

# Psychological Distress among Caregivers of Children with Down Syndrome at Al Najaf Province

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## Abstract

Psychological Distress has recently been shown to have a negative impact on caregivers, but there has been little longitudinal research on this subject. A sample (61) caregivers of children with Down Syndrome have been selected Al-Najaf Province centers. The researcher adapts and modifies the questionnaire to fulfill the study's objectives. The results of the study revealed that caregivers of children with DS have severe level of psychological distress (38.7%). There is a significant relationship ( $P < 0.05$ ) between Psychological Distress and some of the socio-demographic characteristics (child age, family member and trainings about down syndrome). The present study recommends providing families with Educational programs to increase parents knowledge about etiology, signs and symptom and treatment of stress and Providing scientific booklet, publication and journal about stress. In addition to increasing schools and institutes specialized in educating children with Down syndrome, as they are few in the province of Najaf, and some of them are far from their places of residence.

**Keywords** - Psychological Distress, Caregivers, Children, Down Syndrome

## Introduction

Globally, mental health disorders have emerged as major public health concerns; disabilities, physical mortality and morbidity, and poor social functioning can all result from psychiatric disorders; furthermore, psychological issues can exacerbate the social burden and economic insecurity in a variety of societies around the world<sup>(1)</sup>. Psychological distress (PD) is a form of emotional turmoil marked by a blending of depression and anxiety symptoms<sup>(2)</sup>. In Europe and the United States, the prevalence of psychological distress among parents of children with chronic diseases is as high as 50%<sup>(3)</sup>, and there are 8.27 individuals with down syndrome for every 10,000 people in the United States

(90 % UI, 6.14-10.62)<sup>(4)</sup>. Psychological distress is broadly defined as an emotional state characterized by symptoms of depression (e.g., loss of interest; sadness; hopelessness) and anxiety (e.g., restlessness; tenseness); these symptoms may be linked to somatic symptoms (such as insomnia, headaches, and a lack of energy), PD is viewed as an emotional disturbance that may impact on the social functioning and day-to-day living of individuals<sup>(5)</sup>. Down syndrome (DS) is the most common chromosomal anomaly which is associated with intellectual disability (ID), typical physical features, and health problems. The incidence of DS is about 1–1.5 of every 1000 live births. DS is the most frequent genetic cause of mental retardation (MR). People with MR have behavioral, emotional, and psychiatric problems more often than the general population. DS exhibits distinctive neurodevelopmental, neurocognitive, and psychopathological patterns when compared to other genetic syndromes leading to ID, albeit higher than the general population. A 28.9% of the children with DS have psychiatric comorbidity<sup>(6)</sup>. Caregivers of children

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with DS are often distressed, many of the children have unmet needs that are not being addressed by services, and the degree of unmet need is related to caregiver distress; these high levels of anxiety are likely to have an effect on the parents' health and ability to care for their children (7). Due to a child's disability, parents may be required to pursue educational and recreational accommodations to ensure that the child has the same opportunities as a child who is not disabled, caring for a child with a chronic condition (such as a child with Down syndrome or DS) causes caregivers to experience additional stress, which may lead to caregiver distress(8). The main person with complete or greater responsibility for the care given to the person being cared for is the family caregiver, and there is no financial reimbursement for the care provided (9,10). Parents are the most common caregivers, since they look after their children in all aspects of their lives (11). The majority of family caregivers are women who perform time-consuming and demanding activities such as personal care, aside from the physical, emotional, and financial effect, there are also limitations in social and recreational activities(12).

**Materials and Methods**

A descriptive (correlational) quantitative design study was carried throughout the present study to identify

the psychological distress among caregivers of children with Down Syndrome. During the period from 15th September 2020 to 15th April 2021. A non-probability sampling technique (purposive sample) of (61) caregivers of children with Down Syndrome are included in the study. The General Health Questionnaire-12 (GHQ-12) is a tool for assessing current mental health that has been used in the current study .

