Resilience and Coping by Parents of Children with Intellectual Disability in Kerala, South India

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ABSTRACT

Purpose: *This study examined the relationship between the resilience and coping mechanisms of parents of children with intellectual disability.*

Method: *Study participants were recruited from special schools and neighbourhood groups of parents of children with special needs in Kerala, a southern state of India. Around 121 parents completed the Connor-Davidson Resilience Scale and Coping Strategies Screen. The correlational analysis revealed a significant relationship between their coping strategies and resilience.*

Results: *Problem focussed coping strategies such as problem-solving skills, taking professional assistance, seeking information about managing the condition, taking time to discuss the ways of handling child's condition with the family members/significant others and having recreational activities improved parental resilience. Whereas, emotion focused coping strategies for example, reliance on religious leaders for emotional support, weeping, blaming fate and doing nothing decreased their resilience. Rehabilitation professionals may plan interventions to expand problem focused coping skills so as to improve their resilience*

Conclusion: *The findings have specific applications in developing interventions for parents of children with intellectual disability.*

Key words: *resilience, problem-focussed coping, emotion-focussed coping, parents, children with intellectual disability*

INTRODUCTION

Caring for a child with intellectual disability is a demanding task that requires lifelong commitment (Grant et al, 2007). Parents, who primarily take up the

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role of caregivers, often go through a period of emotional upheaval following the diagnosis of the condition (Heiman, 2002; Kandel & Merrick, 2003; Chang & McConkey, 2008; Bruce & Wilmshurst, 2016). They often struggle with the demands of the child's condition, additional financial needs, worry about the child's future, poorly coordinated services, meeting the needs of other family members, spending quality time with them, stigmatising experiences, and lack of support. These prolonged caregiving challenges may also restrict their careers as well as social life, and take a toll on their physical and mental health (Peshawaria et al, 1995; Heiman, 2002; Blacher & Mink, 2004; Pilusa, 2006; Murphy et al, 2007; Reichmann et al, 2007; Gohel et al, 2011; Kishore, 2011; Seltzer et al, 2011; Chadwick et al, 2013).

Apart from these challenges, parents mention several benefits associated with caregiving, mostly in terms of personal growth (Peshawaria et al, 1995; Larson, 1998; Scorgie & Sobsey, 2000; Ferguson, 2002; Hastings & Taunt, 2002; Heiman, 2002; Landsman, 2003; Grant, 2007; Green, 2007; Murphy et al, 2007; Reichmann et al, 2007; Chang & McConkey, 2008; Ryan & Runswick-Cole, 2008; Gohel et al, 2011; Kishore, 2011; Knight, 2013; Beighton & Wills, 2017), perspectival changes(Murphy et al, 2007; Goodley & McLaughlin, 2008), and improved support systems (McConnell et al, 2015). A few examples of such benefits are learning professional skills in caregiving (Chang & McConkey, 2008), becoming more accommodating to disability (Murphy et al, 2007; Goodley & McLaughlin, 2008), taking up advocacy initiatives (Chadwick et al, 2013), and choosing a career in the disability or health sector (Murphy et al, 2007; Beighton & Wills, 2017).

Caregiving is thus associated with both positive and negative experiences. However, in the field of intellectual disability the negative aspects received wider research attention as the studies were mostly guided by the medical model of disability (Ferguson, 2000, 2002; Ryan & Runswick-Cole 2008; Knight, 2013). There has recently been a paradigm shift in the research focus towards identifying parental strengths in caregiving, and thus studies on their resilience have started emerging (Knight, 2013). Such studies better explain how parents attempt to thrive in the context of caring for a child with intellectual disability.

Researchers conceptualised resilience as an outcome or a process (Olsson et al, 2003; Kolar, 2011; Lee et al, 2012; Lee et al, 2013). The former approach considered it as the ability to maintain functionality in the midst of adverse life events. However, the latter approach emphasised the dynamic process of positive adaptation that involves the interplay of risk and protective elements operating from various levels despite adversity (Luthar & Cicchetti, 2000; Luthar et al, 2000). The latter approach is preferred in social science research as it gives importance to personal, familial and contextual influences on resilience (Kolar, 2011).

