

Research Article

Volume 7 Issue 2 - October 2017
DOI: 10.19080/PBSIJ.2017.07.555710

Psychol Behav Sci Int J

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Burden of parents with Children Diagnosed with Pervasive Developmental Disorders and Behavioural Disorders [BD]



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Submission: October 02, 2017; **Published:** October 26, 2017

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Abstract

Theoretical Background: Research indicates that the presence of one or more children with developmental and behavioral disorders increase the psychological burden of parents

Purpose/Objective: The objective of this study is the investigation of the burden of parents with children with Pervasive Developmental Disorders [PDD] and Behavioural Disorders [BD] who come to Children's Mental Health Centers and Advisory Stations.

Materials and Methods: 104 parents [either mother or father] of children of both sexes suffering from Pervasive Developmental Disorder [PDD] took part in the research, and an additional 25 parents [either mother or father] of children of both sexes with Behavioral Disorders [BD] also participated. The questionnaire was used for the data collection was the Zarit Burden Interview.

Results: More specifically it is statistically borderline evident and important ($p=0,057$) that mothers on average ($11,74 \pm 5,00$) experience the intensity of the care-giving role more profoundly as opposed to the men ($9,93 \pm 6,03$). Additionally, it is statistically significantly evident ($p=0,007$) that mothers on average ($8,41 \pm 4,00$) experience the relationship deprivation more profoundly than their male counterparts ($6,39 \pm 4,24$). Also, it is statistically significantly evident ($p=0,036$) have on average ($39,05 \pm 16,54$) a higher total care giving coping burden in relation to men ($33,07 \pm 18,84$).

Conclusion: Parents with children that suffer either from pervasive developmental disorders or behavioral disorders, experience a psychological burden. Parents with children that suffer either from pervasive developmental disorders have higher psychological burden than parents with children with behavioral disorders. Mainly it is noteworthy that mothers are burdened more than fathers.

Keywords: Psychological Burden, Parents of children with pervasive developmental disorders, Parents of children with behavioral disorders

Introduction

Child care with autism spectrum disorders and behavioral disorders has increased significantly in recent years, with a higher incidence rate in boys (85.9%) Chakrabarti [1]. This increase is probably due to the fact that it is possible to diagnose, develop and make available services, to raise public awareness, but not to exclude other factors Elsabbagh et al. [2], Fombonne [3]. These children's speech problems White [4], which increases the difficulty of communicating with the social environment, and their desire for communication, results in provocative behavior Chiang [5]. Due to their lack of social skills, they are more likely to experience symptoms of depression, anger, suicidal ideation, provocative behavior Green et al. [6], low self-esteem and anxiety, making their adaptation difficult Lake et al. [7]; Kim et al. [8]. At the same time, according to the National Collaborating Center for Mental Health (UK) (2013), behavioral disorders seen

in childhood and adolescence at the global level are now seen as the most common mental health disorders in children and adolescents.

Most common cause of referral to similar mental health services as early as 1987, Kazdin identifies anti-social behavior in children as a predominant and serious clinical problem. Many children have symptoms of social isolation Bauminger et al. [9], reduced academic performance and progress at school, attention deficit disorder, hyperactivity, which in adolescence are manifested with symptoms of delinquency and antisocial behavior Reid et al. [10], McGilloway [11] On the other hand, research shows that the presence of one or more children with disorders is psychologically burdened by parents Taylor-Richardson [12], Myers [13] report that the autistic child's parents experience the constant anxiety and the burden of

uninterrupted care and supervision together with provocative behaviors, social isolation, struggle for school and lack of respite, resulting in the calm of the family is disturbed. According to Weiss [14], the family's internal capabilities, members' needs, external resources and subjective assessments often lead to a crisis. At the same time, Gona [15] note that the challenges that parents face, regardless of their cultural or religious background, are stigma, financial burden, lack of proper treatment, and especially the burden of care, which affects them their mental wellbeing.

Moreover, the psychological burden of parents whose children experience emotional and behavioral disorders, anxiety about their child's condition, fatigue, depression, as well as the burden of their physical health adversely affect their social interactions, relationships with Meltzer [16] and their efficiency in their work Rosenzweig [17,18] This burden can often come from either the occurring incidents, such as inconvenience to peers and neighbors, police intervention, interruption of employment, financial pressure, disturbed family relationships, or emotions they feel like anger, stigma, guilt, sadness, entrapment and anxiety [19]. In this research study, an effort is being made to investigate the burden of parents of children with diffuse developmental disturbances (DRFs) and behavioral disturbances (ADs) coming to Centers and Counseling Centers of Child and Mental Hygiene, as well as exploring the social and demographic characteristics of parents and children.

