivers of children with DSD with resources and education to reduce their anxiety and depression in an effort to ultimately improve their QoL. If successful, then it will be necessary to determine if improved parent psychosocial functioning translates into improved physical and mental health outcomes for affected children.

Parenting capacities and DSD

Parenting capacities refer to parents' behaviors toward, and beliefs about, their child. Parents of chronically ill children are at increased risk for maladaptive parenting practices that are in turn associated with poor behavioral and social outcomes for their children [10]. For example, parents of children with DSD are at risk for overprotective parenting and perceived child vulnerability [11]. It is important to note that parenting capacities are intertwined with previously discussed negative emotions such as anxiety. Specifically, perceived child vulnerability is associated with increased anxiety for parents of children with DSD [10].

In general, parents of children with atypical genital anatomy are dissatisfied with their child's appearance at birth [7], and as a result these parents view their child as being

vulnerable to being teased [12]. An educational intervention for parents of children with atypical genitalia that includes instruction on how to discuss their child's anatomy in a way that both respects their child's privacy while educating other friends and family members appropriately might reduce overprotective parenting and perceived child vulnerability among caregivers. One way to accomplish this is to listen to other parents' recounts of how they discussed experiences such as diaper changes with people outside of their immediate family [13]. Learning from real examples provided by parents who have experienced similar concerns can be both enlightening and comforting to parents who are new to these challenges.

Parent-reported stigma

Overall, parents of children with DSD report greater child-focused stigma than parent-focused stigma. Mothers report more child-focused stigma than Fathers, although a significant proportion of both parents report moderate to high levels of this. Predictors of increased child-focused stigma include delayed gender assignment, atypical genital appearance at birth (particularly in boys) and discordance between genetic sex and sex of rearing [14].

Interviews with parents of pre-pubertal children with DSD reveal that they often do not tell others about their child's condition and also avoid participating in social interactions that may lead to discovery of their child's genital ambiguity or history of genital surgeries [15]. Parents report the perceived (or real) threat of ridicule of their affected child as the reason for voluntary exclusion from typical activities such as daycare and play groups. Thus, child-focused stigma exerts a negative impact on caregivers' social support and reinforces isolation among family members.

Targeting support for parents who exhibit the greatest needs

Parents of children with 46,XY DSD report the greatest need for psychological support, and this need is amplified when their children exhibit cross-gender behavior [4]. Parents of children with 46,XY DSD are also more likely to decline to participate in research studies, making it difficult to understand their specific needs and concerns. For those who do participate, these parents are more likely to perceive their children as vulnerable compared to parents of children with 46,XX DSD [11]. Additionally, parents of boys with DSD report increased illness uncertainty compared to parents of girls [7]. Thus, while all caregivers of children with DSD should have access to mental health resources and support, the limited data that exist at this time indicate that individualizing support according to type of DSD and sex of rearing of an affected child is warranted. As we learn more about the real life experiences of caregivers of children with DSD, an even more personalized approach to delivering support that translates into improved psychosocial adaptation and QoL for parents is possible. It is hoped that by achieving this goal, psychosocial adaptation and QoL of the affected children will also be optimized.

Conclusion

Raising a child with DSD can be a stressful and isolating experience that negatively impacts psychosocial adaptation and parenting capacities for caregivers. Certain caregivers, such as mothers and parents of children with 46,XY DSD, are at increased risk for elevated stress, anxiety and depression, as well as decreased QoL. Perceived, or real, child-focused stigma is often cited by parents as a reason for not seeking help and support from their network of family and friends. Evidence is starting to accumulate to allow for personalized approaches to provide support and education from the mental health community to caregivers of children with DSD.

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Abbreviations

DSD	disorders of sex development
CAH	congenital adrenal hyperplasia
21-OH	21-hydroxylase
QoL	quality of life

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Key Points

1. Because the presentation and natural history of conditions categorized as DSD vary widely, parents responses to their child's DSD diagnosis and treatment options also vary widely.
2. Parents report increased stress, anxiety and depression, as well as decreased mental health QoL, in relation to their affected child's atypical genital appearance.
3. Parents perceive their child with DSD as vulnerable to teasing and thus exhibit overprotective parenting practices that may in turn result in poor social and behavioral outcomes for their child.
4. Perceived or real threats of ridicule or stigma concerning their child's DSD results in parents' voluntary exclusion from social support from friends and family.
5. Preliminary evidence from studies of parents of children with DSD indicate that a personalized approach to providing them with mental health support is possible.