

Do Mothers of Children with Autism are at Higher Risk of Depression? A Systematic Review of Literature*Ahmed Kamel AlHorany¹, Najati Ahmad Younis², Marwan Zaid Bataineh³, *Siti Aishah Hassan¹¹ Department of Counselor Education & Counseling Psychology, Faculty of Educational Studies, Universiti Putra Malaysia (UPM), 43400, UPM Serdang, Selangor Darul Ehsan, Malaysia² Special Need Department, College of Education, King Abdulaziz University, Jeddah 80200, Saudi Arabia³ Department of Psychology, College of Education, King Saud University, Riyadh 11451, Saudi Arabia*ah_horany2002@yahoo.com; najati_yunis@yahoo.com; marwanzaid76@yahoo.com;*siti_aishahh@putra.upm.edu.my

Abstract: We aimed to systematically review studies that examine factors affecting depression among parents of children with disabilities, especially, the autistic children. Besides, we emphasized the effects of gender on depression among the parents. There were at least 27 articles reviewed. The related journal articles on factor affecting depression were downloaded with cut off limit from 1997 to 2013. The articles were then analyzed and organized according to the definitions of depression and various factor affecting depression. We found there was no conclusive evidence regarding the factors affecting the depression among parents of children with autism. There was conclusive evidence from the reviewed literature regarding gender effect, yet the number of article supporting it was small. Mothers of children with autism were more affected in the depression as compared to fathers. Finally, with conclusion we then suggest for future interventional study.

[AlHorany, AK, Younis, NA, Batainah, MZ, Hassan SA. **Universiti Putra Malaysia (UPM), 43400, UPM Serdang, Selangor Darul Ehsan, Malaysia.** *Life Sci J* 2013;10(1):3303-3308]. (ISSN: 1097-8135). <http://www.lifesciencesite.com>. 418

Keywords: systematic review, depression, autism, gender, parents

1. Introduction

Autism is a prevalent disorder with tremendous impact on individuals, families, and society (Joshi et al., 2010). It occurs ubiquitously, regardless of races, nationalities, cultures, and social classes. It is nevertheless most common among males; four of every five people with autism are males.

The most common criteria used for the diagnosis of autism are defined by the Diagnostic and Statistical Manual of Mental Disorders Text Revision, Fourth Edition (DSM-TR- IV, 2000). The DSM-TR-IV classifies autism as a childhood developmental disorder with symptoms present before age three. The core diagnostic features of autism include impairments in social interaction and communication, as well as restricted and repetitive patterns of behavior such as hand flapping (American Psychiatric Association, 2000). Generally, the common features of autistic disorder include having trouble interacting with others and a tendency to odd interests. These hallmarks of autistic characteristics affect the whole family system (AlHorany et al, 2013).

Parenting children diagnosed with autism is a demanding task with unique concerns and exceptional challenges. Children with autism more often than not exhibit impaired communication, dysfunctional social relations, aggression, self-injurious behavior, inappropriate affect, tantrums, obsessive-compulsive behavior, and life-long dependency; each of which

contributes to high stress levels in the family (Alisa, 2004). In short, results indicated that these families are under pressures due their handicapped children.

As the number of children diagnosed with autism increases around the world, whilst it has been estimated that two to ten out every 10,000 people will be diagnosed with this disorder (Baird et al., 2006), more parents are confronted with the impact of this diagnosis, both individually and as a family.

As parents of children with autism face and suffer several problems in their life, many of these parents seek knowledge, skills and education about the disorder and possible effective interventions. Nevertheless, most of the interventions and treatments revolve around the individual with autism, neither on the parents' feelings nor marital conflicts as a result of having a child with autism. Therefore, support interventions such as learning new suggestions and ways of constructively coping with stressors should be included.

Therefore, we aimed to systematically review the literature on factors affecting depression among parents of the children with autism. Additionally, gender effect on depression among the parents was emphasized. However, we first reviewed on the definitions of depression. At last, we suggest for future studies.

2. Material and Methods

2.1. Material

There were at least 27 articles reviewed. Of 27 articles there were 12 articles on factors affecting depression. The articles were empirical and meta-analysis review on the factors affecting depression among parents of children with disabilities.