The Kessler Psychological Distress Scale (K10) was used as indicator of psychological symptoms .

**Results**

The caregivers in this study are within ages of 37 and 46 (39.3%), female caregivers (75.4 %), mother's age (49.2 %), child age (57.4 %), those are graduated in institute and college (27.9 %), those with barely sufficient monthly income (54.1 %), those who are married (86.9 %) ; those who are housewives (52.5 %) ; those who live in urban areas (85.2 %) ; those who are freehold owning their houses (78.7 %) ; those who were not trained for down Syndrome (78.7 %) ; those with no physical disorder (73.8 %) ; those with no psychiatric disorder (93.4 %) .

**Table (1) : Descriptive statistics of caregiver's subgroups according to their total mean of score of GHQ-12**

Caregiver Subgroups	GHQ-12 Assessment		
	Good	Moderate	Poor
Frequency	23	37	1
Percentage	37.70	60.66	1.64

**Good : MS = 0-0.99 ; Moderate : MS = 1-1.99 ; Poor : MS ≥ 2**

Table (1) illustrate the descriptive statistics of caregiver's subgroups according to their total score of GHQ -12 .They reveal that the majority of caregiver have (moderate) level of general health assessment

(60.66%) ; while (37.7%) of them have (good) level of general health assessment ; finally only (1.64%) of them have (poor) level of general health assessment .

**Table (2) : Descriptive statistics of caregiver’s subgroups according to their total score (K10) of Kessler Psychological Distress Scale**

Caregiver Subgroups		K10 total score assessment			
		Good	Mild Disorder	Moderate Disorder	Severe Disorder
	Freq.	8	13	17	24
	%	12.9	21.0	27.4	38.7

Good : K10 Score = 10-19 ; Mild disorder : K10 Score = 20-29 ; Moderate disorder : K10 Score: = 30-39 2 ; Severe disorder : K10 Score = 30 – 50

Table (2) advance the descriptive statistics of caregiver’s subgroups according to their total score of Kessler Psychological Distress Scale .They reveal that the majority of caregiver have (Severe Disorder) level of Kessler Psychological Distress Scale assessment (38.7%) ; while (12.9 %) of them have (good) level of Kessler Psychological Distress Scale assessment ; only (21 %) of them have (Mild Disorder) level of Kessler

Psychological Distress Scale assessment ; and finally (27.4 %) of them have (Moderate Disorder) level of Kessler Psychological Distress Scale assessment . Table (3) illustrates the relationship between overall assessment of Kessler Psychological Distress Scale for caregivers and their demographic data. It reveals that there is no significant relationship between overall assessment of Kessler Psychological Distress Scale for caregivers and their demographic data (P>0.05) .

**Table (3) : Relationship between total score assessment of Kessler Psychological Distress Scale for caregivers and their demographic data**

Demographic Data	Chi Square	Df	P value
Caregiver age	9.74	3	0.37
Gender	3.27	3	0.35
Mother’s age at child birth	9.73	6	0.13
Child age	23.3	9	0.006
Number of Family member	12.09	6	0.05
Marital Status	12.33	12	0.41
Educational status	15.51	15	0.41
Economic Status	2.56	6	0.86
Job	5.85	6	0.44
Trainings about Down Syndrome	18.83	9	0.02
House Ownership	10.95	9	0.27
Residence	5.02	3	0.17
Physical Disorder	0.98	3	0.8
Psychiatric Disorder	1.74	3	0.62

df : degree of freedom

## Discussion

Psychological distress (PD) is a popular community mental health problem,<sup>(14)</sup>. The influence of caregiver stress, which can lead to distress, on caregivers' mental wellbeing has been well recorded, caregivers of people with a range of physical and psychological disabilities have higher rates of anxiety and depression than noncaregivers, and caregivers are twice as inclined to seek mental health treatment emulated with noncaregivers<sup>(15)</sup>. Globally, mental health problems accounted for 13% of the overall burden of disease, and 31% of all years lived with disability.