Materials and Methods

The survey was conducted at a Child Psychotherapeutic Center, at a Child Psychiatric Center and at a Day Center, which serve as centers for prevention, diagnosis, treatment, counseling support aimed at rehabilitating disorders of children and adolescents and their psychosocial support and who receive incidents from all over the country West Greece. In the survey, 104 parents (either mother or father), children of both sexes with Pervasive Developmental Disorder (PDD) and 25 parents

(either mother or father), children of both sexes with Behavioral Disorders Counseling and Child Psychiatric Centers in their quest to tackle the problem. Completion of the questionnaire was carried out with the help of a professional while the parents were in the waiting room and the specialist was alone with the child.

The data collection process took place over a period of 7 months, from October 2016 to April 2017. For the collection of data, the Zarit Burden Interview Zarit [20] was used. The Zarit Burden Interview measurement scale 1987 was designed to assess the burden of American caregivers of dementia patients. According to Zarit [20], the burden of carers refers to their physical health, psychological well-being, economic factors, their social life and their relationship with the family member they take care of. It was translated into Greek and weighed to Greek Cypriot caregivers with dementia by [21] and according to the results of their study constitutes a valid and reliable tool for anyone who would like to use it in the Greek population. According to the questions (a total of 22) the dimensions of the burden of care are: personal tension, the intensity of the role, the deprivation of relationships and the care of the care. During the completion of the questionnaire, clarifications were requested from the parents where they were given. The time to complete the questionnaire given to the parents was about 5-10 minutes

Results and Demographics

A higher percentage (62.5%) of both fathers of children with PDD compared to mothers and fathers (80.0%) of children with BD compared to mothers participated in our research (Table 1). Of the children in the study, PDD boys were in a higher percentage (82.7%) than girls with PDD and boys with a higher percentage (72.0%) than boys with AD (Table 2). Parents of children with PDD 89.4% declare married to parents of children with BD who declare married to 68.9%. The difference observed is statistically significant ($\chi^2 = 7.365$; $p = 0.007$) (Table 3).

Table 1: Gender Relationship of Parents Responding to Children with PDD and BD.

| Gender | | Parents | Children with PDD | Parents | Children with BD | Total |
|--------|-------|---------|-------------------|---------|------------------|--------|
| | Man | | 65 | | 20 | 85 |
| | | | 62,5% | | 80,0% | 65,9% |
| | Woman | | 39 | | 5 | 44 |
| | | | 37,5% | | 20,0% | 34,1% |
| | Total | | 20 | | 104 | 25 |
| | | | 100,0% | | 100,0% | 100,0% |

Table 2: Relationship gender of Children with PDD and BD.

| Gender | | Children with PDD | Children with BD | total |
|--------|-------|-------------------|------------------|--------|
| | Boy | 86 | 18 | 104 |
| | | 82,7% | 72,0% | 80,6% |
| | Girl | 18 | 7 | 25 |
| | | 17,3% | 28,0% | 19,4% |
| | Total | 104 | 25 | 129 |
| | | 100,0% | 100,0% | 100,0% |

Table 3: Work Relationship of Parents Responding to Children with PDD and BD.

| | | Parents of children with PDD | Parents of children with PDD | Total |
|------------------|-----------------------------|------------------------------|------------------------------|---------|
| | | | | |
| Work | State employee | 22 | 5 | 27 |
| | | 21,2% | 20,0% | 20,9% |
| | Private employee | 26 | 3 | 29 |
| | | 25,0% | 12,0% | 22,5% |
| | Farmer - Worker | 4 | 1 | 5 |
| | | 3,8% | 4,0% | 3,9% |
| | Professional - Trader | 14 | 6 | 20 |
| | | 13,5% | 24,0% | 15,5% |
| | Unemployed | 33 | 9 | 42 |
| | | 31,7% | 36,0% | 32,6% |
| | Retired | 5 | 1 | 6 |
| | | 4,8% | 4,0% | 4,7% |
| Family situation | Married | 104 | 25 | 129 |
| | | 100,0% | 100,0% | 100,0% |
| | Single / Divorced / Widowed | 93 | 17 | 110 |
| | | 89,4% | 68,0% | 85,3% |
| | Total | 11 | 8 | 19 |
| | | 10,6% | 32,0% | 14,7% |
| | Pearson Chi-Square | 104 | 25 | 129 |
| | | 100,0% | 100,0% | 100,0% |
| | Value | 7,365 | Df | p-value |
| | | | 1 | 0,007 |

