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CAREGIVER BURDEN AND PSYCHOLOGICAL DISTRESS AMONG MOTHERS OF CHILDREN WITH PHYSICAL ILLNESS VERSUS PSYCHOLOGICAL ILLNESS

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Abstract

The current study aims to find out the difference between the level of caregiver burden and psychological distress (depression, anxiety, and stress) among mothers of children with Physical illness (Major Thalassemia) and psychological illness (Autism). Sample size (N=100), 50 in each group. Mothers filled out a booklet containing 1) Inform Consent 2) Demographic Form 3) Burden Assessment Scale (BAS) Urdu version contains 19 items has a reliability of 0.78 and 4) Urdu version of the Depression Anxiety and Stress Scale DASS-21 which has 21 items and good reliability 0.93 coefficient alpha. The study hypothesized that (1) There will be a significant difference in the level of caregiver burden between mothers of children with physical illness (thalassemia) and mothers of children with psychological illness (autism). 2) There will be a significant difference in the level of psychological distress (depression, anxiety, and stress) between mothers of children with physical illness (thalassemia) and mothers of children with psychological illness (autism). Moreover, an independent t-test was done to compare the level of burden and distress among both

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groups and it was revealed that the difference is insignificant between both groups.

Key Words*: Caregiver burden, psychological distress, well-being, autism, thalassemia, health.*

Introduction

Over the recent years, it has been seen that dangerous and fatal diseases are emerging day by day. Scientists and doctors are wondering and still working on the treatment of those diseases. The illness or disorder gradually becomes turmoil for the family because a direct affected person might be the only one but being a caregiver parents especially the mother suffers a lot whether it is any physical illness or psychological illness.

A medical disease or pathological condition is a condition involving body parts and, in this condition, a system or an organ must be involved. It is characterized by a group of sign and symptoms which is identifiable and caused by multiple factors (Dictionary.com, 2002). Whereas, mental illness or psychological disorders are health conditions that include changes in the following domains: thinking, feeling, or behavior or they can manifest in combination. Psychological disorders are related to disturbed functioning in the family domain, and social domain, and it is also related to distress (Ranna, 2018).

Thalassemia a medical condition is an inherited blood disorder that causes severe anemia, due to the inability to make enough hemoglobin organs become ravenous for oxygen and are not able to function properly. There are two main forms of Thalassemia disease: Alpha Thalassemia disease and Beta Thalassemia disease. Alpha Thalassemia disease itself has 2 types including Alpha Thalassemia Major and Hemoglobin H disease. However, in alpha thalassemia, anemia begins even before birth. It is a very severe condition for mother and child both. However, Beta Thalassemia Major also termed Cooley’s anemia is a severe condition that appears in the form of poor appetite, paleness of skin, and, irritability. Manifestation of symptoms occurs in the first two years of life (John, 2012). However, there is a condition called Minor thalassemia (Beta thalassemia minor). In minor thalassemia, carriers inherit faulty hemoglobin genes from one parent but normal genes from the other. Other than mild anemia there is no manifestation of any illness but they become vulnerable passing past the faulty genes on the two next generation ("Thalassemia", 2009).

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by delay and deviance of social skills and communication skills, restricted patterns of behavior, and demands for sameness (Society, 2018). As individuals with autism have a range of symptoms and this is the reason it is called a "spectrum" disorder. (Autism Spectrum Disorder, 2019). Skills such as learning, problem-solving, and cognitive abilities may range among people with Autism. Some individuals require more assistance in their daily living tasks and some require less support from caregivers. Autism Spectrum Disorder includes several conditions that used to be diagnosed separately: Asperger syndrome, Autism disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). These conditions are now all called autism spectrum disorder (CDC, 2019).

A caregiver is any individual, who looks after another person in a condition such as cancer, dementia, brain injury, or any other condition that requires assistance in the performance of daily tasks which are often basic in nature. Family caregivers or informal caregivers are those who are not given any tangible rewards in return for their caregiving services. By prioritizing the patient’s needs and health consequences, a family caregiver neglects his/her own health (Ansari & Qureshi, 2013).