In the field of intellectual disability, Olsson (2008) proposed a resilience model for parents, emphasising the interplay of child and disability-related intrapersonal and socio-ecological risk as well as protective factors. According to Olsson, both risk and protective factors need to be simultaneously studied. However, the existing studies mostly highlighted the role of intrapersonal or familial protective factors such as hope (Lloyd & Hastings, 2009), parent-child relationship, well-being (Gerstein et al, 2009), meaning making (Gardner & Harmon, 2002; Knestrict & Kuchey, 2009; Breitkreuz et al, 2014), benefit finding (Gardner & Harmon, 2002; Bayat, 2007; Knestrict & Kuchey, 2009; Breitkreuz et al, 2014), families' ability to have a rhythm (Knestrict & Kuchey, 2009), their communication skills, knowledge of disability, acceptance of the child with disability (Greeff & Walt, 2010), and spirituality (Bayat, 2007; Greeff & Walt, 2010).The emphasis is seldom on the risk factors except for a few elements such as problem behaviours of children (Lloyd & Hastings, 2009; McConnell et al,2014), restrictions in social life, lack of support (Breitkreuz et al, 2014) and financial difficulties (Knestrict & Kuchey, 2009; Breitkreuz et al, 2014; McConnell et al, 2014). In addition to these risk and protective factors, Olsson's model considered coping strategy as another intrapersonal factor of resilience. According to Olsson, emotion-focussed coping can act as a risk whereas problem-focussed coping is a protective element. There is limited research on this population that shows the relationship of these coping strategies with resilience.

Emotion-focussed coping involves the attempts to manage or reduce the emotional consequences of a stressful situation (Lazarus & Folkman, 1984). Kishore (2011) referred to these strategies as negative coping as they do not solve the problem directly. They are helpful in the initial exposure to the stressful situations that are unchangeable or beyond one's control (Lazarus & Folkman, 1984; Lazarus, 1993; Ylvén et al, 2006). Since disability is this type of a situation, this kind of coping is likely (Essex et al, 1999; Olsson, 2008; Mirsaleh et al, 2011). However, long-term reliance on this leads to psychological problems (Lazarus, 1993). Similarly, among parents of children with intellectual disability, studies revealed that the increased use of these strategies is associated with less positive parental outcomes such as higher levels of subjective burden (Kim et al,2003), depression (Dunn et al,2001; Kim et al, 2003; van der Veek et al, 2009) and stress (Seltzer et al,1995), poor mental health (McConkey et al,2008), spousal relationship issues (Dunn et al, 2001), social isolation (Dunn et al, 2001), and poor parent-child relationships (Kim et al, 2003). Furthermore, such dependency affected their mood (Pottie & Ingram, 2008) and sense of competence (Judge, 1998).

On the other hand, problem-focussed coping refers to the efforts to alter or prevent a stressful situation or reduce its effects (Lazarus & Folkman,1984). They help the person under stress to manage the situation by confronting the problem, generating strategies and mobilising resources, and hence Kishore (2011) referred to them as positive coping. They are effective in those situations that are perceived as changeable or controllable (Folkman, 1984; Lazarus, 1999; Ylvén et al, 2006). Parental use of these strategies resulted in more positive outcomes such as greater well-being (Seltzer et al, 1995), family strengths (Judge, 1998), family adaptation (Greeff & Walt, 2010), mental health (Bourke-Taylor et al, 2012; Zablotsky et al, 2013) and positive mood (Pottie & Ingram, 2008). They improved the quality of their relationship with their child (Kim et al, 2003) and lowered their levels of depression (Dunn et al, 2001; Kim et al, 2003), burden (Kim et al, 2003), stress (Koydemir-Özden & Tosun, 2010; Lyons et al,2010; John, 2012; Zablotsky et al, 2013), spousal relationship problems (Dunn et al, 2001), and negative mood (Pottie & Ingram, 2008).

Peer and Hillman (2014), in their review of the research on parental stress and adaptation, suggested that the reliance on problem-focused strategies protected parents from the emotional turmoil associated with caregiving and had the potential to promote resilience. Similarly, Grant et al (2007) in their parental resilience model proposed that these methods helped them to maintain control over caregiving demands and could influence the resilience process. The general resilience literature (Patterson, 2002; Rutter, 2006, 2007, 2013; Walsh, 2003, 2008; Wu et al, 2013) also highlighted the protective nature of active coping methods.