2.2. Procedure

The articles were mainly downloaded using University Putra Malaysia subscribed data based. Scopus, Springer and Ebscohost were among the frequently used. In addition, Google scholar was also employed. The related journal articles on factor affecting depression downloaded with cut off limit from 1997 to 2013 only. The downloaded articles were then summarized and organized in the following sections

3. Results

First, the downloaded articles were analyzed on definition of depressions. Second, they were on various factors affecting depression among parents of children with disabilities, third on parents with autistics children. Finally, an emphasis of gender effect on depression of the parents was reviewed.

3.1. Definitions of depression

Depression is a common mental disorder which is indicated by depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These problems can become chronic or recurrent and lead to substantial impairments in an individual's ability to ensure the smooth running of his or her everyday responsibilities. At its worst, depression can lead to suicide.

Depression is a complex mental disorder which involves body and mood with varied types from mild to severe and from a relatively short lived to a chronic condition. Depression affects people in several different ways and symptoms are spread over different aspects of functioning: Motivation, Emotional, Cognitive, Behavioral, and Biological (Gilbert, 2000). Depression can be an acute onset within short period of time or maybe come on gradually as a result of accumulations of the life events surrounded people.

Gilbert (2000) illustrated depression as a complex web of interaction, which is representing the essence of the biopsychosocial approach. For example, "a negative life event may increase the production of stress hormones. As this happens our cognitions and emotions are affected and we focus more on negative events which further increases the production of stress hormones. A negative event may trigger underlying negative beliefs (e.g. of being

worthless, useless or unlovable). As the beliefs seem 'more true' they increase stress and that releases more stress hormones and increases the symptoms of stress (e.g. poor sleep and poor concentration). This adds to feelings of exhaustion and of being 'useless; Or a cognitive beliefs like 'I am boring – people will get fed-up with me' may lead to reduces social behavior and further feelings of aloneness – all of which affect the stress hormones"(p. 4).

3.2. Factors Affecting depression

There is a clear relationship between stressful life events and the severity of mental health illnesses and disorders, particularly depression (Gilbert, 2000). Through, Gilbert's reviewed to compare depressed and non-depressed people, findings of the study found that those who were depressed experienced significantly more recent stressful life event and life strains than did the non-depressed people. Furthermore, they found an association between the severity of the depression and the number of stressful life events recently experienced.

Having a severely disabled child constitutes more than a single stressful event. It is an ongoing source of stress which lasts for the lifetime of the individual or the family. Being a parent to a child with autism includes many distressing challenges, many of those parents face emotional distress, guilt, anxiety, sadness, isolation, and feel overwhelmed by their environmental stressors.

Studies indicated that child symptom severity predictor of affect mental health problems of parent having a disabilities child. (Hastings 2002). Children having autism exhibit a wide range of problematic symptoms and behaviors which can lead to parenting stress. In other angel, parents of having a child with autism suffering set of internal and external stressors such as, financial burden, lack of social support, and inability to adapt with crisis. Under such circumstances, an increase in secondary stressors may result in parents experiencing increased negative emotions which in turn, may lead to increased depressive symptoms in parents and the whole family members (Hastings 2007).

Generally, the challenging symptoms and behaviors of children with autism that have the potential of severely disrupting caregiver roles, relationships, and activities in a variety of areas, including finances, work, and family life, thereby leading to depression and other problematic outcomes (NICHD, 2005; Hastings 2007).

3.3. Depression and Parents of Children with Disabilities

Previous researches focused on families of children with developmental disabilities have often been reported that parents experience high levels of psychological problems than parents of typically developing children (Olsson & Hwang, 2001; Yahya, 2003; Najjar, 2006; Singer, 2006). Being a parent to a child with autism includes many distressing challenges; it noticeably modifies the daily life of each member of the family. Family caregivers of children diagnosed with autism are known to be exposed to confusion, feelings of fear, and stress. Studies showed that families of children with disability face several challenges and experience high level of depression as well as other psychological problems; anxiety, emotional distress, guilt, restrictions of duties, roles and activities, feel overwhelmed by their environmental stressors, and marital conflict (NICHD, 2005; Shu et al., 2000).

Several studies have documented the considerable impact of caring for children with disabilities on the parents' quality of life. Furthermore, other findings showed that caregivers of disabled children are at a considerably higher risk of loneliness, anxiety, stress, and depression than parents in typical families. (Hastings, 2007; Nachshen and Minnes, 2005; Olsson and Hwang, 2001; Singer, 2006).

