Positive contributions of children with autism to their families

Sean González-Lambert, Encarnación Sarriá & Beatriz López
Evidence of resilience in families of children with autism

M. Bayat


Introduction

Over the last 10 years, the interest in finding why some families face adversity better than others has caught the attention of a number of family researchers. Family resilience is defined as the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful.

The concept of family resilience is part of a movement in positive psychology that aims to identify factors of health as opposed to negative symptoms. While research in family resilience in the disability field is limited, research in families with children who have autism is extremely scarce.

The study

The overall aim of the present study was to identify aspects of family resilience in families with children with autism. The study used surveys on a group of 175 mothers and fathers, carers and guardians of children with autism. The participants were recruited from an autism society from Illinois, USA. In order to participate in the study the family had to have a child with a diagnosis of autism, and the child had to be between 2 and 18-years-old.

Parents were asked to describe in three open-ended questions: (1) the positive and/or negative effects of autism on their family life, (2) the positive and/or negative effects of autism on their personal life, and (3) their child.

Findings

The findings suggest that family resilience is related to four specific processes: (1) Making a positive meaning out of autism, and changing their global view of the world and life, (2) Pulling resources together and becoming united and closer as a family, (3) Finding greater appreciation of life in general and becoming more compassionate and finally, (4), Gaining spiritual strength and/or belief system.

Conclusion

The current study provides evidence indicating that despite the difficulties faced by families of children with autism, many of these families displayed factors of resilience. In particular, the data from this study supported the positive aspects of raising a child with autism.

The author suggests that further research is required to clarify how individual resilience factors might contribute to the resilience in the family, and how these factors might be strengthened within the family. Furthermore, the findings have implications for the provision of strengths-based services for family members of children with autism, rather than services focusing on negative aspects of family life.
"My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives

B.J. Myers, V.H. Mackintosh & R.P. Goin-Kochel
Research in Autism Spectrum Disorders (2009)

Introduction

As the title suggests, having a child with ASD changes every aspect in the daily lives of many parents and families. Research shows high levels of parental stress in families with children with ASD. Parental stress has been associated to the severity of their child’s symptoms and challenging behaviours. Parents however also report that having a child with ASD has had a positive impact in their lives as it has led to reviewing their belief systems, values and priorities. Despite all this research, there is still a lack of knowledge into how autism affects families and how they function as a whole.

The study

The aim of the current study was to listen to parents’ own words on how raising a child with autism affected their lives as well as their families’ lives. A group of 493 parents from 6 English-speaking countries (> 90% mothers) took part in the study who all had children with ASD.

They were asked to answer an open-ended question on an online questionnaire: “How has your child in the autism spectrum affected your life and your family’s life?”. Parents’ answers were grouped by their tone, namely, positive, negative, mixed or unclear. Once the grouping was complete, they were categorised for into positive and negative themes.

Findings

The findings from this study identified 15 negative themes and 9 positive themes from the parents’ responses which were further categorised into 5 clusters: (1) Stress, (2) Child’s behaviour and demands of care and therapy, (3) Impact on parents; personal well-being, work lives, and marital relationship, (4) Impact on the family as a whole, including siblings and extended family and finally, (5) Social isolation. Almost half of the responses were completely negative, a third had a mixed tone and only 10% offered positive comments. It’s not surprising given that over 70% of the parents’ responses expressed stress in their lives.

Conclusion

This study concludes that there was a mix of themes from parents’ responses on how having a child with ASD affected their and their families’ lives. Although the mix of positive and negative themes are apparent in this study and it is clear that having a child with ASD presents challenges, parents still have a positive viewpoint on life.
Coping strategies and parents’ positive perceptions of raising a child with Autism Spectrum Disorders

E. Sarriá and P. Pozo


Introduction

Parents of children with Autism Spectrum Disorders (ASD) have to adapt their lives in order to raise and care for their children. Parents manage the situation in different ways and have to restructure their lives in order to cope with the daily demands that come with looking after a child with ASD. Most research focuses on the negative influence that raising a child with ASD has on parents’ psychological well-being. In contrast, little is known about positive perceptions parents have on the situation.