Objective

The present study aimed to examine the relationship between parents' resilience and their coping strategies, using a correlational design. Based on the above findings it was hypothesised that when parents rely on emotion-focused coping strategies they experience lower resilience, and when they rely on problem-focused coping strategies they experience higher resilience. More knowledge about this link can guide the rehabilitation professionals in formulating intervention plans to expand parental coping strategies and thus enhance their resilience.

METHOD

Study Participants

The study participants were recruited from Kerala, a southern state of India, through two sources: (a) special schools and (b) neighbourhood groups of parents of children with special needs. From these two sources, 121 parents met the inclusion criteria for this study.

Included were:

Parents whose child, 5 years of age or older, had been diagnosed with intellectual disability at least two years earlier.

Excluded were:

Single/ parents, stepparents, parents with mental illness, and parents with intellectual disability, as previous studies reported that these factors affect the resilience process (Luthar, 1991; Winders, 2014).

The mean age of the parents was 43.18 years (SD: 6.92, range: 30-60). There were 54 fathers and 67 mothers. From 17 families, both parents were participants, whereas from each of the 87 families only one parent participated. With regard to education, 59% had finished high school, 27% had completed intermediate, and 14% had some college-level education. The mean number of years that they had lived with the child since the diagnosis of the condition was 12.07 years (SD: 5.15, range: 2-29). Among the parents, 88% resided in rural areas. With regard to their monthly income, 75% were earning up to Rs. 5000, 7% were earning between Rs. 5001-10,000, and 17% were earning more than Rs. 10,000.

The mean age of the children with intellectual disability was 14.01 years (SD: 5.14, range: 5-32).Among them, there were 72 males and 49 females. Regarding the severity of disability, 46% had mild, 31% had moderate, 18% had severe, and 5% had profound intellectual disability.

Measures

Connor-Davidson Resilience Scale (CD-RISC)

The Connor-Davidson Resilience Scale (CD-RISC), a five-point rating scale, was used to assess the resilience of the participants. The total score ranges from ‘0’ to ‘100’, and a higher score indicates greater resilience. The scale has an internal consistency of 0.89 and test-retest reliability of 0.87. The convergent validity was found by correlating the scale scores with hardiness, perceived stress, stress vulnerability, and social support measures. The CD-RISC had a positive correlation with hardiness and social support, but an inverse correlation with stress and stress vulnerability (Connor & Davidson, 2003).

Coping Strategies Screen (CSS)

The Coping Strategies Screen (CSS), a three-point rating scale consisting of 14 items, assessed the coping strategies commonly used by parents in the context of their child’s disability. Among the 14 items, 5 indicate problem-focused coping strategies while the remaining items indicate emotion-focused coping strategies. The scale generates scores for both types of strategies separately, by providing a total score for items in each category. The inter-rater reliability of the scale was 0.95. The content and face validity were established by consensus among the professionals working in the field of intellectual disability (Kishore, 2011; Kishore et al, 2004).

Procedure

The parents were requested to bring their child’s medical records and disability certificate (a document issued by the district medical board that provides information about the child’s disability and is essential for availing of government schemes and benefits), in order to collect information about the child’s diagnosis, associated difficulties, and level of severity of disability. They were also asked to bring their own medical records to rule out any history of terminal/mental illness or intellectual disability. They filled in the demographic information in the demographic data sheet. The CD-RISC and CSS were administered to them in their native language, and they marked their responses in the space provided.

Data Analysis

The IBM SPSS Statistics Version 21.0.0 was used to analyse the data. Descriptive statistics were calculated for the study variables. Pearson correlation coefficients were used to assess the relationship between resilience and coping strategies.

Ethics Approval

Ethical approval was given by the Central University of Karnataka.

Parents were met individually and informed about the purpose of the study. They were included after they gave their consent and were assured of confidentiality.

RESULTS

Table 1 gives the descriptive statistics of the study variables. Among the emotion-focused coping strategies, approaching religious leaders or gurus for emotional and moral support (74%) was the most used strategy. The least used emotion-focused strategies were blaming fate and doing nothing (43%) and venting negative feelings on the child (43%). On the other hand, the most preferred problem-focused coping strategy was approaching professionals for guidance and help (93%), whereas seeking technical information regarding the management of the problems (50%) was the least preferred problem-focused strategy.

