Relationship between Psychological Well-Being and Coping Strategies among Parents with Down syndrome children

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Abstract

The study investigated the relationship between coping strategies and psychological well-being among parents with Down syndrome children. The sample comprised of 120 parents (60 fathers, 60 mothers of diagnosed 60 children with Down syndrome) collected through purposive sampling. The study was an exploratory study and used co-relational research design. The study planned to investigate all possible relationships among variables and demographic variables. Results showed significant correlations between psychological well-being and coping strategies. Those parents who relied more on active avoidance coping, reported lower levels of psychological well-being as compared to those who relied on problem-focused coping strategies. Fathers scored significantly high on psychological well-being than mothers. Data analysis suggested significant differences in parental psychological well-being and coping strategies with the increasing age of the children. Gender differences were also explored which suggested that parents with girl-child had comparatively higher levels of psychological well-being than parents with boy-child.

Keywords: Psychological Well Being, Coping Strategies, Down Syndrome, Developmental Psychopathology, Rehabilitation Psychology, Learning Disabilities, Special Education, Educational Psychology

1. Introduction

The present study explored the areas of abnormal psychology, clinical psychology and developmental psychopathology and how they are related to Down syndrome disorder. This disorder is one of the most prevailing disorders in the field of psychopathology and most of the researches have been done on it to know about the causes and occurrence of this disorder which shows that it is a developmental disorder. The focus of this study is to know about the coping strategies and psychological well-being amongst the parents of the Down syndrome children. In abnormal psychology the Down syndrome has been taken as the reason behind the mental retardation which occurs as a result of chromosomal abnormality (Smith, Bierman, & Robinson, 1970). It is considered as a disorder in this field. Researches show that people with Down syndrome have moderate to severe mental retardation. Down syndrome is a disorder of intellectual disability. The children who are unable to memorize things properly or do not speak words properly become sample of this disorder. These children need a lot of training and require much time to adjust in the normal environment. The aim of this study is to provide them certain coping strategies to make them acceptable for the society and make them able to move in the society by their own selves. The past researches have shown that such children have not given much medical care.

In last 20 years the research has been ongoing on this issue and psychologists have focused on the problems of these children as well as the parents of such children. Clinically it is proven that such children can have certain infectious diseases as well. In Pakistan, there has been less research on such children and the main problem behind it is that these children are not identified at the early age. Sometimes parents are not willing to accept this reality and which results in the delay of the identification and also towards the cure of this disorder. As a common disorder it is important to look over all the aspects of this disorder. As in DSM there is no certain criteria given for this disorder and this might be the reason that this disorder has been neglected. In current settings now people know that it is a genetic disorder and it occurs during pregnancy. To deal with such children is really a tough job to do but on the other hand it is important to pay attention towards this disorder now. This research will also focus on the developmental disability as it is directly related to the Down syndrome and there are certain aspects of disability that must be kept in mind while diagnosing any disorder that occurs in the individual at the time of birth and that affects the overall development of the individual throughout the life span. It is commonly believed that the process of rearing a child is one of the toughest jobs to do. Parents have focused and spent a lot of time in bringing up their children but if parents have children with any kind of disability that can be physical or mental makes the rearing process difficult and problematic for the parents as they become bound and they spend much time of their lives in bringing up their children. Parents of disabled children are affected badly due to this problem as they have to face stressful events in their lives.

They find bringing up of their children as a challenging task and they face problems in coping with it. Various studies have been done in this perspective as (Stoneman, 1997) has witnessed that children with developmental disability specifically to Down syndrome and autism can be interrupted, devastating not for the parents but also to the whole family. Such families may suffer from the financial crises that are concerned with the medical issues, special paraphernalia, as they have to send such children to special education institutes. They also need care givers that can look after their children in the absence of the parents. As caregivers have to devote more time to such children, they sometimes delay their meetings which affect their social life. In fulfillment of such demands parents face psychological straining and encumbrance. They feel irresistible in accomplishing their responsibilities. As compared to the parents who have normal or typical developing children, the parents of disabled children face more challenges than them. This problem can lead them towards the higher risk for psychological distress, mental health problems, poor health, adjustment issues and low levels of psychological well-being.