This study uses the Positive Contributions scale which measures three different factors: (1) happiness and fulfilment, (2) strength and family closeness and (3) personal growth and maturity.

The study

The overall aim of the study was to analyse the relationship of parents’ perceived positive contributions of raising a child with ASD, their psychological well-being and perception of family quality of life.

A sample of 217 Spanish parents (127 mothers and 90 fathers) were asked to fill in six questionnaires to evaluate well-being, perception of family life and perceived positive contributions. It was predicted that mothers would have higher levels of perceived positive contributions than fathers.

Findings

The findings from this study support the claim that parents perceive that raising a child with ASD has positive contributions for both parents and also that these perceptions play a role on psychological well-being and family quality of life. The results also indicate differences between mothers and fathers in terms of coping strategies. Mothers reported higher levels of perceived positive contributions which were associated to greater use of positive and problem focused coping strategies. In turn, active avoidance (denial, distraction and guilt) has a negative influence on psychological well-being.

Conclusion

Although this study has its limitations, it contributes to a better understanding of the factors relating to the psychological well-being of parents when raising a child with ASD. This research is important as it could facilitate the development of intervention strategies to promote parents’ well-being. Furthermore, the current findings highlight the importance of coping strategies and positive perceptions of disability for parental psychological well-being and family quality of life.
N.C. Charles & R. C Berman
Journal of the Motherhood Initiative for Research and Community Involvement (2009)

Introduction

Current literature exploring mother-child relationships in mothers of children with autism spectrum disorders (ASD) usually presents these relationships from a negative perspective. They describe these relationships as stressful, non-existent and disorganised.

In addition, previous research is based on attachment theory which focuses on the child more than on the mother and very fixed ideas of motherhood. However, both of these approaches do not take into account the experiences of mothers who have children with ASD.

The study

This study took a feminist approach in order to explore positive aspects of the mother-child relationship of mothers of children with ASD.

Five Canadian mothers, aged between early 40s to early 50s, were chosen to take part in an oral history interview where they could tell their individual experiences from the past and present. Three of the five women were single mothers and two were married. A list of seven general questions was devised as a guideline for the interview.

Findings

From the interviews, it is clear that mothers of children with ASD can experience their mother-child relationship as a positive bond through the mothers’ self-reflection and growth. The findings from this study suggest that their perspective could be classed into three themes: (1) “building a bond through learning and growth of the self”, (2) “you will grow with them and your love will grow”, and (3) “find support where you can from people who will understand”.

Conclusion

As this is the first study in this area to use a feminist approach, it begins to pave the way for mother-centred research in terms of listening to their experiences and to facilitate social change. While the findings of this study are very informative, it is hoped that further research will help mothers get the support they need with their children with ASD, in terms of building, discovering and strengthening their mother-child relationship.
Introduction

In previous research, it has been reported that parents of children with autism experience more stress than parents of children with/without other disabilities and/or chronic illnesses. Generally, it is mothers who experience more stress than fathers.

However, recent research shows that parental outcome may include positive as well as negative dimensions. Unfortunately, positive outcomes have rarely been investigated in families of children with autism.

The study

The aim of the present study was to explore the extent to which child and partner’s characteristics impact on parental well-being and mental health.

Parents of pre-school children with autism (48 mothers and 41 fathers) enrolled in research associated with the Southampton Childhood Autism Programme (SCAmP).

Parents completed questionnaires measuring their child’s characteristics and the severity of their autistic symptoms, their own levels of anxiety and depression, parental stress and family problems and finally about the extent to which they thought having a child with autism had a positive impact in the family.

Findings

The findings show that parental stress is highly determined by their partner’s stress levels and in the case of mothers, also by their child’s behaviour problems and also by their partner’s levels of depression. Results also showed that mothers hold more positive perceptions than fathers and that father’s positive perceptions are higher when maternal depression levels is lower.