Results of burden Interview of Parents

The personal intensity of the interviewed parents in total ranged from 0 to 32 with an average of 13.85 ± 7.81 showing a minimal to moderate burden (see the corresponding tables with the price levels of all the indicators) (Table 4). The intensity of the role of the interviewed parents overall ranged from 1 to 25 with an average of 11.12 ± 5.46 showing a modest burden (Table

4). The deprivation of the interviewed parents' relationships in total ranged from 0 to 16 with an average of 7.72 ± 4.18 showing a moderate to severe burden (Table 4). The management of the care of the interviewed parents overall ranged from 0 to 8 with an average of 4.31 ± 2.38 , which also shows a moderate to severe burden (Table 4). Finally, the total psychological burden of care for respondents in parentheses ranged from 7 to 77, averaging 37.01 ± 17.52 , showing a modest burden (Table 4).

Table 4: Indicators of Burden Care interview Indicators of Responding Parents of Children.

| Indicators/scales | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------------------|-----|---------|---------|--------------|----------------|
| Personal intensity | 129 | 0 | 32 | 13,85 (36,0) | 7,81 |
| Intensity of role | 129 | 1 | 25 | 11,12 (28,0) | 5,46 |
| Loss of relationship | 129 | 0 | 16 | 7,72 (16,0) | 4,18 |
| Care of management | 129 | 0 | 8 | 4,31 (8,0) | 2,38 |
| Total psychological burden of care | 129 | 7 | 77 | 37,01 (88,0) | 17,52 |

Table 5: Burden Care interview Indicators of Responding Parents of Children with PDD.

| Indicators / scales | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------------------|-----|---------|---------|--------------|----------------|
| Personal intensity | 104 | 0 | 32 | 14,18 (36,0) | 7,75 |
| Intensity of role | 104 | 1 | 25 | 11,35 (28,0) | 5,51 |
| Loss of relationship | 104 | 0 | 16 | 7,86 (16,0) | 4,32 |
| Care of management | 104 | 0 | 8 | 4,42 (8,0) | 2,46 |
| Total psychological burden of care | 104 | 7 | 77 | 37,81 (88,0) | 17,60 |

Table 6: Burden Care Questionnaire Indicators of Responding Parents of Children with BD.

| Indicators / scales | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------------------|----|---------|---------|--------------|----------------|
| Personal intensity | 25 | 1 | 29 | 12,48 (36,0) | 8,06 |
| Intensity of role | 25 | 3 | 24 | 10,20 (28,0) | 5,27 |
| Loss of relationship | 25 | 2 | 13 | 7,16 (16,0) | 3,56 |
| Care of management | 25 | 0 | 8 | 3,84 (8,0) | 2,01 |
| Total psychological burden of care | 25 | 8 | 73 | 33,68 (88,0) | 17,15 |

In Tables 5 & 6 it is obviously that all the indicators-dimensions of burden of parents of children with BDD are higher than that of the parents interviewed of children with BD.

By checking the indicators of the gender-based Parental Care Questionnaire for parents of parents, we found that: The personal intensity of the mothers interviewed was 14.52 ± 7.43 (Table 7), higher than that of the fathers interviewed, which was 12.57 ± 8.43 (Table 8) without the difference being observed statistically significant ($U = 1532, 500$; $p = 0,093$) (Table 9). Similarly, the management of the care of the mothers interviewed was 4.38 ± 2.46 (Table 7), higher than the same indicator of the fathers interviewed, which was 4.18 ± 2.24 (Table 8) without the difference being observed statistically significant ($U = 1814,$

000 ; $p = 0.777$) (Table 9). In contrast, the intensity of the role of the mothers interviewed was 11.74 ± 5.00 (Table 7), higher than the intensity of the interviewed fathers, which was 9.93 ± 6.03 (Table 8). The difference observed is marginal statistically significant ($U = 1488, 000$; $p = 0.057$) (Table 9). The deprivation of mothers' relationships was 8.41 ± 4.00 (Table 7), much higher than the same index of fathers interviewed, which was 6.39 ± 4.24 (Table 8). The difference observed is statistically very significant ($U = 1330, 500$; $p = 0,007$) (Table 9). Finally, the total maternal care burden was 39.05 ± 16.54 (Table 7), much higher than the same index of fathers interviewed, which was 33.07 ± 18.84 (Table 8). The difference observed here is statistically significant ($U = 1447, 500$; $p = 0,036$) (Table 9).

