

REVIEW ARTICLE

A Framework for Resilience Research in Parents of Children with Developmental Disorders

Kota SUZUKI¹⁾ Tomoka KOBAYASHI^{1) 2)} Karin MORIYAMA^{1) 3)}
Makiko KAGA^{1) 4)} Masumi INAGAKI¹⁾

1) Department of Developmental Disorders, National Institute of Mental Health,
National Center of Neurology and Psychiatry (NCNP)

2) Department of Pediatrics, Social Health Insurance Central General Hospital

3) Graduate School of Humanities and Social Sciences, University of Tsukuba

4) Tokyo Metropolitan Tobu Ryoiku Center

Abstract

The challenges of rearing a child with developmental disorders are associated with high levels of parental stress, depression, and other negative emotions. Thus, clinicians frequently set one of the intervention goals to be parent adaptation to such challenges, which we call parenting resilience for rearing children with developmental disorders. In this article, we reviewed research on general resilience and mental health in parents of children with developmental disorders and proposed a construct of parenting resilience for this population. In our framework, parenting resilience is defined as the process of positive adaptation to the difficulties of rearing children with developmental disorders and consists of internal (e.g., positive perception, skill, coping style, and efficacy) and external (e.g., social support) factors. We discussed future directions for the application of parenting resilience in parents of children with developmental disorders.

<Keywords>

resilience, parents, developmental disorders, developmental disabilities,
developmental psychology

Received
August 30,2013

Accepted
October 12,2013

Published
October 30,2013

kt.suzuki@ncnp.go.jp (Kota SUZUKI)

Asian J Human Services, 2013, 5:104-111. © 2013 Asian Society of Human Services

I. Introduction

Rearing children with developmental disorders such as autism spectrum disorder (ASD) or attention deficit hyperactive disorder (ADHD) requires psychological and physical demands, effort, time, and energy. These experiences pose unique challenges for parents, which may cause stress or mental illness (Kogel et al., 1992, Breen & Barkley, 1988). However, not all parents of children with developmental disorders are adversely affected by these challenges and most adapt well to this role.

Adaptation to rearing children with developmental disorders is often an intervention goal when the child, family, or both are receiving therapy services. Hence, it is important for interventions to clarify the process of adaptation and its associated characteristics. The process of adaptation is thought to refer to resilience, which has been studied in several domains (e.g., poverty, disaster, death of partner).

The aim of this article is to apply the concept of resilience to the domain of parents of children with developmental disorders, which we call “parenting resilience.” We begin this article with a brief overview of the construct of resilience. Then, we propose a construct of parenting resilience for parents of children with developmental disorders.

II. A brief review of resilience

Resilience is typically comprised of two parts: 1) exposure to adversity and 2) the achievement of positive adaptation (Luther et al., 2000). That is, resilience refers to the process or phenomenon of positive adaptation to adversity.

Pioneers in resilience research discussed resilience in their cohort studies (Rutter, 1976, 1985, Garmezy et al., 1984, Werner, 1989). These cohort studies traced the development of children exposed to conditions thought to be associated with poor developmental outcome. Some of the children who adapted well to the conditions were called “resilient” children and their characteristics were examined. The concept of resilience has been applied to various domains since these pioneering studies. For example, Bonanno investigated adult resilience after the death of partner (Bonanno et al., 2005) and high levels of exposure to terrorist attacks (Bonanno et al., 2006). Walsh (1996) and Hawley & DeHaan (1996) extended the concept of resilience from the individual level to the family level.

There is a weak relationship between results of resilience studies in different domains. Bonanno (2005) proposed that the construct of resilience is different in adults and children. These findings are reasonable, because adversity and environment vary among domains, which, in turn, influence the adoption of positive adaptation. On the other hand, domain specificity is more useful in practice than a global definition of resilience (Kathleen & Dyer 2004). In addition, the definition of diversity can lead to varying conclusions despite similar risk groups (Luthur et al., 2001). Therefore, in the

following sections, we propose a definition of parenting resilience as it relates to developmental disorders from the perspectives of “adversity” and “adaptation.”