One study found less parenting competence, marital satisfaction, psychological well being (e.g. depression and anxiety), and family adaptability reported by the parents of children with autism (Shu et al., 2000). The aim of this research was to investigate the impact of children with autism on the mental health of their mothers. The research showed that mothers of children with autism have greater caregiving burden, depression, and anxiety than mothers of children with other chronic diseases.

Singer, (2006) conducted a research to review findings from comparative researches of depression among mothers of children with and without disabilities. Effect sizes for 18 studies conducted between 1984 and 2003 were determined in this study. Results of the study revealed that effect size of 0.39 demonstrated a high level of depression in mothers of children with intellectual disorders. The available research indicates that mothers of children with intellectual disabilities are at high risk of depression compared to mothers of children with no disorders.

Benson & Karlof (2009) indicated that raising an autistic child can result in considerable psychological distress, greater levels of anger, and depressive symptoms. Amongst other important findings, their study indicated that anger can influence caregiver's health in both direct and indirect ways. In

addition, findings found informal social support to decrease parent depressed mood over time.

To evaluate parenting depression in parents of children with and without disabilities, Olsson and Hwang (2001) conducted a study by using the Beck Depression Inventory in 216 families with children with autism and/or intellectual disability, and in 214 typical families. Findings showed that mothers of children with autism had higher depression than mothers of children with intellectual disability, who in turn, had higher depression levels than fathers of children with autism, fathers of children with intellectual disability, and typical mothers and fathers. In addition, 45 % of mothers with children with intellectual disability and 50% of mothers of children with autism had increased depression levels compared to 15-21% in the other groups. Interestingly, stepmothers of disabled children were found to be more vulnerable to high depression than mothers living with a partner.

Furthermore, other studies exploring within-group differences have also showed considerably elevated levels of depression-related symptomatology with other disorders, especially Down's syndrome (Abbeduto et al., 2004).

However, it cannot be assumed that the existence of a disabled child causes an increase in depression among parents. In some cases, parents have already mood disorders before the birth of children (Cohen & Tsiouris, 2006).

In general, parents are affected by having children with developmental disabilities depend on both external and internal circumstances. Essential external circumstances include the financial support and the extent to which the disabled individuals are accepted and welcomed into family and society activities (Park, Turnbull, & Turnbull, 2002). Internal characteristics include preexisting troubles in the whole family (e.g., symptoms of the depression or marital problems (Singer, 2006), spirituality and involvement in spiritual activities (Poston & Turnbull, 2004), and the extent to which parents join support groups seeking education and assistance from community and family members (Ainbinder et al., 1998). Generally, most of the research demonstrates the difficulties involved in parenting a children with developmental disorders.

3.4. Gender effects

To date, the majority of previous researches on depression to having a child with Autism Spectrum Disorders was mostly based on mothers' reports and rarely included fathers as informants (AlHorany, et al 2011).

Considerable research has been conducted examining the adverse effects of raising a child with

autism (e.g., Hastings, 2002; Olsson and Hwang 2001; Ekas, Lickenbrock & Whitman, 2010). Gray (2003) indicated that mothers were much more likely to claim that their child's autism had severely affected their emotional well-being. Also, mothers were the parent who was most likely to be held responsible for their child's behavior. Moreover, Gray found that almost all parents with children with autism have felt stigmatized in public situations (for example at the supermarket or a shopping mall), and that mothers of younger and/or more severely disabled children felt more stigmatized.

In their study, Ekas et al. (2010) indicated that mothers of children with autism have been found to display increased rates of depression. This study examined whether and how the resources such as, religious beliefs, religious activities, and spirituality were related to maternal socio-emotional functioning. Thus, mothers completed scales assessing religiosity, spirituality, depression, stress. However findings of this study also, revealed that religious beliefs and spirituality were associated with better positive outcomes.

Olsson and Hwang (2001) conducted a study to assess parental depression by using the Beck Depression Inventory (BDI) in 216 families with children with autism and/or intellectual disability (ID), and in 214 control families. Their results were found that Mothers with children with autism had higher depression scores (mean = 11.8) than mothers of children with ID without autism (mean = 9.2), who in turn, had higher depression scores than fathers of children with autism (mean = 6.2), fathers of children with ID without autism (mean = 5.0), and control mothers (mean = 5.0) and fathers (mean = 4.1). However, Hastings et al. (2005) studies 48 pairs of parents of children with ASD and found that the fathers were less depressed than the mothers.