Table 1: Descriptive Statistics of Study Variables

Variable	n	%	M	SD
Emotion-focused Coping			6.32	2.93
Approaching religious leaders/gurus for emotional and moral support	90	74.38	.93	.66
Blaming fate and doing nothing	52	42.98	.55	.71
Crying/Weeping	77	63.64	.76	.66
Indulging more in domestic or professional activities to divert attention from the problem	82	67.77	.83	.67
Neglecting child with disability for a while or till feeling better	56	46.28	.47	.52
Neglecting other duties and focusing on child only	80	66.12	.94	.79
Performing religious rituals to divert attention or to feel better	77	63.64	.83	.72
Venting negative feelings on child	52	42.98	.45	.53
Venting negative feelings on spouse	63	52.07	.56	.58
Problem-focused Coping			5.21	2.16
Approaching professionals for guidance and help	113	93.39	1.45	.62
Discussing with others or family members how to solve the problem	104	85.95	1.12	.63

Taking up recreational activities	86	71.07	.86	.65
Seeking more technical information regarding management of the problem	60	49.58	.58	.64
Trying to solve the problem myself by analysing the situation	98	80.99	1.20	.74
Resilience			65.15	15.74

Note: n = 121

Table 2 presents the findings of correlational analysis of predictor variables with resilience. The results revealed a significant inverse correlation between resilience and emotion-focused coping. Among the strategies, approaching religious leaders for emotional and moral support, blaming fate, crying, diverting attention using domestic or professional activities, neglecting the child with disability, and venting negative feelings on child and on spouse decreased their resilience. It also indicated a significant positive relationship of resilience and problem- focused coping. The strategy-wise analysis revealed the same too.

Table 2: Pearson Correlation Coefficients of Resilience and Coping

Variable	***r***	***p***
Emotion-focused Coping	-.43**	< .001
Approaching religious leaders/gurus for emotional and moral support	-.26**	0.002
Blaming fate and doing nothing	-.39**	< .001
Crying/Weeping	-.39**	< .001
Indulging more in domestic or professional activities to divert attention from the problem	-.17*	0.028
Neglecting child with disability for a while or till feeling better	-.27**	0.002
Neglecting other duties and focusing on child only	.11	0.126
Performing religious rituals to divert attention or to feel better	-.11	0.118
Venting negative feelings on child	-.32**	< .001
Venting negative feelings on spouse	-.23**	0.005
Problem-focused Coping	.59**	< .001
Approaching professionals for guidance and help	.31**	< .001
Discussing with others or family members how to solve the problem	.34**	< .001
Taking up recreational activities	.47**	< .001

Seeking more technical information regarding management of the problem	.35**	< .001
Trying to solve the problem myself by analysing the situation	.47**	< .001

$^{*}p < .05$, $^{**}p < .01$

DISCUSSION

Parents experienced lower levels of resilience when they relied more on emotion-focused coping strategies. This supports Olsson's model and the findings of parental stress and well-being literature (Seltzer et al, 1995; Kim et al, 2003; McConkey et al, 2008). According to Lazarus and Folkman (1984), when a life event is perceived as unalterable, individuals tend to develop learned helplessness, become passive and restricted in coping skills. Subsequently, they start using a greater number of emotion-focused coping strategies (Luthar, 1991; Wu et al, 2013). Rutter (1999) stated that when a person relies more on maladaptive ways of coping following an adversity, it is more likely that negative chain reactions will persist. The presence of such reactions over a longer period of time may influence him/her to carry forward the ill effects of adversity, and makes him/her more vulnerable to further adversities. In the context of parents as well, these strategies delay their active response towards the stress or burden associated with raising a child with disability and affects their competence and sense of control (Judge, 1998). Thus, when parents lack mastery over the situation, they tend to get entangled with the challenges of caregiving and experience low resilience (Grant et al, 2007; Breitkreuz et al, 2014). In the present study, the emotion-focused strategies such as approaching religious leaders for support, blaming fate and doing nothing, crying, diverting attention using domestic or professional activities, neglecting the child with disability for some time or till they feel better, and venting negative feelings on child and on spouse decreased their resilience. There is previous evidence that the strategies like self-blaming and detaching oneself from the stressful situation by engaging in other activities affected their mood, made them more depressive, and lowered their sense of commitment and control (Judge, 1998; Pottie & Ingram, 2008; van der Veek et al, 2009).