Table 7: Indicators of Burden Care interview Indicators of Responding mothers.

| Indicators/ scales | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------------------|----|---------|---------|-------|----------------|
| Personal intensity | 85 | 1 | 30 | 14,52 | 7,43 |
| Intensity of role | 85 | 3 | 24 | 11,74 | 5,07 |
| Loss of relationship | 85 | 1 | 16 | 8,41 | 4,00 |
| Care of management | 85 | 0 | 8 | 4,38 | 2,46 |
| Total psychological burden of care | 85 | 8 | 73 | 39,05 | 16,54 |

Table 8: Indicators of Burden Care interview Indicators of Responding Fathers.

| Indicators/ scales | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------------------|----|---------|---------|-------|----------------|
| Personal intensity | 44 | 0 | 32 | 12,57 | 8,43 |
| Intensity of role | 44 | 1 | 25 | 9,93 | 6,03 |
| Loss of relationship | 44 | 0 | 15 | 6,39 | 4,24 |
| Care of management | 44 | 0 | 8 | 4,18 | 2,24 |
| Total psychological burden of care | 44 | 7 | 77 | 33,07 | 18,84 |

Table 9: Correlation of indicators of burden of Responding Parents according the gender.

| Scales | Gender | Mean rank | Sumo franks | Mann-Whitney U | p-value |
|------------------------------------|--------|-----------|-------------|----------------|---------|
| Personal intensity | Mother | 68,97 | 5862,50 | 1532,500 | 0,093 |
| | Father | 57,33 | 2522,50 | | |
| Intensity of role | Mother | 69,49 | 5907,00 | 1488,000 | 0,057 |
| | Father | 56,32 | 2478,00 | | |
| Loss of relationship | Mather | 71,35 | 6064,50 | 1330,500 | 0,007 |
| | Father | 52,74 | 2320,50 | | |
| Care of management | Mother | 65,66 | 5581,00 | 1814,000 | 0,777 |
| | Father | 63,73 | 2804,00 | | |
| Total psychological burden of care | Mother | 69,97 | 5947,50 | 1447,500 | 0,036 |
| | Father | 55,40 | 2437,50 | 1447,500 | 0,036 |

Discussion

This study involved 129 parents (father or mother) of children with Diffuse Developmental Disorders and Behavioral Disorders. Of the 104 parents of children with PDD, 65 were fathers and 39 were mothers. Of the 25 parents with children with a BD, 20 were fathers and 4 mothers. It is characteristic that the child was accompanied by the father (65.9%) to the Child Psychotherapy-Hygiene Center, compared with the mother (34%) of the total. Regarding professional employment, it is characteristic that 32.6% of the total are unemployed, with a higher percentage of 36.0% being the parents of children with Behavioral Disorders. A study by Costello [22] states that children from very poor families were more at risk of developing comorbidities of emotional and behavioral disorders. Typically, Gatsa [23] report on the child's aggressive schooling and psychological well-being that the father's unemployment was of particular significance on the part of the victim. In a similar study, children of long-term unemployed parents, along with Christoffersen [24] are isolated at school, their psychosomatic balance is disturbed, they have low self-esteem and school performance, or they may even fall victim to intimidation. It is a fact that there is a burden on families with socio-economic problems. At the same time, similar study findings indicate that child behavioral disorders (difficulty of adaptation, aggression, substance use) are also observed in families with financial comfort and social background Luthar, Ansary [25] Luthar, Latendresse [26] due to limited bibliography.