4. Discussion

Our review found that a substantial amount of articles have documented that being a parent of an autistic child shows wide spectrum of feelings expressed (e.g. great stress, physically health attached, feelings of guilt, anger, marital problems with the spouses, etc). In fact, parents of children with disabilities don't have the choice of escaping or hiding their situation.

Typically, most of the support groups revolve around the autistic individuals, making matters worse is that many parents do not seek help for themselves and their own feelings as a result of having an autistic child. However, those parents need to balance their attention to all of the family members as well as their psychological well being itself.

Individual differences in coping style have been highlighted as possible influencers of the

relationship between parenting stress, depression and anxiety for parents both of children with a developmental disorder in general. Stress as a state of physiological or psychological response to internal or external stressors, influencing how one feels and behaves and directly or indirectly causing mental and physical illness.

Cooper et al (1997) indicated that several stressors was directly and indirectly related to stress, for example, people suffering from stress can suffer a range of ailments including tension headaches, allergies, back problems, colds and flu, depression, anxiety, irritation, tension and sleeplessness.

In an effort to investigate and describe the interpersonal nature of depression, Sandberg & Harper (2000) used statistics on levels of depression, psychological distress, and marital conflict in 535 couples was analyzed. In particular, the findings found that marital discord was significantly associated with levels of depression for both partners. Results have also found that levels of stress and/or health in either partner were directly and indirectly associated with depression for husbands and wives. To summarize, Table 1 shows there is no conclusive evidence regarding the factors affecting the depression among parents of children with autism. However, there is consistence evidence on gender effect.

5. Suggestion

Based on our review, it is suggested that group counseling may help parents to cope with challenges and demands of adapting to change and loss consequent to illness and disability.

The volume of literatures on the efficacy of cognitive behavior therapy (CBT) on depression is well documented. Yet, there is still a gap in the literature for depression faced by parents of children with autism. Moreover, the way parents are affected by having children with mental disabilities depends on both individual family characteristics and external circumstances. Depression is a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These problems can become chronic or recurrent, thus leading to substantial impairments in an individual's ability to take care of his or her everyday responsibilities. At its worst, depression may lead to suicide. Thus, new researches have strengthened the efficacy of CBT on depression via a new targeted population (Khoshbooi, 2011).

Furthermore, it is important for counseling practitioners to be aware of understanding these families which increase in the stressful events and experience much emotional turmoil such as having a disabled child where the parents scarify to help their

children. Hence, specific interventions which focuses on strengthening and assisting parents with their feelings regarding being a parent to an autistic child may be employed so that the therapy may reduce some of these feelings and provide parents with much needed relief.

Cognitive behavioral therapy (CBT) is a treatment process that helps clients to correct their false self-beliefs that lead to unwanted mood and certain behaviors. This type of treatment has been

proven to yield positive outcomes, including increased feelings of value and happiness. A CBT therapist helps clients to identify unwanted thoughts and teach strategies to replace those negative thoughts in more optimistic frameworks. Since parents with children with autism exhibit signs and symptoms of depression and stress, an appropriate intervention based on CBT principles and techniques have been used to decrease the symptoms.

Table 1: A summary of studies on factors influencing depression and gender effects

NO	Author (Year)	Source	Type of articles	Factors affects Depression	Findings
1	Abbeduto et al (2004)	American Journal on Mental Retardation,	Empirical	mental health problems	Negative relationship
2	Baker et al (2002)	Am J Mental Retardation	Empirical	levels of stress	Negative relationship
3	Benson & Karlof (2009)	Journal of Autism and developmental Disorders	Empirical	levels of angers, psychological distress and social support	positive, positive and negative relationships
4	Cohen & Tsiouris (2006)	Journal of Autism & Developmental Disorders	Empirical	parental mood disorders	positive association
5	Ekas, Lickenbrock & Whitman (2010)	Journal of Autism and Developmental Disorders	Empirical	Gender religious beliefs religious activities spirituality	positive association
6	Gray (2003)	Social Science and Medicine	Empirical	emotional well-being gender	
7	Hasting(2002)	Journal of Intellectual & Developmental Disability	Empirical	child symptom severity	Positive relationship
8	Nachshen and Minnes (2005)	Journal of Intellectual Disability Research	Empirical	caring for disabled children	Negative relationship
9	Olsson & Hwang (2001)	Journal of Intellectual Disability Researc	Empirical	parental depression gender	positive association
10	Sandberg & Harper (2000)	Aging and Mental Health	Empirical	gender	direct effect indirect effect
11	Shu et al (2000)	Journal of Intellectual Disability Research	Empirical	marital satisfaction less parenting competence family adaptability	Negative relationship
12	Singer (2006)	American Journal on Mental Retardation	Meta-analysis	gender	positive association

Acknowledgments:

We would like to thank UPM library and Dr. Nil Farakh Sulaiman who edited our work. However, the remaining errors are due to authors.