The reliance on problem-focused coping methods improved parental resilience. This confirms Olsson's model and the findings of general resilience literature (Patterson, 2002; Rutter, 2006, 2007, 2013; Walsh, 2003, 2008; Wu et al, 2013). The strategies that facilitated parental resilience were: approaching professionals for guidance, seeking information about the child's condition and its management, discussing with others or family members about how to deal with the problem, taking up recreational or pleasurable activities, and utilising problem-solving skills. These proactive methods helped them to gain control over demands of caregiving, allocate time to care for themselves in the midst of caregiving responsibilities, and find new ways to grow out of difficulties (Judge, 1998; Gardner & Harmon, 2002; Heiman, 2002; Chang & McConkey, 2008; Pottie & Ingram, 2008; Greeff & Walt, 2010; Koydemir-Özden & Tosun, 2010; Bourke-Taylor et al, 2012). Achieving control over demands further helps them to re-evaluate their caregiving skills, maintain a considerable degree of stability and predictability in daily caregiving, and prevents them from feeling trapped in caregiving responsibilities (Grant et al, 2007). Thus, when they move from crisis reactive mode towards a proactive mode of functioning, they become more resilient (Walsh, 2003, 2008).

Parents used both problem-focused and emotion-focused coping methods to deal with their child's disability. This corresponds with the previous finding that the problem-focused approaches they relied on did not prevent them from using emotion-focused approaches. As disability is an unchangeable situation, they tend to use both methods in spite of knowing that the latter methods are less helpful (Essex et al, 1999; Olsson, 2008; Kishore, 2011).

The findings imply that parental problem-focused coping can function as a protective mechanism in the context of resilience, whereas emotion-focused coping can be a risk element. As parents tend to rely on both coping strategies, professionals need to follow a flexible approach while assisting them. They can place more emphasis on adaptive methods such as teaching problem-solving skills, receiving professional guidance, seeking information about the management of the condition, discussing with family members or significant others about various ways to deal with the problems at hand, and taking up recreational activities. Methods such as seeking emotional and moral support from religious leaders, blaming fate and doing nothing, crying, diverting attention using domestic or professional activities, neglecting the child with disability for some time or till they feel better, and venting negative feelings on child and on spouse, need not be encouraged though parents may indulge in them at times.

Study Limitations

Majority of the parents had some school education, earned a low income, and were residing in rural areas. These factors could influence their access to various resources or services to deal with their child's disability. Hence, future studies need to select a representative sample by considering these variables. The present study recruited parents from special schools and parent groups. These sources provide access to various services and a platform for similar parents to meet up and discuss their issues. This has the potential to influence their coping behaviours. Future research can consider including a group of parents who do not receive such services. The data can be enriched by adding a qualitative component, for example in-depth interviews, and thus explore the phenomena of resilience from a mixed method approach.

CONCLUSION

Parents used both the problem-focused and emotion-focused coping methods to deal with their child's disability. These methods influenced their resilience process. Problem-focused coping contributed to their resilience whereas emotion-focused coping lowered their resilience.

REFERENCES

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*(9), 702–714. https://doi.org/10.1111/j.1365-2788.2007.00960.x, PMid:17845239

Beighton, C., & Wills, J. (2017). Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration. *Journal of Intellectual Disabilities, 21* (4), 325-345. https://doi.org/10.1177/1744629516656073, PMid:27352854 PMCid:PMC5703033

Blacher, J., & Mink, I. T. (2004) Interviewing family members & care providers: concepts, methodology & cultures. In E. Emerson, C. Hatton, T. Thompson, & T. R. Parmenter (Eds.), *The International Handbook of Applied Research in Intellectual Disabilities* (pp. 133–153). Wiley. https://doi.org/10.1002/9780470713198.ch6

Bourke-Taylor, H., Pallant, J. F., Law, M., & Howie, L. (2012). Predicting mental health among mothers of school-aged children with developmental disabilities: The relative contribution of child, maternal and environmental factors. *Research in Developmental Disabilities*, *33*(6), 1732–1740. https://doi.org/10.1016/j.ridd.2012.04.011, PMid:22699247

Breitkreuz, R., Wunderli, L., Savage, A., & McConnell, D. (2014). Rethinking resilience in families of children with disabilities: a socioecological approach. *Community, Work & Family*, *17*(3), 346–365. https://doi.org/10.1080/13668803.2014.893228

Bruce, A. W., & Wilmshurst, L. (2016). *Essentials of intellectual disability assessment and identification*. Wiley.

Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., … Harrington, G. (2013). Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26*(2), 119–132. https://doi.org/10.1111/jar.12003, PMid:23225734

Chang, M.Y., & McConkey, R. (2008). The perceptions and experiences of Taiwanese parents who have children with an intellectual disability. *International Journal of Disability, Development and Education, 55*(1), 27–41.https://doi.org/10.1080/10349120701827961

Connor, K. M., & Davidson, J. R. T. (2003). Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety, 18*(2), 76–82. https://doi.org/10.1002/da.10113, PMid:12964174

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39–52. https://doi.org/10.1023/A:1026592305436, PMid:11300666

Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation, 104*, 545–563. https://doi.org/10.1352/0895-8017(1999)104<0545:DICEAW>2.0.CO;2

Ferguson, P. M. (2000). Mapping the family: Disability studies and the exploration of parental response to disability. In G.L. Albrecht, K.D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 373-395). Sage. https://doi.org/10.4135/9781412976251.n15, PMid:11692516

Folkman S. (1984) Personal control and stress and coping processes: a theoretical analysis. *Journal of Personality and Social Psychology, 46*, 839–852. https://doi.org/10.1037/0022-3514.46.4.839

Gardner, J., & Harmon, T. (2002). Exploring resilience from a parent's perspective: A qualitative study of six resilient mothers of children with an intellectual disability. *Australian Social Work, 55*(1), 60–68. https://doi.org/10.1080/03124070208411672

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981–997.https://doi.org/10.1111/j.1365-2788.2009.01220.x, PMid:19874449 PMCid:PMC2796238

Gohel, M., Mukherjee, S., & Choudhary, S. (2011). Psychosocial impact on the parents of mentally retarded children in Anand district. *Healthline, 2*(1), 62–66.

Goodley, D & McLaughlin, J. (2008). Productive parental alliances. In J. McLaughlin, D. Goodley, E. Clavering, et al. (Eds.), *Families raising disabled children Enabling care and social justice* (pp. 78-104). Palgrave Macmillan. https://doi.org/10.1057/9780230583511_5

Grant, G., Ramcharan, P., & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. *Journal* *of Applied Research in Intellectual Disabilities, 20*(6), 563–575. https://doi.org/10.1111/j.1468-3148.2007.00407.x

Greeff, A. P., & Walt, K.-J. van der. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities*, *45*(3), 347–355.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64* (1), 150-163. https://doi.org/10.1016/j.socscimed.2006.08.025, PMid:17014946

Hastings, R.P. & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation 107*, 116-127. https://doi.org/10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2

Heiman, T. (2002). Parents of children with disabilities: resilience, coping and future expectations. *Journal of Developmental and Physical Disabilities, 14*(2), 159–171. https://doi.org/10.1023/A:1015219514621

John, A. (2012). Stress among mothers of children with intellectual disabilities in urban India: Role of gender and maternal coping. *Journal of Applied Research in Intellectual Disabilities*, *25*(4), 372–382. https://doi.org/10.1111/j.1468-3148.2011.00672.x, PMid:22711485

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations*, *47*(3), 263–268. https://doi.org/10.2307/584976

Kandel, I., & Merrick, J. (2003). The birth of a child with disability: Coping by parents and siblings. *The Scientific World Journal, 3*, 741-750. https://doi.org/10.1100/tsw.2003.63 PMid:12953123 PMCid:PMC5974612

Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, *47*(4/5), 313–327. https://doi.org/10.1046/j.1365-2788.2003.00493.x, PMid:12787163

Kishore, M. T. (2011). Disability impact and coping in mothers of children with intellectual disabilities and multiple disabilities. *Journal of Intellectual Disabilities*, *15*(4), 241–251. https://doi.org/10.1177/1744629511431659, PMid:22158461

Kishore, M. T., Behera, P., & Verma, R. K. (2004). Perceived burden and coping strategies in mothers of children with multiple disabilities. In *Proceedings of NIMH Conference on Multiple Disabilities* (pp. 123–131). National Institute for the Mentally Handicapped, India.