(Zarit, Reever, & Peterson, 1980) Defined burden as ‘‘the extent to which caregivers perceived their emotional physical health, social life, and financial status as a result of caring for their relative’’. The term caregiver burden is now more widely used to refer to the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for a chronically ill or impaired family member. The concept of caregiver burden applies to parents caring for a child with a chronic illness as well as a spouse or adult caring for an ill or aging parent (Kuei-Ru Chou, 2000).

Psychological distress is often applied to the undifferentiated combinations of symptoms ranging from depression and general anxiety symptoms to personality traits, functional disabilities and behavioural problems (Mwale, Kauye, Gladstone, & Mathanga, 2018).

As diagnosis of disease is a painful and distressing experience for the parents. Being a mother and being close to child mothers suffer a lot during this process. They have mixed emotions to express including sorrow, guilt, and distress (Georganda, 1990).

In Pakistan, there seems lack of acceptance of trained caregiver or the trained care givers are more expensive than people from a certain background can afford them only. However, change in socio-cultural perspective is highlighting the burden of caregivers as an issue. Hence require consideration at all levels (Sabzwari, Badini, Fatmi, Jamali, & Shah, 2016).

Being parents, seeing an own child going through a life-threatening condition could be a predisposing factor to developing psycho-social disorders and can manifest stress (Aziz, Sadaf, & Kanwal, 2012). However, Mothers are at higher risk of depression, because they bear greater stress than fathers. They usually take active roles in the care of their ill children and even might quit their jobs or favorite activities. Another research conducted in Pakistan showed that female spouse caregiver reflects more symptoms of depression than male (Khan, Taj, Fatima, & Kazmi, 2015)

Being the main caregivers they are exposed to more strain as the patient’s biological, psychological, and social needs are prioritized in contrast to their own; therefore, the level of exhaustion they experience due to constant pressure impacts their quality of life (Dehkordi, Hekmatpou, & Baghban, 2019).

Now whether it is a medical condition or psychological disorder it affects not only the person dealing with it, but it creates psychological distress and feeling of burden among parents. Psychological illness and

Physical illness, both have their separate demands from the caregiver. Research suggests that caregiver reflects 17.5% anxiety whereas non-caregivers reflect 10%. A higher anxiety rate among caregivers reflects a higher intake of psychotropic drugs (Parks & Novielli, 2000).

Such as for the increase in stress levels among parents of children with Autism several factors work. Firstly, parenting stress may increase due to the understanding that there is no cure available for the disorder. The single caregiver must maintain a schedule as a child doesn't like changes. Children need to take care in public and private spaces because children with autism are sensitive to sounds, textures, and behaviors. Furthermore, by taking the child to different groups of specialists including behavioral therapists, occupational therapists, or speech therapists, there is a need to be alert all the time, and requires a lot of energy since the condition can be managed only (Rezendes & Scarpa, 2011).

The research was conducted with the objective to acquire a representation of caregiver burden among caregivers having children with Autism Spectrum Disorder. Zarit Burden Interview was used to assess burden. Results showed moderate to severe level of burden levels among caregivers. Moreover, depression and anxiety were found to be related to caregiver burden (Pandey & Sharma, 2018).

Prior research consistently put focused on stressors of parenting related to the upbringing of a child with Autism Spectrum disorder. Researches also explored a relationship between the behavior patterns of children with developmental disorders and anxiety/depression among parents (Rezendes & Scarpa, 2011).

However, medical condition like major thalassemia requires different kind of attention from caregiver. Taking care of child's food intake is the priority. Moreover, caregiver needs to take care that may not involve in excessive physical activity. It's a life-threatening disease and creates a lot of emotional burden onto parents. Cross-sectional study was conducted in Iran to study caregiver's burden and social support in mothers of children with thalassemia. In results it was observed that 51.5% mothers show low social support and 49.5% of mother shows high level of social support However, with respect to caregiver’s burden, it was observed that 20%, mothers reported high level of burden whereas 29% and 51% of mothers reported moderate and low level of burden. It was suggested that Parents or Caregivers of children with β-thalassemia major face multiple challenges in the process of fulfilling the needs of their loved one, so this leads of frustration also (Mashayekhi, Jozdani, Chamak, & Mehni, 2016).