III. Adversity

Overall, parents of children with developmental disorders show higher levels of stress, depression, and other negative emotions than those of typically developing children (Koegel et al., 1992, Breen & Barkley, 1988). Thus, the experience of rearing a child with developmental disorders can be an adversity.

However, the severity of symptoms due to developmental disorders does not always negatively influence parental emotions. General behavior problems are strongly associated with negative emotions in parents rather than symptoms (Hasting et al., 2005, Harrison & Sofronoff, 2002). These findings suggested that the rearing difficulties associated with children who have developmental disorders are related to their behavior problems. As a result, parents seem to show high levels of stress, depression, or distress. Therefore, the challenge of rearing children with behavior problems is considered to be an adversity for parents of children with developmental disorders.

Several articles reported that the diagnosis of developmental disorders leads to a parental crisis (e.g., impact, denial, grief, focusing outward, and closure; Fortier & Richard, 1984). Even after adapting to the diagnosis, most parents suffer chronic sorrow, and, in some cases, regress to the point of denying the diagnosis (Olshansky, 1961, Nakata, 2002). On the one hand, it is possible that a parent adapts to the difficulties of rearing a child with developmental disorders despite suffering chronic sorrow. Hence, we propose that parenting resilience is independent of chronic sorrow.

IV. Adaptation

Although high levels of stress were reported in parents of children with developmental disorders, they do not seem to report fewer positive perceptions (Hasting & Taunt 2002). Some of them described very positive feelings associated with their experience of rearing children with developmental disorders. Hasting & Taunt (2002) suggested that the positive perception functions to help parents adapt to the difficulties of rearing the child.

Adaptation is sometimes accomplished through intervention. In treatment of child behavior problem, clinicians intervene with not only children but also parents. Parent training programs are some of the most well-established and widely used interventions with parents, designed with the aim of reducing child behavior problems and improving parent competence for handling challenging behaviors. Pisterman et al. (1992) reported that the benefit of parenting training extended to parental mental health, suggesting that the acquired skills enable parents to adapt to the difficulties of rearing the child.

In our operational definition, we assume that “adaptation” signifies stable mental health, and that this is determined by internal (e.g., positive perception and skills obtained during parenting training) and external (e.g., social support) factors. In the following section, we also review other factors that may lead to adaptation.

V. Possible factors of resilience

A construct of resilience generally includes internal and external factors. For example, Werner (1989) examined resilient children exposed to adversities (e.g., poverty, perinatal stress, and parental psychopathology), and found that resilience was associated with internal factors (e.g., activity level and sociability) as well as external factors (e.g., family and external support system). Although resilience in parents of children with developmental disorders is not yet understood, previous studies have shown many variables that affect parent mental health. Here, we speculate on factors related to parenting resilience for parents of children with developmental disorders based on previous findings.

In addition to positive perception and skills acquired during intervention (see, IV. Adaptation), previous studies have reported several internal factors related to parent mental health. Dabrowska and Pisula (2010) found that emotion-oriented coping increased stress levels in mothers of children with autism. Moreover, the effect of severity of autistic behavior on parental pessimism was alleviated by parent beliefs about the efficacy of the intervention (Hasting & Johnson 2001). Harrison & Sofronoff, (2002) reported that the mothers of children with ADHD who perceived control over child behavior showed lower levels of parental stress and depression.

External factors (e.g., social support) are associated with parental mental health (for a review see Boyd 2002). Lack of social supports predicted an increase in depression and stress for parents of children with autism (Konstantareas & Homatidis, 1989, Sanders & Morgan, 1997). Specifically, informal supports (e.g., spouse, relative, and other parents of children with developmental disorders) were found to be effective resources for parents (Boyd 2002).

Therefore, it is important for parents of children with developmental disorders to have internal and external resilience factors. Although this article does not directly study these factors in parents of children with developmental disabilities, it will be important for future research on resilience to confirm these factors.