Knestrict, T., & Kuchey, D. (2009). Welcome to Holland: Characteristics of resilient families raising children with severe disabilities. *Journal of Family Studies*, *15*(3), 227–244. https://doi.org/10.5172/jfs.15.3.227

Knight, K. (2013). The changing face of the "good mother": trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, *28*(5), 660–673. https://doi.org/10.1080/09687599.2012.732540

Kolar, K. (2011). Resilience: Revisiting the concept and its utility for social research. *International Journal of Mental Health and Addiction*, *9*(4), 421–433. https://doi.org/10.1007/s11469-011-9329-2

Koydemir-Özden, S., & Tosun, Ü. (2010). A qualitative Approach to understanding Turkish mothers of children with autism: Implications for counselling. *Australian Journal of Guidance & Counselling*, *20*(1), 55–68. https://doi.org/10.1375/ajgc.20.1.55

Landsman, G. (2003). Emplotting children's lives: developmental delay vs. disability. *Social Science & Medicine*, *56*(9), 1947–1960. https://doi.org/10.1016/S0277-9536(02)00215-0

Larson, E. (1998). Reframing the meaning of disability to families: the embrace of paradox. *Social Science Medicine, 47* (7) 865-875. https://doi.org/10.1016/S0277-9536(98)00113-0

Lazarus, R. (1993). Coping theory and research: past, present, and future. *Psychosomatic Medicine, 55*, 234–247. https://doi.org/10.1097/00006842-199305000-00002, PMid:8346332

Lazarus R (1999). *Stress and Emotion: A New Synthesis*. Springer.

Lazarus R, Folkman S (1984). *Stress, Appraisal, and Coping*. Springer.

Lee, J. H., Nam, S. K., Kim, A.-R., Kim, B., Lee, M. Y., & Lee, S. M. (2013). Resilience: A Meta-Analytic Approach. *Journal of Counseling & Development*, *91*(3), 269–279. https://doi.org/10.1002/j.1556-6676.2013.00095.x

Lee, T. Y., Cheung, C. K., & Kwong, W. M. (2012). Resilience as a Positive Youth Development Construct: A Conceptual Review. *The Scientific World Journal*, *2012*, 1–9. https://doi.org/10.1100/2012/390450, PMid:22623893 PMCid:PMC3353472

Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *53*(12), 957–968. https://doi.org/10.1111/j.1365-2788.2009.01206.x, PMid:19744261

Luthar, S. S. (1991). Vulnerability and resilience: a study of high-risk adolescents. *Child Development*, 62(3), 600–616.https://doi.org/10.1111/j.1467-8624.1991.tb01555.x, PMid:1914628 PMCid:PMC4235608

Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychopathology*, *12*(4), 857–885. https://doi.org/10.1017/S0954579400004156, PMid:11202047 PMCid:PMC1903337

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. https://doi.org/10.1111/1467-8624.00164, PMid:10953923 PMCid:PMC1885202

Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy, A. M. (2010). The Impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies*, *19*(4), 516–524. https://doi.org/10.1007/s10826-009-9323-5

McConkey, R., Truesdale-Kennedy, M., Chang, M.-Y., Jarrah, S., & Shukri, R. (2008). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies*, *45*(1), 65–74. https://doi.org/10.1016/j.ijnurstu.2006.08.007, PMid:17022985

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, *35*(4), 833–848.

https://doi.org/10.1016/j.ridd.2014.01.015, PMid:24491480

McConnell, D., Savage, A., Sobsey, D., & Uditsky, B. (2015). Benefit-finding or finding benefits? The positive impact of having a disabled child. *Disability & Society*, *30*(1), 29–45. https://doi.org/10.1080/09687599.2014.984803

Mirsaleh, Y. R., Rezai, H., Khabaz, M., Afkhami Ardekani, I., & Abdi, K. (2011). Personality dimensions, religious tendencies and coping strategies as predictors of general health in Iranian mothers of children with intellectual disability: A comparison with mothers of typically developing children. *Journal of Applied Research in Intellectual Disabilities*, *24*(6), 573–582. https://doi.org/10.1111/j.1468-3148.2011.00639.x