Studies that have been done on the children with developmental disability have shown that parents of such children have experienced stress, anxiety, depression, guilt, deprived social and marital adjustment, low level of life satisfaction, do not have a good parent-child relation, possess increased mental suffering and desperateness (e.g., Gray & Holden 1992; Abbeduto et al., 2004).

According to Bower et al., 1998; Hanson, 2003; Muscott, 2001, many of the literature about the experiences of families having children with disabilities indicate some commonalities in parenting styles, but their impact differ among families. Similarly an essay explored by Risdal and Singer (2004) reported that although there was a negative impact, the effect was much smaller than expected. Bower et al (1998) have witnessed in their research that parents with Down syndrome children can no longer be seen as the facilitator for the family difficulties and family dysfunctions. They have given an idea that the way the family faces challenges, play a vital role in understanding the life styles of the parents as well as families. The concept of extended family has been found as a positive aspect in this perspective as it can overcome the burden of the parents with such disabilities. Cunningham (1996) has viewed that intervening impact of families with a teenager who is a Down syndrome is ordinariness. Influences that have an impact on the well-being of families are more or less same among most of the families. They have also quoted the positive behaviors of the families as they have courage to maintain and have resources to encounter with the situation. However, a family may also require different levels of support to manage the demands required by specific health, behavioral and education needs of their child for whom they have little knowledge or experience.

In past most of researches have been done on the perception and attitudes of the parents towards these children but in the recent decades the researchers have now moved on further to the implications and problems that are related to the psychological distress, psychological well-being and coping approaches of the parents with developmentally incapacitated offspring.

The most important thing in this perspective is that most of the studies have been conducted on the mothers rather than on fathers so it is hard to know about the experiences of the fathers of developmentally disabled children. This present study will focus on the psychological well-being of fathers as well as of mothers. The focus of this study will also build on examining the previous researches in knowing the differences between the maternal and parental psychological well-being. The current study was done by keeping in view all the past researches and the practical importance of the problem. The study centered to examine the correlation between the coping strategies and psychological well-being among parents with Down syndrome children.

1.1 Objectives

The study was done by keeping in view the following objectives:

- 1. To explore the relationship between coping strategies and psychological well-being among parents with Down syndrome children.
- 2. To associate the coping strategies and psychological well-being of parents with Down syndrome children.
- 3. To find the difference in coping strategies and psychological well-being of fathers and mothers with Down syndrome children.
- 4. To investigate the impact of child gender and age with coping strategies and psychological well-being.

1.2 Hypotheses

The following hypotheses were formulated for the present study:

- 1. Problem focused coping strategies were positively correlated with psychological well-being among parents with Down syndrome children
- 2. Fathers had higher level of psychological well-being as compared to mothers.
- 3. Fathers reported more use of problem focused coping strategies as compared to mothers.
- 4. Parents with girl-child had higher levels of psychological well-being than parents with boy-child.
- 5. Parents of younger children had higher level of psychological well-being as compared to parents of older Down syndrome children.
- 6. Parents of younger children reported more use of problem focused coping as compared to parents of older Down syndrome children.

2. Methodology

2.1 Operational Definitions of Variables

2.1.1 Psychological Well-Being

Psychological well-being is operationally defined as scores of respondents on three indicators (i.e. anxiety, depression and stress) of Hospital Anxiety Depression Scale and Parental Stress Scale.

2.1.2 Depression

Depression is operationally defined as scores on subscale (Depression) of Hospital Anxiety Depression Scale (Zigmond & Snaith 1983). High score would indicate high level of depression and low scores would indicate low level of depression.

2.1.3 Anxiety

The anxiety is operationally defined as scores on subscale (Anxiety) of Hospital Anxiety Depression Scale (Zigmond & Snaith 1983). High score would mean high level of anxiety and low scores would indicate low level of anxiety.

2.1.4 Stress

Stress is operationally demarcated as scores of defendants on Parental Stress Scale (Berry & Jones 1995). High score would mean high level of stress and low scores would indicate low level of stress.

2.1.5 Coping Strategies

Coping strategies were operationally defined as scores on Brief COPE (Carver (1997), which is assessed in terms of Problem-Focused Coping, Religious/Denial Coping, Positive Coping and Active Avoidance Coping. The high score on separate subscale is suggestive of more use of that specific coping strategy.