Conclusion

This is one of the first studies to examine parental perceptions of both the positive and negative contributions that children with developmental disabilities make to the family. Further research is needed to explore the differences of parents with different disabilities in terms of stress and positive perceptions. The well-being of parents of children with autism can have an impact in their child well-being as well as that of siblings. Therefore is important to support parents to have positive perceptions of how the child contributes to the family as it can affect their stress levels and coping strategies.
Parent views of the positive contributions of elementary and high school-aged children with Autism Spectrum Disorder and Down Syndrome

G., King, L. Zwaigenbaum, A. Bates, D. Baxter & P. Rosenbaum
Child: Care, Health and Development (2011)

Introduction
Parents of children with disabilities experience various emotions throughout their lives with the hardships that face them. It is difficult for any parent of a child with a disability to take the news of their child’s diagnosis. However, there are always benefits that can make parents really proud of their child. Although the well-being of parents has been explored, little attention has been paid to the positive contributions children with disabilities have on family life or society.

The study
The primary aim of the study was to examine the nature of the benefits seen by parents of children with autism spectrum disorders (ASD) and Downs Syndrome to their family and society. Secondly, the study investigates whether these benefits differed for families of older and younger children or by type of disability.

A total of 16 families from Ontario, Canada took part. Parents were interviewed on 2 occasions with a gap of between 2-5 months of each other. In the first session, parents talked about themselves, other family members and what was important to them. The second session aimed to obtain more information after parents had time to reflect on their family priorities and on society.

Findings
The transcripts from the parents identified three main levels at which their children made positive contributions: Parental level, Family level and Social level. There were no differences between parents of children with ASD and Downs Syndrome. However, parents of high school-aged children (15-17) were more likely to mention family and societal benefits. The majority of families mentioned ways in which their children had improved their parenting, the lives of family members and society.

Conclusion
The study suggests that there are positive contributions in raising a child with a chronic disability at many levels. Despite the hardships, parents can trigger positive perceptions that can lead to family resilience and other benefits. For instance, taking a positive perspective in decision making, transitional periods and adapting to family life. The study’s findings may be used to change the publics’ opinion on disability in a positive manner as they can be just as important to society.
Feeling good, feeling bad: Influences of maternal perceptions of the child and marital adjustment on well-being in mothers of children with an Autism Spectrum Disorder

D. M., Lickenbrock, N. V., Ekas & T. L. Whitman
Journal of Autism Development Disorders (2011)

Introduction

Previous research has reported that parents of children with ASD experience more stress than children with other disabilities. Research also shows that mothers experience more stress than fathers as they typically have more responsibility in the child’s care.

The well-being of mothers of a child with ASD can depend on the quality of their marital relationship. There is some research that shows increased rates of divorce and separation in parents of children with disabilities. In contrast, other research suggests the opposite, that children with developmental disabilities have brought both parents and the whole family closer together.

The study

The overall aim of the study was to examine the direct effect of marital adjustment on maternal well-being as well as looking at the positive and negative maternal perceptions of their child in mothers of children with ASD.

Forty-nine mothers participated in a 30 day diary. They completed daily questionnaires measuring negative and positive perceptions of their well-being, relationship with their partner, their child and life events. It was predicted that marital adjustment would be directly related to positive maternal affect and that the mothers’ positive and negative perceptions of the child would be related to maternal well-being.

Findings

The findings revealed that marital adjustment was related to positive perceptions and good maternal well-being. Mothers who reported higher levels of positive perceptions for the child were higher in marital adjustment and well-being. It was also found that marital adjustment determined the relation between negative perceptions and maternal effect. Mothers who were low in marital adjustment had negative perceptions of the child and low maternal well-being.