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x, PMid:17291322

Olsson, C. A., Bond, L., Burns, J. M., Vella-Brodrick, D. A., & Sawyer, S. M. (2003). Adolescent resilience: a concept analysis. *Journal of Adolescence*, *26*(1), 1–11. https://doi.org/10.1016/S0140-1971(02)00118-5

Olsson, M. B. (2008). Understanding individual differences in adaptation in parents of children with intellectual disabilities: A risk and resilience perspective. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation* (Vol. 36, pp. 281–315). Academic Press https://doi.org/10.1016/S0074-7750(08)00008-6

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family*, *64*(2), 349–360.https://doi.org/10.1111/j.1741-3737.2002.00349.x

Peer, J. W., & Hillman, S. B. (2014). Stress and Resilience for Parents of Children With Intellectual and Developmental Disabilities : A Review of Key Factors and Recommendations for Practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 92–98. https://doi.org/10.1111/jppi.12072

Peshawaria, R., Menon, D., Ganguly, R., Roy, S., Pillay, R. P. R. S., & Gupta, A. (1995). U*nderstanding Indian families having persons with mental retardation*. National Institute for the Mentally Handicapped, India.

Pilusa, N. E. (2006). *The impact of mental retardation on family functioning* [Master's thesis, University of Pretoria]. UPSpace Institutional Repository. https://repository.up.ac.za/handle/2263/28013

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology*, *22*(6), 855–864. https://doi.org/10.1037/a0013604, PMid:19102606

Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of Child Disability on the Family. *Maternal and Child Health Journal*, *12*(6), 679–683. https://doi.org/10.1007/s10995-007-0307-z, PMid:18060488

Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Annals of the New York Academy of Sciences*, *1094*, 1–12. https://doi.org/10.1196/annals.1376.002, PMid:17347337

Rutter, M. (2007). Resilience, competence, and coping. *Child Abuse & Neglect*, *31*(3), 205–209. https://doi.org/10.1016/j.chiabu.2007.02.001, PMid:17408738

Rutter, M. (2013). Annual research review: Resilience - clinical implications. *Journal of Child Psychology and Psychiatry*, *54*(4), 474–487. https://doi.org/10.1111/j.1469-7610.2012.02615.x, PMid:23017036

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*, *23*(3), 199–210. https://doi.org/10.1080/09687590801953937

Scorgie, K., & Sobsey, D. (2000) Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation 38*, 195–206. https://doi.org/10.1352/0047-6765(2000)038<0195:TOAWPC>2.0.CO;2

Seltzer M. M., Greenberg J., & Krauss M. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging* 10, 64–75. https://doi.org/10.1037/0882-7974.10.1.64

Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, *116*(6), 479–499. https://doi.org/10.1352/1944-7558-116.6.479, PMid:22126660 PMCid:PMC3263696

van der Veek, S. M. C., Kraaij, V., & Garnefski, N. (2009). Down or up? Explaining positive and negative emotions in parents of children with Down's syndrome: Goals, cognitive coping, and resources. *Journal of Intellectual and Developmental Disability*, *34*(3), 216–229. https://doi.org/10.1080/13668250903093133, PMid:19681002

Walsh, F. (2003). Family Resilience: A Framework for Clinical Practice. *Family Process*, *42*(1), 1–18. https://doi.org/10.1111/j.1545-5300.2003.00001.x, PMid:12698595

Walsh, F. (2008). Understanding theory to support a family resilience framework in practice. *Social Work Now*, *39*, 5–14.

Winders, S. (2014). From extraordinary invulnerability to ordinary magic: A literature review of resilience. *Journal of European Psychology Students, 5*(1), 3–9. https://doi.org/10.5334/jeps.bk

Wu, G., Feder, A., Cohen, H., Kim, J. J., Calderon, S., Charney, D. S., & Mathé, A. A. (2013). Understanding resilience. *Frontiers in Behavioral Neuroscience*, *7*(February), 1–15. https://doi.org/10.3389/fnbeh.2013.00010, PMid:23422934 PMCid:PMC3573269

Ylvén, R., Björck-Åkesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(4), 253–270. https://doi.org/10.1111/j.1741-1130.2006.00089.x

Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(6), 1380–1393. https://doi.org/10.1007/s10803-012-1693-7, PMid:23100053