2.1.6 Active Avoidance Coping

Active avoidance coping included all of the items from the original Brief COPE subscales for the substance use, behavioral disengagement, self-blame, venting of emotions, and one item from the distraction scale (item no. 1, 4, 6, 9, 11, 13, 16, 19, 21, 26).

2.1.7 Problem-Focused Coping

Problem-focused coping included all the items from the original Brief COPE, subscales for planning, active coping, seeking instrumental social support, and one item each from the acceptance and emotional social support scales (12, 15, 17, 18, 20, 24, and 28).

2.1.8 Religious/Denial Coping

Religious/Denial coping is a varied factor that included all the Brief COPE items for religious coping and denial (3, 8, 22, 27).

2.1.9 Positive Coping

Positive coping includes all items of Brief COPE of active coping, use of emotional support, planning, and use of instrumental support (2, 7, 5, 10, 15, 14, and 25).

2.2 Research Design

The present study used co-relational design as it was an exploratory research and purposive sampling was used to collect data. The present study consisted of two parts.

- **1.** Pilot testing
- 2. Main study

2.3 Pilot Study

The part I of the study included the pilot study, which was designed to figure out the psychometric properties of the Parental Stress Scale, Brief COPE, and the Hospital Anxiety Depression Scale. The sample of the pilot study included 30 participants. In this part of the study, Urdu version of three scales were used which included Hospital Anxiety Depression Scale for measuring depression and anxiety, Parental Stress Scale to investigate the stress and Brief COPE Inventory to examine coping. The data was collected from Army Special Education Academy, Chambelli Institute for Mentally Handicapped Rawalpindi and Ibn-e-Sina Institute for Mentally Retarded Children Islamabad.

2.4 Main Study

The part II consisted of main study that was directed to test the articulated hypotheses. All the necessary analysis was made by keeping in view the objectives and hypothesis of main study.

2.5 Sample

The sample that has been taken for this study was comprised of 120 parents (Fathers=60 & Mothers= 60) of identified 60 children with Down syndrome. The age of parents fall from the 25-56. The age range of children was 4-18 years. The children were separated into two groups due to the difference in their age range, i.e. younger children 4-9 and older children 10-18. Children selected had both parents alive. The sample was purposively taken from different hospitals and institutions of mental retardation in two cities of Pakistan: Islamabad and Rawalpindi.

2.6 Instruments of the Study

The following instruments were used in the study.

2.6.1 Parental Stress Scale (PSS)

Urdu version of Parental Stress Scale, originally developed by Berry & Jones (1995), was used to measure parental stress. It is a self-report measure that contains 18 items representing pleasure or constructive refrains of parenthood comprising emotional welfares, self-enrichment, personal development and negative constituents such as demands on possessions, prospect costs and limitations. Respondents were asked to agree or disagree with items in lieu of their distinctive relationship with their child or children and to rate each item on a five-point scale: strongly disagree (1) disagree (2), undecided (3) agree (4) strongly agree (5). The 8 positive items were contrary scored so that possible scores on the scale ranged from18 to 90. Score on all the items was summed to get a total score. Higher scores on the scale specify greater stress and low scores indicates minor scores.

The scale is proposed to be used for the valuation of parental stress for both mothers and fathers and for parents of children with and without clinical problems. The Parental Stress Scale confirmed acceptable levels of internal reliability (.83) and test re-test reliability (.81). The scale demonstrated satisfactory convergent validity with various measures of stress, emotion and role satisfaction, including perceived stress, work/family stress, emotion, loneliness, anxiety, guilt, marital satisfaction, marital commitment, job satisfaction and social support. Discriminant analyses verified the capability of the scale to discriminate between parents of typically developing children and parents of children with both developmental and behavioral problems.