Conclusion

The current study demonstrates the important role that marital adjustment plays in the relationship between maternal perceptions of the child and well-being. It is also important to recognise the positive and negative aspects of raising a child with ASD. This study was the first to address the extent to which mothers’ perceptions of their children with an ASD is associated with both marital adjustment and maternal well-being across 30 consecutive days. However, more research is needed to explore this field on other family members.
Belief systems of families of children with Autism Spectrum Disorders or Down syndrome
G. King, D. Baxter, P. Rosenbaum, L. Zwaigenbaum & A. Bates
Focus on Autism and Other Developmental Disabilities (2009)

Introduction

Every family has their own views and values of the world which allows them to adapt to live their own lives. This is better known as family belief systems. They provide a sense of optimism in difficult situations, a sense of meaning in life and of purpose. They are also considered to be a key process involved in family resilience. Despite the great amount of literature into the experiences of parents with children with disabilities, relatively little is known about how families as a whole adapt to their situation.

The study

The overall aim of the present study was to directly examine family belief systems. The study also aimed to compare families of children with Autism Spectrum Disorders (ASD) and Down Syndrome during transitions periods such as starting elementary (6-8 years) and moving to high school (15-17).

Sixteen families from Ontario, Canada participated (8 for each disability) in 2 separate interviews. As in King et al 2011 (also in this issue), in the first interview parents generally talked about themselves, other family members and what was important to their family. The second interview was used to obtain more in-depth information after parents had time to reflect on their family worldviews and priorities. Parents also completed questionnaires to measure parents’ perceptions of the impact of the disability on the family and the family environment.

Findings

Parents reported three main positive attitudes: optimism, acceptance or appreciation and striving to meet their child’s needs and provide a supportive environment. Optimism was related to parents’ aim to expose children to challenging situations where they can learn. Acceptance was related to the view that the family should live as normal life as possible. Parents of high-school children were more involved in advocacy and more concerned about independence while parents of younger children were more concerned about physical safety. No major differences were found between families of children with ASD and Down Syndrome.

Conclusion

The attitudes and beliefs held by parents provide families with a sense of hope, meaning and control over their situation. They also highlight the strengths and resilience of families when facing difficult times. Parental perspectives on their role as parents can bring meaning to the experience of raising a child with a disability. Parents of children with ASD described having expanded roles which can cause stress but do feel rewarded.
“I like that he always shows who he is”: The perceptions and experiences of siblings with a brother with Autism Spectrum Disorder

M.A. Petalas, Hastings, R.P., Nash, S., Dowey, A. & Reilly, D.

Introduction

Much research shows that parents of children with Autism Spectrum Disorders (ASD) experience more stress than parents of any other disability. However, little is known about what is the experience of siblings of children with ASD. There have been mixed results in terms of how siblings adjust to living and growing up with a brother or sister with ASD. Research to date, however, comes from data obtained by parents and not the siblings themselves.

The study

The aim of the study was to investigate the perceptions and lived experiences of typically developing siblings, in middle-childhood, who were growing up with a brother with ASD.

A group of 8 siblings (out of 22) from Bangor, Wales, who had brothers with ASD, were chosen for this study based on the children’s age (9-12 years old). The siblings were interviewed about two main areas: (1) Their knowledge and perception of their sibling with ASD and 2) their perception of their relationship with their sibling with ASD.

Findings

Five main themes were identified from the interview transcripts: Siblings’ accounts of the impact on themselves and their families, tended to be quiet negative. Siblings also talked about others’ reactions which sometimes made them feel anxious, embarrassed and angry.

However, they also reported positive views and experiences. For instance, they talked about acceptance of their sibling as how he/she was, of feeling proud of their achievements and of having fun with them. Another theme they talked about was the sources of support they had (i.e., parental, professional or other siblings).

Conclusion

The current research highlighted both positive and negative sibling’s attitudes towards their brothers/sisters with ASD. Despite the fact that some of the siblings expressed a positive acceptance of their circumstances, others wanted change and in some cases a sense of tension was also found in the siblings’ accounts.

Alongside this, positive perceptions were identified which included positive interactions between siblings, feelings of pride and appreciation toward their brother/sister with ASD and a sense of gaining from their sibling relationships. These positive perceptions may serve an important role in siblings’ adaptation to growing up with a brother/sister with ASD.