VI. Summary

Throughout our review, we proposed the construct of parenting resilience as it relates to parenting children with developmental disorders (Fig. 1). We operationally defined resilience as the process of adaptation to the difficulties of rearing a child caused

by child behavior problems. The process is considered to be carried out by internal and external factors.

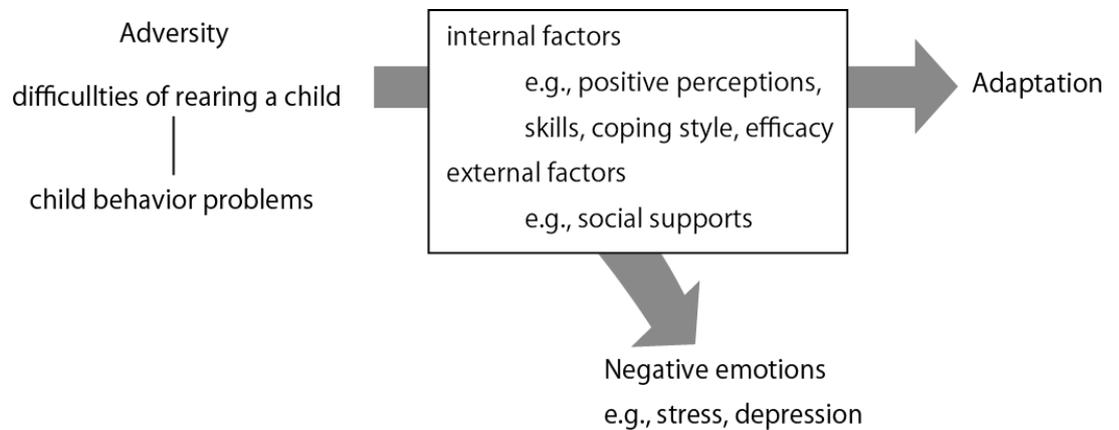


Fig. 1 A possible construct of resilience for parents of children with developmental disorders

VII. Future directions

Our proposed construct of parenting resilience is based on previous findings in the areas of general resilience and mental health in parents of children with developmental disorders. In the future, the construct of parenting resilience for parents of children with developmental disorders should be confirmed based on empirical data. However, currently, parenting resilience is not measurable. A reliable and valid rating scale will help researchers to investigate characteristics of parenting resilience for parents of children with developmental disorders. Therefore, the development of such rating scales seems necessary to continue research in this area.

In discussing resilience in this article, we have used the term “developmental disorders” to include disorders such as ASD and ADHD. Because symptoms vary according to the type of developmental disorder, we expect that parents will experience different difficulties depending on their child’s specific developmental disorder. For example, children with ASD often have sensory sensitivities, characteristics of which are diverse among individuals. Hence, parents of children with ASD need knowledge about both ASD itself and the specific way it is manifested in their child. Knowledge might be a more important factor of parenting resilience for parents of children with ASD than those with ADHD. Therefore, it is important for future research to investigate how factors associated with resilience vary among developmental disorders.

Additionally, the reviewed articles include samples of children with a wide range of intelligent quotient (IQ). High IQ children with developmental disorders have the ability to succeed well in studies and jobs, so that their parents sometimes have lofty ideals, but these expectations are not always realized. Thus, the difference between the ideal image and reality leads to negative emotions in parents. When considering

parenting resilience in parents of children with high IQ, therefore, it is necessary to discuss negative emotions that may arise when there is a discrepancy between the ideal image and reality.

Although we described parenting resilience to be independent of chronic sorrow, a relationship between them is speculated. In addition, the process of adaptation to the diagnosis of developmental disorders (Lutz et al., 2012) also may be involved with parental resilience. We need to examine the relationship between these factors and parenting resilience.

As noted above, there are several problems to solve in future resilience studies, including the development rating scales to measure resilience, the clarification of the differences among developmental disorders and the range of IQ, the relationship between parental resilience and chronic sorrow, and factors associated with parental adaptation to diagnosis. Further assessment and understanding in these areas is integral to helping clinicians understand parental resilience and create appropriate interventions for this subset of parents.