Caregivers of people suffering from psychiatric illness are at risk of lower psychological wellbeing and at risk of developing consequences such as anxiety, depress and burnout. There is a lack of data present on comparison of the caregiver burden of psychiatric patients with caregiver of people having chronic medical illness patients (Ampalam, Gunturu, & Padma, 2012).

Likewise, having a child with chronic illness who requires intense care and regular blood transfusions, build up the difficulty that leads to mental imbalance in parents. Pressure of responsibility creates different psychological reactions among them, and family relationships are seriously affected. It may cause fear, guilt, helplessness, and hopelessness. Families faced multiple psychological and emotional problems (Aziz, Firouzkouhi, Abdolghani, & Jamile, 2017)

A comparative study was conducted with Aim to compare the caregiver burden in psychiatric illness and chronic medical illness. It also aimed to study the relationship of caregiver burden with demographic variables including duration of caregiving, age, and gender. 50 members from each group were included. Results showed that caregivers of individuals with psychiatric illnesses scored high in caregiver burden as compared to caregivers of individuals with medical illnesses. Moreover, it was revealed that there was a positive relationship between the age of the caregiver, duration of illness, and caregiver burden (Ampalam, Gunturu, & Padma, 2012).

The research was done to make a comparison between the level of psychiatric disorders present in mothers of children with chronic disease and mothers of healthy children. It was an observational case study that included mothers of chronically ill children. Results revealed that there seems presence of psychiatric disorders among mothers of children with chronic as compared to mothers of healthy children (Shahrakiet, et al., 2017).

Current study looked upon the differences among mothers who have been caring for a child with physical illness versus mothers who has been caring for a child with psychological disorder and their wellbeing is affected by having a child with illness. As it has been observed over the past few years, not only medical illness but prevalence of mental illnesses has increased.

Research Objectives:

- To find out any significant difference in level of caregiver burden between mothers of children with physical illness (thalassemia) and mothers of children with Psychological illness (autism)
- To find out any significant difference in level of psychological distress (depression, anxiety and stress) between mothers of children with physical illness (thalassemia) and mothers of children with psychological illness (autism)

Research Hypotheses:

- There will be a significant difference in level of caregiver burden between mothers of children with physical illness (thalassemia) and mothers of children with psychological illness (autism)
- There will be a significant difference in level of psychological distress (depression, anxiety and stress) between mothers of children with physical illness (thalassemia) and mothers of children with psychological illness (autism)