2.6.2 Brief COPE

The Brief COPE initially established by Carver (1997) and interpreted into Urdu by Akhtar (2005), was used to categorize the coping strategies used by parents. Brief COPE is a briefer form of COPE Inventory (Carver, 1989) consisted of 28 items categorized into 14 subscales (Self distraction, Active coping, Denial, Substance abuse, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, humor, Acceptance, Religion, Self-blame). Items are arranged in a 4-point Likert format (1=Never, 2= Very less, 3= Sometimes, and 4= A lot). Item No. 1 and 19 pertains to "Self distraction" subscale, Item No. 2 and 7 pertains to "Active coping" subscale. Item No.3 and 8 pertains to "Denial" subscale. Unit No. 5 and 15 pertains to "Use of emotional support". Unit No. 10 and 23 pertains to "Use of instrumental support" subscale. Item No. 6 and 16 pertains to "Pentains to "Positive reframing" subscale. Item No 14 and 25 pertains to "Planning" subscale. Unit No. 18 and 28 pertains to "Humor" subscale. Unit No. 20 and 24 pertains to "Acceptance" subscale. Unit No. 22 and 27 pertains to "Religious" subscale. Unit No. 13 and 26 pertains to "Self-blame" subscale. The substances are summed for each subsection separately to get a total score on all 14 categories.

In the current investigation, structure of Hastings et al. (2005) for Brief COPE (Carver, 1997) was used. He reported four subscales for Brief COPE namely: Active avoidance coping, Problem-Focused coping, Positive coping and Religious/Denial coping. Problem-focused coping included all the items from the original Brief COPE, subscales for Planning, Active coping, Seeking instrumental social support, and one item each from the Acceptance and Emotional social support scales (12, 15, 17, 18, 20, 24, and 28). Active avoidance coping include all of the items from the original Brief COPE subscales for the substance use, Behavioral disengagement, Selfblame, Venting of emotions, and one item from the Distraction scale (item no. 1, 4, 6, 9, 11, 13, 16, 19, 21, 26). Religious/Denial coping is a varied factor that included all the Brief COPE items for religious coping and denial (3, 8, 22, 27). Positive coping includes all items of Brief COPE of active coping, use of emotional support, planning, and use of instrumental support (2, 7, 5, 10, 15, 14, and 25). The items are summed for each subscale separately to get a total score on all 4 categories. The high score on each subscale indicates more use of that specific coping strategy and low score indicates less use of that coping strategy.

2.6.3 Hospital Anxiety Depression Scale (HADS)

Hospital Anxiety Depression Scale was established by Zigmond & Snaith (1983) and transformed by Tareen, (1991). This is a self-screening questionnaire for depression and anxiety. Although it was planned for hospital General Medical Outpatients, it has been widely used in community research. The HADS has two subscales, Depression and Anxiety. It consists of 14 items, seven for anxiety, and seven for depression. Earlier research with parent's children with Down syndrome has shown that the HADS retains good reliability (internal consistency) within these populations for both fathers and mothers (Hastings, 2003; Hastings and Brown, 2002). The score range of each subscale is 0-21. Even items have been made for depression and for anxiety Odd questions have been used. Each is scored separately. A score of 8 or more is substantial, and a score of 11 or more is highly significant. High score indicates high level of depression and anxiety.

2.6.4 Demographic Information Sheet

Demographic information sheet involved age of parents, gender of child, child age and other information sought from the parents.

2.7 Procedure

For the purpose of this research the data was gathered from different institutes of mental retardation and hospitals of Rawalpindi and Islamabad. At initial stage the permission was taken from all the concerned authorities in order to avoid problems then the sample was approached independently. Sample was taken after getting the surety about the criteria essential for the research.

They were instructed about the purpose of the research and guaranteed that the information obtained from them will be kept confidential and will only be used for research purpose. After getting their consent different instruments along with demographic sheet were administered. Purposive sampling was done to include the participants. There was no time limit and approximately 50 minutes were taken to complete the booklet. SPSS was used to analyze the data.

Results

The results of the study were as follows.

 Table 3.1: Correlation between Scores on Subscales of Brief COPE and Indicators of Psychological Well-Being (N=120)

Indicators of PWB	Anxiety	Depression	Stress	
Active Avoidance Coping	.673**	.553**	.598***	
Problem Focused Coping	241**	313**	242**	
Positive Coping	221*	306**	227**	
Denial/Religious Coping	118	184*	010	

*p<.05 and ** p <.01, ***p<.001

Table 3.1 showed correlation between Brief COPE subscales and indicators of psychological well-being. Problem-focused coping was negatively associated with the three indicators of psychological well-being. The greater the problem-focused coping, lower the levels of depression, anxiety and stress indicating a higher levels of psychological well-being. Results also indicated significant correlation of active avoidance and positive coping with three indicators of psychological wellbeing. Religious/Denial coping was negatively associated with depression but no significant correlation was found between religious/denial coping and anxiety and stress.