The analysis of findings revealed that most of sample were married mothers of children with down syndrome, fall in the age group (37- 46) years old, graduated from institute or college (27.9%) with barely sufficient monthly income. These findings have revealed that parenting of DS children fell overwhelmingly on the hands of mothers more than fathers; these mothers are responsible for their children's care. Fathers generally play a secondary role in the care for children or sometimes no role at all, leaving the primary caregiver responsibility to the mother. This finding was backed up by Rodrigue and his colleagues, who found that mothers accounted for 74% of all parents. Peishi Wang and his colleagues discovered that 59.2 percent of parents were mothers, which provided additional support. Also this approves with study of<sup>(16)</sup>, The study results indicate that the more caregiver is the mother's (74%),<sup>(17)</sup> mention that (53.8%) of caregivers were mothers.

The results showed that the majority of the subjects' job (52.5%) are house wife, In the point of view that is in our culture, fathers spend most of their time in work and had provider responsibility, and mothers have the responsibility for household and child care, so mothers spent all her time for their children. This finding comes along with<sup>(18)</sup> who found that (70%) of samples are housewives. Supplementary support was found by<sup>(19)</sup> the study that show (71.4%) of samples are housewives.

Concerning the training cycle, the results show that caregivers without a training cycle account for the largest

percentage of those with training. This result agrees with<sup>(16)</sup>. Table (1) reveal that the majority of caregiver have (moderate) level of general health assessment (60.66%); while (37.7%) of them have (good) level of general health assessment.

This result accords with Dijkstra-de Neijs & his colleagues (2020) whose studies show that most of parents of children with chronic disabilities suffer from disturbance in mental health and well-being. Furthermore, the results were in line with those of Sangeetha, et al. (2017), who found that (40 %) caregivers are experienced moderate to severe level of general health assessment, Depression was detected in (63%) and (53.8%) of The caregivers' psychological well-being was clinically disturbed.

Table (2) and Figure (4.3) assert that the majority of caregivers have severe disorder (24) of K10 assessment (38.7%). It is clear that some of individual who participated in the study have severe disorder, this may be due a history of anxiety and depression as a result of stressful situations. This result is consistent with previous research that indicates chronic illness or a negative self-evaluation of one's health is related to increased psychological distress. This result is agree with<sup>(17)</sup> the study assures that (57.7%) of caregivers have psychological distress.<sup>(20)</sup> who found that (39.6%) of caregivers had GHQ score suggesting severe level of psychological distress. Additionally supporting was done by<sup>(21)</sup> who reported that (60.5 %) of caregivers experience elevated level of psychological distress.

Tables (3) display that there is a significant relationship between psychological distress among caregivers of DS children and child's age. This result may be due to the fact that children of this age (8-13 years) have more mobility and their needs are more than the youngest and older children. This result almost agree a study by Johnson and his colleagues, (2013) who found that the majority of children (7.7 to 8.8 years) with chronic conditions contribute to increase distress of their parents. The current result agrees with Gilbert, (2009) he revealed that there is a significant association between

age of the child and psychological burden. They are positively correlated and the child's age increases with the increase in respondent's burden.

### Conclusions

The researcher has reached the following conclusions based on the discussion and analysis of the study findings : The study concluded that most of the caregivers were to have moderate psychological distress. Psychological distress was statistically significant among females . Family member, child age and Training about Down Syndrome were statistically significant while other parameters regarding socio-demographic characteristics of caregivers were not significant . The caregivers were under the age of fifty, and more than three quarters of the caregivers' children were females (mothers). The majority of the subjects were married, had a high degree of education, and had a meager income .

**Ethical Clearance** : Taken from University of Kufa ethical committee

**Source of Funding** : Self

**Conflict of Interest** : Nil

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