THEORETICAL FRAMEWORK

Intervention Model

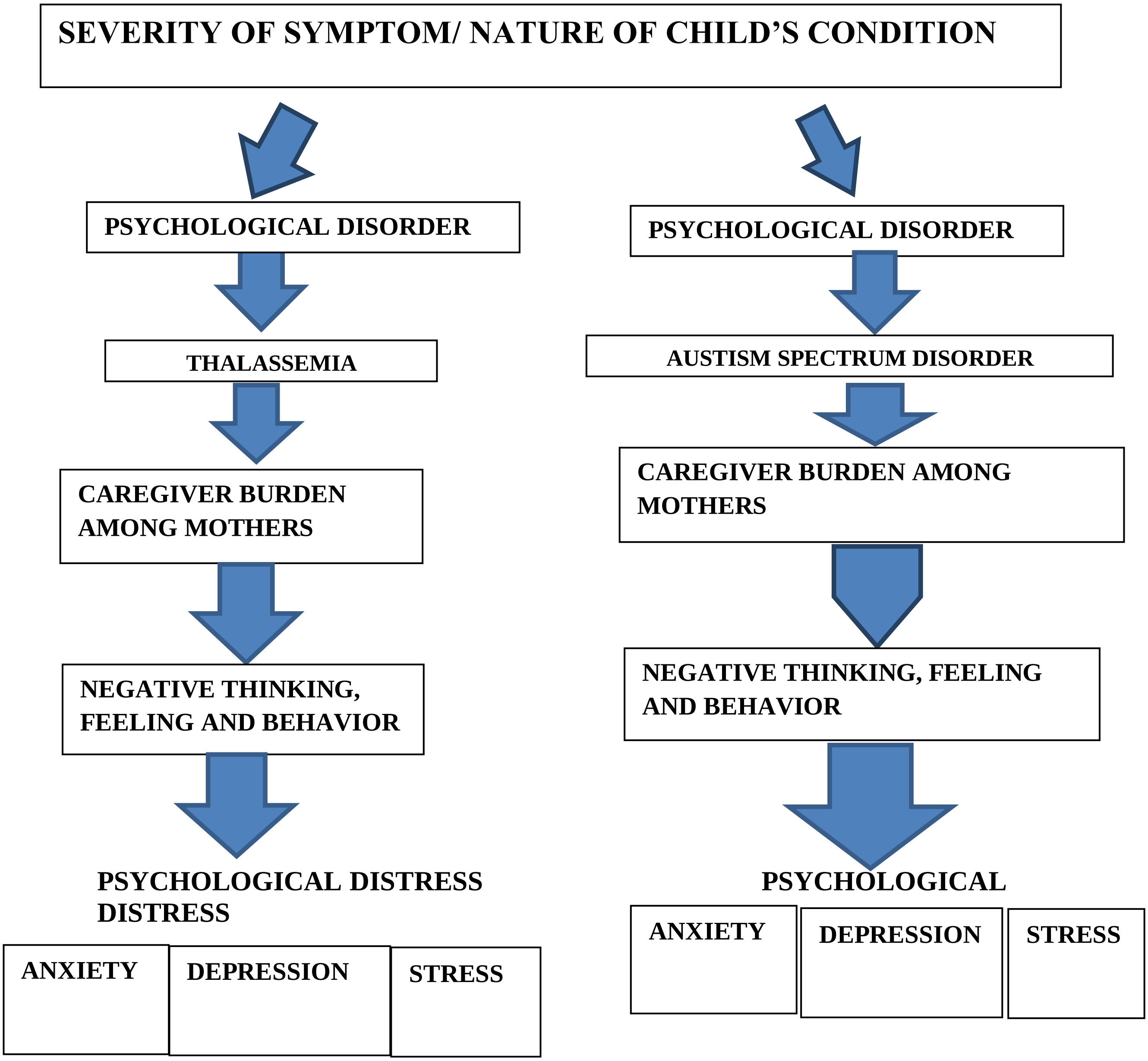
The intervention model was presented by Potasznik & Nelson (1984) to study the burden experienced by families. According to the model, the perception of the mentally ill family member as a burden can be seen as a function of two major variables: (a) The level of patient symptomology which is characterized as the degree of the stressful life condition (b) Within and outside the family available social support. These two variables determine how much-burdened caregiving is. Moreover, support from family and community is considered to be of equal importance in this model (Potasznik & Nelson, 1984).

Cognitive Behavioral Theory

According to Dr. Aaron Beck, primary cause of depressive condition is the negative thoughts, generated by faulty beliefs. Severity of depressive symptoms has direct link with the severity and number of negative thoughts a person is having. In other words, the more the negative thinking pattern is, the more you become depressed. Depressed people’s thinking tends to overpowers by 3 main dysfunctional belief system: 1) Negative view of themselves 2) Negative view of world 3) Negative view of future. These three themes are termed as the Negative Cognitive Triad. Depression is likely to occur when this kind of belief system exists (Nemade, staats, & Dombeck, 2013).By looking at theories of depression and anxiety, it can be assumed that people are vulnerable for depression and anxiety by the way they experience things. Because how the illness is perceived and dealt by parents, doctors and other significant adults may cause more of a problem than the illness of a child itself. Some of these fears and worries may be realistic; a lot of them, however, have to do not with the actual condition of the child, but with our misconceptions of how terrible it must be to be ill, with our own fear of death and vulnerability (Georganda, 1990). According to Cognitive theory perspective thoughts pave the way to moods and that distorted beliefs lead to evocation of negative emotion such as anxiety and depression (Schimelpfening & Nancy, 2018).