VIII. Acknowledgements

This work was supported by a Health and Labour Sciences Research Grant for Comprehensive Research on Disability Health and Welfare (H24 - SHINTAI/CHITEKI – IPPAN - 007) from the Japanese Ministry of Health, Labour and Welfare.

Reference

- 1) Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F. R., & Plienis, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22(2), 205-216.
- 2) Breen, M. J., & Barkley, R. A. (1988). Child psychopathology and parenting stress in girls and boys having attention deficit disorder with hyperactivity. *Journal of Pediatric Psychology*, 13(2), 265-280.
- 3) Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71(3), 543-562.
- 4) Rutter, M., Tizard, J., Yule, W., Graham, P., & Whitmore, K. (1976). Isle of Wight studies, 1964–1974. *Psychological Medicine*, 6(2), 313-332.
- 5) Rutter, M. (1985). Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *The British Journal of Psychiatry*, 147, 598-611.
- 6) Garmezy, N., Masten, A. S., & Tellegen, A. (1984). The study of stress and competence in children: A building block for developmental psychopathology. *Child Development*, 55(1) 97-111.
- 7) Werner, E. E. (1989). High-risk children in young adulthood: A longitudinal study

- from birth to 32 years. *American Journal of Orthopsychiatry*, 59(1), 72-81.
- 8) Bonanno, G. A., Moskowitz, J. T., Papa, A., & Folkman, S. (2005). Resilience to loss in bereaved spouses, bereaved parents, and bereaved gay men. *Journal of Personality and Social Psychology*, 88(5), 827.
 - 9) Bonanno, G. A., Galea, S., Bucciarelli, A., & Vlahov, D. (2006). Psychological resilience after disaster: New York City in the aftermath of the September 11th terrorist attack. *Psychological Science*, 17(3), 181-186.
 - 10) Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process*, 35(3), 261-281.
 - 11) Hawley, D. R., & DeHaan, L. (1996). Toward a definition of family resilience: Integrating life-span and family perspectives. *Family Process*, 35(3), 283-298.
 - 12) Bonanno, G. A. (2005). Clarifying and extending the construct of adult resilience. *American Psychologist*, 60(3), 265-267
 - 13) Tusaie, K., & Dyer, J. (2004). Resilience: A historical review of the construct. *Holistic Nursing Practice*, 18(1), 3-10.
 - 14) Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.
 - 15) Harrison, C., & Sofronoff, K. (2002). ADHD and parental psychological distress: Role of demographics, child behavioral characteristics, and parental cognitions. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(6), 703-711.
 - 16) Olshansky, S. (1962). Chronic sorrow: A response to having mentally defective children. *Social Casework*, 43, 190-193.
 - 17) Nakata, Y. (2002). Kosodate to kenko shirizu Kodomo no shogai o do juyosuruka. Otsuki shoten (in Japanese).
 - 18) Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *Journal Information*, 107(2), 116-127.
 - 19) Pisterman, S., Firestone, P., McGrath, P., Goodman, J. T., Webster, I., Mallory, R., & Coffin, B. (1992). The effects of parent training on parenting stress and sense of competence. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, 24(1), 41.
 - 20) Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3), 266-280.
 - 21) Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders*, 31(3), 327-336.
 - 22) Harrison, C., & Sofronoff, K. (2002). ADHD and parental psychological distress: Role of demographics, child behavioral characteristics, and parental cognitions. *Journal of*

- the American Academy of Child & Adolescent Psychiatry, 41(6), 703-711.*
- 23) Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17(4), 208-215.*
- 24) Konstantareas, M. M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry, 30(3), 459-470.*
- 25) Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child & Family Behavior Therapy, 19(4), 15-32.*
- 26) Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward adaptation. *Journal of Pediatric Nursing, 27(3), 206-213.*

Received

August 30,2013

Accepted

October 12,2013

Published

October 30,2013