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Psychological Problems in Parents of Children with Orthopedic Pediatric Congenital Disorders

Hilmi Muhammad¹, Anung Budi Satriadi², Hendra Cahya Kumara², Zaky Asad Alhaq¹

¹Orthopedics and Traumatology Division, Department of Surgery, Faculty of Medicine, Public Health, and Nursing, Gadjah Mada University/ RSUP Dr. Sardjito, Yogyakarta, Indonesia

²Department of Orthopedics and Traumatology, Sebelas Maret University/Prof. Dr. R. Soeharso Orthopedic Hospital Surakarta

ABSTRACT

Background: Parenting a child born with a congenital disorder can be very unsettling and stressful for a long period of time. It takes patience, strength, and fortitude as well as a high sense of attention. Parents of children with congenital disorders are expected to collaborate along with healthcare professional and expect to receive support in return. Other than the medical team, parents are hopeful to find acceptance and comfort from the community around them. However, information regarding congenital disorders in society may not be as easily understood which limits their responses.

Main Discussion: This review explores the psychological issues faced by parents of children with congenital disorders of the musculoskeletal system. It is only natural for parents to experience emerging feelings of distress after knowing the unexpected truth. The additional care required for the child's medical and social aspects adds to the parent's personal and emotional baggage. Either by stigmatizing or providing support, society's response to the child with congenital disorders is pivotal to determine the mental health of these parents. Eventually, the coping mechanism opted for by parents might affect their decision making process and eventually, the quality of care they provide for their child.

Conclusion: By recognizing the potential roots of distress one family might endure, healthcare professionals are expected to provide holistic and comprehensive services for parents of children with congenital disorders, including their psychological state.

Keywords: psychology, parents, congenital disorders, orthopedics

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Corresponding author : Hilmi Muhammad, MD. Email: hilmimuhammadortho@gmail.com

INTRODUCTION

One of the basic desires as a human being is to be accepted by society and interact with other individuals. In the past, individuals born with congenital disorders were segregated as their differences were stigmatized by society. The ancient Greeks perceived having a congenital disorder as a form of punishment from God or as a retribution for evil behavior in a past lifetime. The ancient Romans apparently held a similar viewpoint, as they were apparently instructed to murder babies born with congenital disorders.¹

Children with congenital disorders were seen as embodiments of the devil and were linked to parents who practiced black magic throughout the Middle Ages.² Around the same time, Martin Luther also considered devil reincarnation in the form of a congenital disorder and recommended killing the child.¹ As we entered the 19th century, a shift of attitude toward congenital disorders by ruling out these superstitious explanations and associated these congenital differences with environmental factors from study results instead.¹

Parenting a child born with congenital disorder can be frustrating and a continuous source of stress. In addition to the common duties of caring for young children, these parents are also faced with different expectations from the birth of a healthy and normal child.

PARENT'S INITIAL REACTION

According to Drotar *et al.* in 1975, parents would react in 5 different stages when they welcome a child with congenital disorder which include shock, denial, sadness, anger, adaptation and reorganization (Figure 1).^{3,13} The first state of shock is often accompanied by feelings of guilt, sadness, and hopelessness.⁸ Parents of a child with congenital disorder diagnosis may feel waves of emotions comparable to those with suicidal thoughts, and the extent of distress felt by parents, particularly mothers, may even continue to depression.¹² Compared to mothers whose children have no such diagnosis, a congenital abnormality diagnosis serves as an extra emotional burden for parents. According to Sapkota *et al* (2017, p. 29) children raised by depressed mothers showed developmental disturbances compared to other children.¹²