In the light of above-mentioned theories, theoretical framework of the current study developed, which entails that child's health condition build caregiver burden among mothers. However, as physical and mental health conditions are two different conditions in nature and severity within and as compare to each other, so the level of caregiver burden differs in both groups of mothers. As above mentioned, theories suggest that perception of burden is dependent of two factors and that perception then leads to effects mental health of caregiver or family. So, model of this study postulates that caregiver burden then leads to negative thinking, feeling and behavior which eventually perpetuates depression, stress, and anxiety among mothers. Moreover, Depression, stress, and anxiety occur due to negative thinking patterns which may occur due to environmental factors (Caregiving burden). As cognitive theories suggest that it's the perception that leads to negative thinking, emotion, and behavior, so caregivers might lose hope by seeing their child in such a condition which is life longing and has no cure. Caregivers might not be able to attend to all other needs of themselves and others which may lead to depression, stress, and anxiety. However, there will be differences among levels of depression, anxiety, and stress among mothers of children with physical illness versus psychological disorders. Because autism and thalassemia are two different kinds of conditions thus vary in severity also, so they both might have a different impact on the caregiver.

Figure (A) Illustrates the comparison of caregiver burden, depression, anxiety, and stress among mothers of children with Thalassemia and Autism.



Sample

This study included mothers of children with thalassemia and autism. However, the sample of 100 participants (50 participants for each group) selected through purposive convenient sampling technique and snow ball technique. On the basis of following inclusion and exclusion criteria sample were equalized. The research was conducted during Covid so the desired population for difficult to reach hence kept the sample size of 100.

Inclusion Criteria:

Mothers who have only 1 child being diagnosed with autism/thalassemia and at least a year have been passed since the diagnosis. Mothers of children with mild, moderate and severe level on Autism Spectrum Disorders were included

Exclusion Criteria:

Mothers of children whose diagnosis has been made recently and has more than 1 child diagnosed with autism/ thalassemia.

Measures:

Informed Consent Form

Before survey, consent was taken from participants. In order to obtain permission from them, through these form participants was provided with assurance for confidentiality, the purpose of research and available option to withdraw anytime in between the study.

Demographics

Hundred participants responded to this study and their responses were analyzed by using SPSS 21. All the participants were female with various age groups. The demographic form contained following information: Age, Occupation, No, of Children, Ages of children, income group, No. of children diagnosed with illness, years passed since the diagnosis made.

Burden Assessment Scale is self-report inventory containing 19 items developed by Susan C.Reinhard and Horwitz in 1992. The scale measures level of subjective and objective burden experienced by the primary caregivers. 10 items evaluate the amount of objective burden experienced by caregivers because of fulfilling their caregiving responsibilities. Objective burden refers to the potentially observable behavioral effects of caregiving in several areas including financial problems, and limitations on personal and social interactions. However, subjective burden is assessed by remaining 9 items which covers areas including, guilt, worry, grief, stigma, and resentment. The scale has good reliability of 0.89 (Reinhard, Gubman, Horwitz, & Minsky, Burden Assessment Scale for families of the seriously Mentally ill, 1994).

The Urdu Version of the scale was used in this study. The scale was translated by Sarosh Sadiq in 2013. The scale has a reliability of 0.78 coefficient of alpha (Sadiq & Sohail, 2013).