Table 3.2: Mean, Standard Deviation & t-value of Fathers and Mothers on the Scores on Indicators of Psychological Well-Being (N=120)

Indicators of PWB	Fathers (N=60)		Mothers (N=60)		t	р
	М	S.D	Μ	S.D		_
Depression	4.98	3.98	4.70	2.80	3.870***	.02
Anxiety	6.59	3.77	5.53	2.56	2.703*	.00
Stress	46.90	8.31	44.30	7.66	2.804**	.01

df=118,*p<.05,**p<.01

Table 3.2 showed differences in the mean scores of mothers and fathers with Down syndrome children. Significant differences were found on three indicators of psychological well-being. The findings revealed that mothers of Down syndrome children have lower level of psychological well-being as compared to fathers.

Table 3.3: Mean, Standard Deviation and t-value of Fathers and Mothers on the scores on Subscales of Brief COPE (N=120)

Subscales	Fathers N=60		Mothers N=60		t	р
	М	S.D	М	S.D		
Active Avoidance	17.86	4.75	20.33	5.07	2.760**	.03
Problem-focused	23.34	4.21	11.26	4.66	1.383*	.02
Positive coping	13.60	2.82	14.18	2.59	1.232	.09
Religious/Denial	11.77	1.73	11.89	1.81	.397	.06

df=118, *p<.05,**p<.01

Table 3.3 presented gender differences in the mean scores of fathers and mothers on the subscales of Brief COPE. Significant gender differences were found on "Active Avoidance Coping" (t=2.760, df= 118, p<.01) and "Problem-focused Coping" (t=1.383, df= 118, p<.05). Active avoidance coping was high in mothers as compared to fathers. Whereas, Problem focused coping was high in fathers as compared to mothers.

Table 3.4: Mean, S.D, and t-value of Parents of Boy-Child and Girl-child on the Scores on Indicators of Psychological Well-Being (N=120)

Parents (Boy-Child)		Parents (Girl-Chil	d)		р	
Indicators of PWB	(n=30)		(n=30)			t
	М	S.D	М	S.D		-
Depression	4.34	4.32	5.92	3.67	2.005*	.00
Anxiety	5.47	4.28	6.92	3.43	1.897*	.00
Stress	45.81	7.39	50.00	8.34	2.053**	.00

df=118,*p<.05,**p<.001

Table 3.4 showed differences in mean scores of parents having boy-child and girl-child on indicators of psychological well-being. The findings suggested that parents having girl-child had comparatively higher levels of psychological well-being than parents having boy-child.

Table 3.5: Mean, SD, and t-value of Parents of Younger and Older Children on the Scores on Indicators of
Psychological Well-Being (N=120)

Indicators of PWB	Parents (Older Children) (n=30)		Parents (Younger ((n=30)	Children)	t	р	
	Μ	S.D	М	S.D			
Depression	5.50	4.11	6.10	4.09	1.964**	.00	
Anxiety	5.45	2.83	7.53	4.58	2.412*	.00	
Stress	49.38	6.93	46.13	9.26	2.013**	.00	

df =118, *p<.05, **p<.01

Table 3.5 showed differences in mean scores of parents having Younger and Older children on subscales of psychological well-being. Significant differences were found on three indicators of psychological well-being. The findings suggested that parents having younger children showed higher levels of psychological well-being as compared to parents having older children. The mean score of younger children were higher than the means scores of older children on the variable of stress.

Table 3.6: Mean, Standard Deviation and t-value of Younger and Older Children on the Scores on
Subscales of Brief COPE (N=120)

Subscales	Pare (Older Ch N=	ildren)	Parents (Younger Children) N=30		t	р
	М	S.D	М	S.D		
Active Avoidance	11.66	3.15	10.33	4.86	2.120**	.03
Problem-focused	13.31	2.11	31.26	4.99	1.763*	.02
Positive coping	23.00	2.22	24.18	3.52	1.782	.07
Religious/Denial	10.66	3.54	11.89	1.81	0.397	.08

Table 3.6 presented gender differences in the mean scores of parents having older and younger children on the subscales of Brief COPE. Significant gender differences were found on "Active Avoidance Coping" (t=2.120, df= 118, p<.01) and "Problem-focused Coping" (t=1.763, df= 118, p<.05). Problem solving coping strategy was used by parents with younger children than parents with older children.