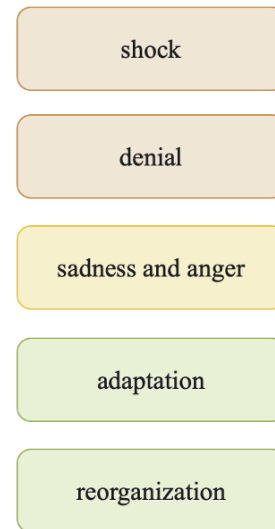


Figure 1. Five stages of parenteral reaction

The sooner parents, especially mothers, recognizes their children could possibly have a congenital disorder, the better their coping mechanism will be, which is essential in determining family's perception and acceptance for the diagnosis.¹¹ A survey study by Skotko (2005, p. 71-2) reported a direct testimony from a mother who received printed medical information regarding their daughter's condition from a social worker and would much preferred to obtain the information straight from their doctor.¹¹ Thus, providing prompt counselling sessions for these parents is a critical intervention point.



Figure 2. Clubfoot Deformity

PSI-SF subscale	Typical Stress Percentile	High Stress Percentile	Clinically significant Percentiles
Parental Distress (PD) - Reflective of adjustment to parenthood	15-80	81-89	90-100 Referral to community support
Parent-Child Dysfunctional Interaction (P-CDI) - Reflective of bonding with child	15-80	81-84	90-100 Referral for professional intervention
Difficult Child (DC) - Reflective of self-regulatory processes (physical or temperamental problems) or child's cooperativeness	15-80	81-89	90-100 <18 months old Referral to <u>pediatrician</u> ≥ 2 years old Referral for professional support
Total Stress	15-80	81-89	90-100

Table 1. PSI-SF guide and interpretation

IMPACT OF OBLIGATION IN DECISION MAKING

Inadequate explanation of the condition to parents may negatively impact a future child's care plans. Collaboration between parents and medical team is pivotal in coordinating follow-up care and is expected to be achieved through thorough education of the disorder.¹⁴

A study conducted by Beresford *et al* (2007, p.2) reported that most parents' main goal is to ensure their children can become self-reliant in their activities and for themselves to have a balanced life between being a caretaker and as an individual.⁴

Rosenberg *et al* described that the more visible the child's condition, the higher the level of stress their parents are enduring.¹³ A similar result is expressed by Bawalsah (2016, p.16) where the severity of physical dysfunction in children is positively related to stress occurring in parents.⁵ In contrast, a qualitative analysis by Cousino and Hazen (2013, p. 821-2) reported that parenting stress was not related to children's illness period or severity but rather associated with the responsibility for managing the disorders' treatment and their poorer ability to adjust psychologically.⁶ Orthopedic congenital disorders, such as those in the hands and feet, have the possibility of increasing stress related to physical appearance disorders, making parents actively seek treatment and medical care.¹²

Regarding parents' medical decision-making for their children, Madrigal *et al.* (2012, p. 2876) concluded that parents tend to participate in a collaborative role with the medical team (semi-active or collaborative role).⁷ Although parents do want to have a thorough understanding of and coverage for their child's congenital disorder care, they do not want to take over the roles of healthcare professionals but rather seek support when parents implement their acquired skills.⁴ The Parenting Stress Index (PSI) and its shorter form, the PSI-SF, are available to evaluate stress level through questionnaire components reported by the parents themselves (Table 1). In parents with a higher Parenting Stress Index (PSI) score, however, medical decisions were taken over by the mothers instead (active role). Kim *et al* (2019, p. 7-8) rationalized this significant association of an active decision-making role with a higher stress level due to maternal guilt and an attempt to make amends to her own feelings.¹³

ASPECTS OF PARENTAL BURDEN

Medical and rehabilitation services are just the tip of the iceberg of financial strain that may impose on parents' funds. Depending on how parents seek treatment, "doctor shopping" or even seeking non-medical treatments such as those offered by faith healers adds to the extra costs associated with caring for children with congenital disorders.¹² Parents with small incomes or even those who do not have insurance protection



Figure 3. Congenital tibial hemimelia which affect child's mobility

certainly have a much higher stress level. Beresford *et al* (2007, p. 4) highlighted the importance of providing parents with funding services in order to safely maintain financial support for the special-needs child.⁴ The family economy would also be weighed down by the additional assistance parents might need in providing long-term care for their children with congenital disorders. Other than basic medical and rehabilitation assistance, parents may need help in the developmental areas of a child, including social and emotional development, academic progression, and independent living skills.⁵