The Depression Anxiety Stress Scale (DASS) was developed by (Lovibond & Lovibond, 1995) at the University of New South Wales in 1995. It is a self-report measure containing 3 scales including the negative emotional states of depression, anxiety, and stress. It consists of total of 42 items and each scale permits 14 items. Participants have to mark each time by keeping in mind what they have felt during the last week. For scoring there is a 4-point Likert scale and scores for Depression, Anxiety, and Stress are calculated by adding the scores for the pertinent items (Lovibond P. , 2018). Psychometric properties have been developed and the scale has good internal consistency Depression .91; Anxiety .84; Stress .90. Thus, confirmed the satisfactory reliability of the three scales. It has strong convergent validity (Lovibond & Lovibond, 1995).

In addition to the basic 42-item questionnaire, a short version, the DASS-21, is available with 7 items per scale. Psychometric properties have been developed for this version. All 3 scales have good reliability with an alpha coefficient for Depression .72 Anxiety .77 and Stress .70. Overall DASS has an alpha co-efficient of .88 depicting strong internal consistency. The scale has good strong criterion validity (Tran, Tran, & Fisher, 2013).

Urdu version of the scale DASS-21 was used in the study for better understanding. Scale translated in Urdu by Naeem Aslam in 2007. The Urdu version has a good reliability with an alpha coefficient of .93. Each scale separately has reliability including stress .83, anxiety .86, and depression .84. It has acceptable construct validity (Aslam & Kamal, 2017).

Procedure

The research was carried out by first contacting the authors via email to get permission to use their scale. The consent form and demographic form were developed to gain the respective information and permission of the participant. After getting permission from respective authors Google form was made in order to get data online as well as in person. The official permission letter was formed to obtain permission from respective authorities including different NGOs providing blood transfusion services to thalassemia children so we can contact their parents. Moreover, different organizations catering to children with Autism were contacted via email and social media, so that their parents can be contacted through them. After getting permission from the respective authorities, a link to a Google form had been sent to them to get the responses online. Moreover, the link to the Google form was shared in different social media portals and groups. The thalassemia organization was visited to get the data in person. However, the Google form and a booklet contained a consent form, demographic form, and the questionnaire Urdu version of the Burden Assessment Scale, and Depression Anxiety Stress Scale (DASS-21). After getting the responses from the participants they were debriefed about the study. Further Statistical Analysis was done for the interpretation of scores, and then a comparison was made among both groups of parents.

Results

This chapter shows the statistical analysis of results that were used to investigate the presence of any significant difference among variables and demographics were also presented in this chapter. The data was analyzed through the Statistical Package for Social Sciences (SPSS) 20th version. In order to explore the difference among difference Independent T-test was done

Table 1

Independent sample t-test of Caregiver Burden, and Psychological Distress between mothers of children Thalassemia and Autism (N = 100)

Variable	**Mothers**	**N**	**M**	**SD**	**df**	**p**	**t**	**95% of Confidence Interval of Difference**	
								Lower	**Upper**

CB	Major thalassemia	50	48.92	8.21	98	.133	-1.513	-7.39	.99
	Autsim	50	52.12	12.49					
PSD	Major Thalassemia	50	47.44	1.53	98	.221	-1.231	-15.67	3.67
	Autism	5SSS0	53.44	2.42					