3. Discussion

The present study was conducted to examine the relationship between coping strategies and psychological wellbeing among parents with Down syndrome children. Depression, anxiety and stress were taken as indicators of psychological well-being. The study was conducted in two phases. The first phase consisted of the pilot study and the second phase was the main study with a sample of 120 parents of Down syndrome children. The main objective of the study was to find relationship between coping strategies and psychological well-being. It is well acknowledged in literature that parents raising a child with developmental disabilities face difficulties that are not shared by parents of normally developing children (Stoneman, 1997). They experience more stress, depression, anxiety and other mental health problems. Often stress is intensified by broken, misinterpreted coping efforts that increase conflict in the family (Carr, 1985; Carver & Carver, 1972; Gath, 1974; Schild, 1979). The results supported the hypothesis representing that problem-focused coping was positively correlated to psychological well-being. The findings of the present research were consistent with the past investigations. Problem-focused coping strategies are viewed as positive responses that can enhance long term functioning of parents of developmentally disabled children. Problem-focused coping was associated with concentrated distress (Essex, Seltzer, Krauss, 1999; Van Riper, 1999; Tunali, 2002; Sullivan, 2004; Abbeduto, Seltzer, Murphy & Shattuck, 2004; Hastings et al., 2005). Problem-focused coping was more effective in buffering challenges than emotionfocused coping (Seltzer, 1995).

Parents also differed in use of coping strategies. Parents with Down syndrome children stressed more use of Problem-focused coping strategies. The most reported coping strategy was active avoidance coping. The more the devastating, demanding, long-lasting and disturbing the infirmity/event is, the more dysfunctional and maladaptive the coping strategies would be. The present findings supported the notion of differential experiences for parents depending upon the explicit diagnosis of their child with a developmental disability. Parents with Down syndrome children showed less maladaptive behaviors and these behaviors may impede and contribute to low parental psychological well-being. In accumulation of the fact that the diagnosis of Down syndrome is made after the birth allows parents to begin the progression of variation to their child's condition when their children are only a few hours old. The results indicated that fathers had greater psychological well-being as compared to mothers. They were found low on depression, anxiety and stress as compared to mothers who experience more depression, anxiety and stress. On comparing coping strategies, fathers reported more use of problem-focused coping than do mothers. The most frequently employed coping strategy was active avoidance. It was hypothesized that parents of younger children reported higher levels of psychological well-being as compared to parents of older children. Significant differences were obtained. In past researches the age of the child had been considered as an important factor in contributing towards mental health problems of parents specifically when children had some disability. Essex et al, (2002) witnessed that stress and family adaptation appear to vary considerably as the child develop through infancy, childhood, adolescence, and into adult. It was also found that parents' levels of stress not only changes linearly but also changes over time. In order to maintain adaptation, adjustment and balance, families need flexible attitudes and changing nature or the adequate frequency of parental coping over time (Patterson, 1988). Similar were the findings of present study. Parents with younger children reported higher levels of Psychological Well-being and used more problem focused coping strategies as compared to parents with older children.

4. Conclusion

It was concluded from the study report that problem-focused coping was positively correlated to psychological well-being. Parents with Down syndrome children used Problem-focused coping strategies i.e. active avoidance coping. Fathers with Down syndrome children had greater psychological well-being as compared to mothers with Down syndrome children. While making comparison between mothers and fathers, it was found that fathers reported more use of problem-focused coping than do mothers as their frequently employed coping strategy was active avoidance.

Parents of younger children reported higher levels of psychological well-being as compared to parents of older children. The overall results were significant in finding the relationship of coping strategies with psychological well-being and significant differences were obtained on other demographic variables like age and gender. The impact of gender of disabled child on parents' psychological well-being and coping strategies was explored in which girl-child was high on depression, anxiety and stress as compared to boy-child. The future studies can focus on the other demographic variables also like socioeconomic status, ethnicity and racial identity, domicile, residence status, place and others. Other disorders of developmental disabilities can also be studied like autism and attention deficit hyperactivity spectrum disorder with parents' well-being dynamics.

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