Parents may receive assistance in one area but not in others. Although parents tend to seek psychological and emotional support from friends or other family members, they will not necessarily feel comfortable asking for their time to take care of their children or other domestic duties in order to personally rest.^{4,8} It is important for parents to identify the strengths and weaknesses of their support system and then develop novel approaches to bridge the gaps that exist. Reminding parents of patients that doing what is best for their child with a congenital disorder does not mean doing everything by themselves is important.

ADAPTATIONS AND COPING MECHANISMS

As there is no specific way to react when welcoming children with congenital disorders into a household, a combination of patience, strength, and a high sense of attention should be the basis of this personalized approach. As time goes by, parents will try to adapt and find new ways to interact as a family. By acknowledging the different reactions of family

members, openness allows lingering cynical thoughts to be released. In response, active listening between family members is key to helping parents rearrange their emotions and allowing them to provide proper care to these special children with a clear head.^{1,8}

Mothers of children with congenital disorders must make many changes in their lives to be able to meet the needs of attention and care for their children. Heiman (2021, p.648) reported confession by one of the mothers with special need child, the dynamic in parental relationship shifted as the mother of became sole primary carer of the child whilst the father ensures financial income to support the family." Frustration and exhaustion are commonly expressed by mothers with this parenting arrangement, as they feel limited in their ability to live their own lives.⁸

An important source of coping mechanisms for stress is social support. Social support is as important in reducing stress, boosting trauma resilience, and lessening hardship.⁹ The presence of another individual could improve the self-confidence of the parents, especially when the attention came from those who are expected to give help, such as extended family members.⁸ Farrell and Corrin in Mason *et al* (2001, p.55) suggested the benefits of social support groups that promoted extensive information regarding congenital disorder conditions, obtaining a sense of acceptance by society, and strengthening healthy coping mechanisms so parents would not feel lonely facing their child's congenital disorder diagnosis.^{1,10}

SOCIAL STIGMA AND HEALTH CARE PROFESSIONAL ROLE

Society's stigma towards children with congenital disorders is one of the most influential factors in the



Figure 4. Preaxial polydactyly is frequently stigmatized due to appearance abnormality

psychological health of their parents.¹ Parents may be reluctant to admit the embarrassment they feel is unavoidable. However, the rejection and exclusion that their children had to endure hurt them the most, especially when they reach school age and social interaction becomes a child's way to make friends.⁸

Community preparedness in responding and accepting children with congenital abnormalities maybe insufficient to provide the already-stressed parents the reassurance they needed.¹ Benjamin in Mason *et al* (2001, p. 68) pointed that due to high level of burden in parents' mind may perceive obtained sympathy into a pitiful act.¹⁵ Thus, it is important to provide parents of children with congenital disorders with the adequate psychological and emotional support they are seeking by assessing their stress level.

Other than relaying comprehensive medical information regarding their child's condition, healthcare professionals are responsible for ensuring the caregivers' physical and mental health. After all, the caretakers, which in most situations would be the parents, will be the ones looking after the child. By informing parents of suspected or found abnormalities within their child and the possible diagnosis as soon as possible and providing multidisciplinary support are ways a healthcare professional can do to reduce stigma. Combining a sense of empathy with knowledge and skills in providing sensitive care reminds us that humanity should live within the hearts of healthcare professionals too.¹⁵

CONCLUSION

By recognizing the potential social stigma a family might endure, healthcare professionals are expected to provide holistic and comprehensive services for parents of children with congenital disorders, including their psychological state. Early provision of information regarding the child's condition, even when it is still a suspicion, might prepare parents to develop better coping mechanisms. Communication skills are key when delivering the news, as it is a very sensitive subject. As trust is built between caretakers and healthcare professionals, it is hoped that children with congenital disorders may receive proper collaborative care for their condition.

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