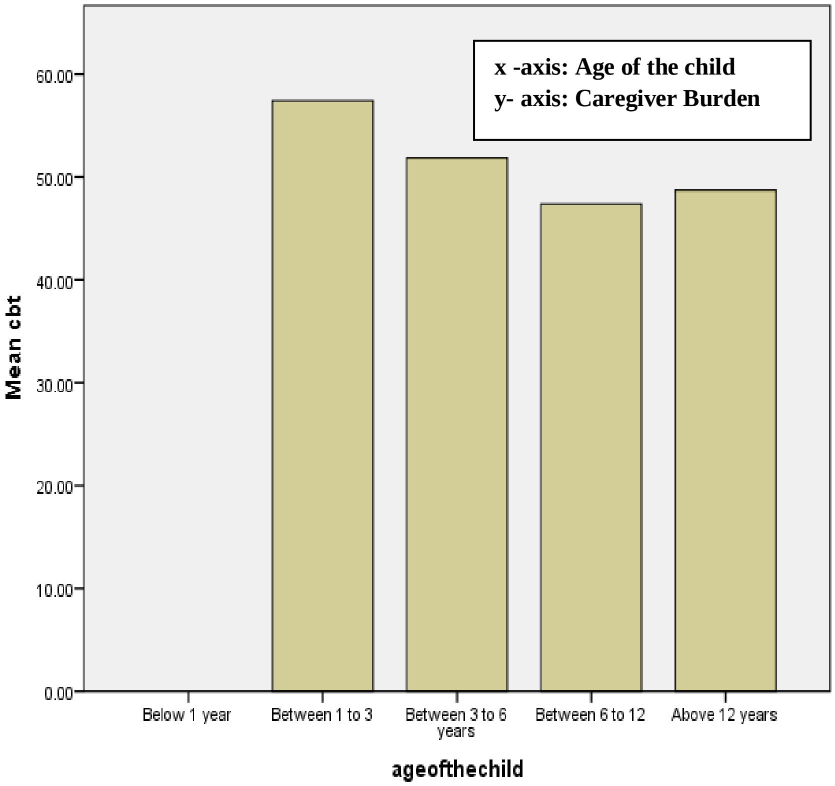
Note: $p<.05$, N= Number of participants, M= Mean, SD= Standard Deviation, t= t test value, df= degree of freedom, P= Significance, CB=Caregiver Burden, PSD= Psychological Distress

Table 1 shows the difference in caregiver burden and psychological distress among mothers of children with Major thalassemia and Autism. The finding reveals that there is no much significant difference in the level of caregiver burden and psychological distress among mothers of both groups' i.e Major thalassemia and Autism. It shows they perceive the burden and distress almost at the same level.

Additional Findings

Figure 2:

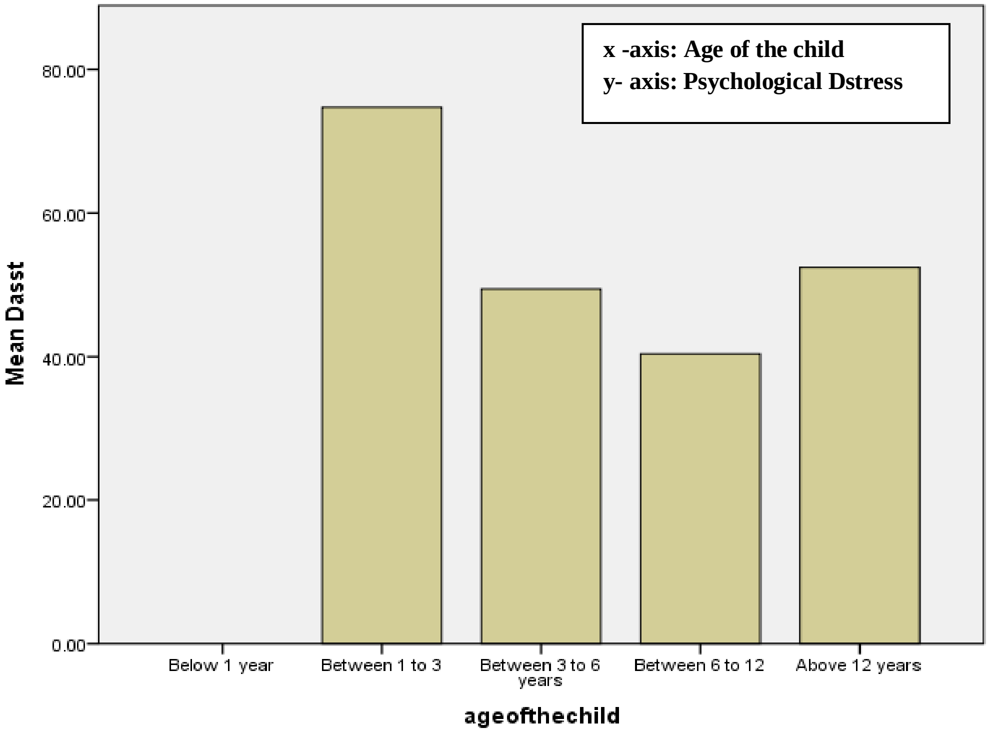
Differencein Caregiver burden of mothers with respect to age of the child



The graph above displays the mean of caregiver burden and age of child. It shows that caregiver burden was comparatively high in mothers who have children in range between 1 to 3 years.