Of course, it is worth noting that only 4.7% of the parents were farmers or workers, which deserves to be explored more in terms of accessibility from rural areas to similar diagnostic,

support and treatment centers. At the same time, in Table 2 it appears that among the children involved in the study, the PDD boys were in a higher percentage (82.7%) than the girls with PDD Chakrabarti [1], as boys with a higher percentage (72.0%) against boys with BD. On the other hand, as regards the marital status, the difference is observed statistically significant ($\chi^2 = 7,365$; $p = 0,007$), where 89,4 parents of children with PDD were married compared to parents of children with BD declared married only 68,9%. Possible behavioral disorders when there are no developmental disorders, which are necessarily inherent, are related to the particular marital status divorce, single parent family Magpantay [27]; Van Roy [28] reports that relationships in the family are an important factor in children's problem behaviors. Relevant studies have shown that ongoing conflicts and disputes between spouses as well as divorce as a fact affect children's behaviors Krishna kumar [29], resulting in difficulties in adapting, substance abuse behavioral problems and performance at school, but and behavioral and emotional disorders Amato and Cheadle [30].

With regard to the total psychological burden of care for respondents, the total number ranged from 7 to 77, with an average of 37.01 ± 17.52 showing a modest burden (Table 4). Of course, the deprivation of relationships and the management of the care of the interviewed parents overall ranged from 0 to 16 with an average of 7.72 ± 4.18 and from 0 to 8 with an average of 4.31 ± 2.38 respectively, showing a moderate to severe burden Ankri [31] (Table 4). Regarding the total psychological burden of care of the respondents parents of children with PDD was 37, 81 ± 17 , 60 (Table 5), higher than the same index of respondents parents of children with BD that was 33, 68 ± 17 , 15 (Table 6)

Cadman 1996. More specifically, the findings of this research show that, in general, all indicators of burden care are higher in mothers than in fathers. In particular, it seems marginal statistically significant ($p=0.057$) that mothers on average (11.74 ± 5.00) experience the role of the role higher than fathers (9.93 ± 6.03). Also, it is statistically very important ($p = 0.007$) that mothers on average (8.41 ± 4.00) experience the deprivation of relationships also higher than men (6.39 ± 4.24). In addition, it is particularly statistically significant ($p = 0.036$) that mothers have a higher average (39.05 ± 16.54) total psychological care over men (33.07 ± 18.84) (Table 8).

The results of this study show a continuity with corresponding studies Fombonne [3], Robinson [32], Herring [33], Karst Van Hecke [34], Meirsschaut [35] demonstrating the mental burden that parents feel confronted with the challenges of caring for their children with pervasive developmental disorders and behavioral disorders. In a relevant research, Stuart, McGrew [36] report that the severity of the symptoms of the disorder Meltzer [16], the accumulation of additional requirements to deal with the condition Gallacher [37] and passive management strategies increase parents' load. Regarding the mental burden of mothers in this study, which was found to be higher than fathers, according to the dimensions of the psychological burden of Zarit [20] it appears that the mothers surveyed feel mainly pressure, anger, Gray [38], Joosten [39] concern that they are locked up, that they do not have personal time for themselves, that they are lagging behind in their work, in their relationships with other family members Meirsschaut [36] and their friends, feel blocked and generally overburdened emotionally due to care.

Conclusion

To a lesser degree they feel depression, weakness, fatigue, despair, negative feelings or guilt because they feel they are not offering what they should be to their child Woodgate [40]; Meirsschaut [36]; Ludlow [21]. In a similar study, Allik [41] reported that the burden of maternal health was greater than that of fathers, especially when behavioral and hyperactivity problems coexisted. Due to the increased care, Dumas [42] found that mothers, compared to fathers, children with autism and behavioral disorders felt more discomfort and depression Davis [43]. In addition, Little [44] found that mothers were more likely to experience high psychosomatic fatigue, had more stress, were pessimistic, had antidepressant treatment and visited specialists. Regarding the dimension of the derailment of relationships that the mothers of the study show higher, Ooi [45], Myers [13] report that mothers of autistic children, in order to take care of the child, were forced to leave work Meirsschaut [36] due to the particularities of their child's inability to work, and to abandon any career opportunities, have limited their job capacity, or have significantly modified their hours. They feel weak and trapped in controlling the behavior of their «normal child» in the social and family environment, feel anger, sadness and frustration and mistrust [46-48].

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DOI: [10.19080/PBSIJ.2017.07.555710](https://doi.org/10.19080/PBSIJ.2017.07.555710)

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