Corresponding Authors:

Siti Aishah Hassan

Ahmed Kamel AlHorany

siti_aishahh@putra.upm.edu.my

ah_horany2002@yahoo.com

References

1. Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M.W., Osmond, G. & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, 109, 237-254.
2. Ainbinder, J.G., Blanchard, L.W., Singer, G.H., Sullivan, M.E., Powers, L.K., Marquis, J.G., Santelli, B., & the Consortium to Evaluate Parent to Parent. (1998). A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology*, 23, 99-109.
3. AlHorany, A., Hassan, S. A., Baba, M. & Juhari, R (2011). Efficacy of Group Cognitive Behavioral Therapy on Depression among Muslim Parents of Children with autism in Jordan, *Australian Journal of Basic and Applied Sciences*, 5, 827-832.
4. AlHorany, A.K., & Hassan, S. A. Bataneih, M.Z. (2013). A review on factors affected Marital Adjustment among parents of autistic children and gender effects. *Life Science Journal*, 10(1), 400-405. ISSN: 1097 – 8135
5. Baker, B. L., Blacher, J., Crnic, K. A, & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *Am J Mental Retardation*, 107, 433-44.
6. Beach, S. Katz, I. Kim, S. Brody, G. (2003). Prospective effects of marital satisfaction on depressive symptoms in established marriages: A dyadic model. *Journal of Social and Personal Relationships*, 20, 355-371.

7. Benson, P. & Karlof, K. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39, 350-362.
8. Cohen, I., & Tsiouris, J. (2006). Maternal recurrent mood disorders and high-functioning autism. *Journal of Autism & Developmental Disorders*, 36, 1077-1088.
9. Cooper, C.L., Kerslake, H. & Rout, U.R. (1997). Working and nonworking mothers: comparative study. *Women in management review*, 12, 264-275.
10. Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 1274-1284.
11. Gilbert ,P. & Bailey, K.G. (2000), *Genes on the couch: Explorations in evolutionary psychotherapy* (pp. 118-150). Hove: Brunner-Routledge.
12. Gray, D. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*, 56, 631-642.
13. Hastings, R. P. (2007). Longitudinal Relationships between Sibling Behavioral Adjustment and Behavior Problems of Children with Developmental Disabilities. *J Autism Dev Disord*. 37, 1485-1492.
14. Hastings, R. (2002). Parental stress and behaviour problems of children with developmental disabilities. *Journal of Intellectual & Developmental Disability*, 27, 149-160.
15. Khoshbooi R., Hassan, S. A., Hamzah, M. S. G., & Baba, M. (2011). Effectiveness of group cognitive behavioral therapy on depression among Iranian women around menopause. *Australian Journal of Basic and Applied Sciences*, 5(11): 991-995
16. Montes, G & Halterman, J. (2007). Psychological Functioning and Coping among Mothers of Children with Autism: A Population-Based Study. *Pediatrics*, 119, 1040-1046.
17. Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research*, 49(12), 889-904.
18. The National Institute of Child Health and Human Development (2005). Autism Overview: What We Know. Retrieved on March 14, 2005 from <http://www.nichd.nih.gov>.
19. Najjar, A. (2006). *Mental health disorders in Jordan*. Alfiker Dar. Amman, Jordan.
20. Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535-543.
21. Park, J., Turnbull, A. & Turnbull, H. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children*, 68, 151-170.
22. Poston, D. & Turnbull, A. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 39(2), 95-108.
23. Sandberg, J. G., & Harper, J. M. (2000). In search of a marital distress model of depression in older marriages. *Aging and Mental Health*, 1, 210-222.
24. Shattuck, P.T., Seltzer, M.M., Greenberg, J.S., Orsmond, G.I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37, 1735-1747.
25. Shu, B. C., & Lung, F. W. (2005). The effect of support group on the mental health and quality of life for mothers with autistic children. *Journal of Intellectual Disability Research*, 49(1), 47-53.
26. Singer, G. H., (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111, 155-169.
27. Yahiya, K. (2003). *Consult Families of People with Special Needs*. Dar Alfiker. Amman, Jordan.