Figure 3

Difference in Psychological distress of mothers with respect toage of the child



The graph above shows the mean of psychological distress and age of the child. It shows that psychological distress seems high among those whose children ages between 1 to 3 years of age.

Discussion

The aim of the present study was to compare the caregiver burden and psychological distress, among mothers who have a child with physical illness, and mothers who have a child with psychological illness. Caregiving seems to be huge responsibility in which caregivers put a lot of effort, time energy in order to take care of their loved ones. In Asian culture where mothers being caregiver has to go through a lot because along with other responsibilities, they have to manage this too. However, over time dangerous and fatal diseases has been increased worldwide. Be it a physical condition or psychological, they both have their own requirements in every aspect. Thus, it was important to explore the factors which are helpful in understanding mothers' mental health.

Finding both the hypothesis results showed that the difference is insignificant among mothers of children with physical illness and psychological illness regarding caregiver burden and psychological distress (Table 2). There could be many plausible explanations for the above-stated results.

The first and foremost rationale behind no significance difference between both groups of mothers is that being a mother figures they all have to go through the pain similarly. Children are dear to all mothers regardless of how the child is. For every mother each of his children carries equal importance. So being a mother of a child who is having any physical illness like Major thalassemia or any psychological disorder such as Autism it doesn't create any difference in their love and care towards them. They put equal effort while taking care of them and fulfilling all other responsibilities too.

Moreover, the burden itself includes a lot of factors including financial, emotional, and physical. Because sometimes as a parent, the caregiver is emotionally and physically available for a child but due to restricted income they feel burdened. They don't have enough money to cater their child's treatment. As in major thalassemia once a week or sometimes twice a week a child has to go for a blood transfusion which requires a good amount of money. As one of research also showed that parents of major thalassemia child suffer from economic crisis (Ishfaq, Naeem, Ahmad, & Zainab, 2016)

Whereas in Autism, a child has to go through occupational therapy, behavior therapy, and sometimes speech therapy so it also requires a great amount of money to cater all these therapies for their child. Along with that, due to their sensitivity towards food, sometimes they require special attention to food. Many caregivers face severe financial crises, high out-of-budget healthcare expenses, and unemployment. Previous studies have stated an overabundance of psychosocial problems impacting the overall well-being of caregivers of children with ASD, extending from depression, anxiety, stress, loss of interest in activities, marital relation issues, and declined physical health (Tathgur & Kang, 2021).

Being a part of the same culture could be one of the other main factors behind these results. In Pakistani culture, most of the responsibilities of taking care of the family are put on the mother's shoulder and there is no such scenario of shared responsibility. So, when there is no one to share the responsibility of that caregiver. And she has to take care of all the household chores and other children's needs too. So, taking care of a child who needs extra attention creates a lot more burden on herself (Mohammad & Khan, 2008) Conducted research in Mardan, Pakistan to examine the socio-economic and cultural constraints of women in the subject study. The results show that decision-making capacity is given to men regarding family matters including expenditure of the household. Whereas, for consultation only elderly women were asked about their opinion as Women were culturally constrained to remain at home and care for their children.

Also, in Pakistani culture where there is no such trend of trained caregivers; responsibilities are on the shoulders of mothers, being a caregiver, they have to manage all the things alone. Moreover, there is an affordability issue for parents as well (Sabzwari, Badini, Fatmi, Jamali, & Shah, 2016). And be it a physical illness such as thalassemia or a psychological disorder such as Autism, though they both have different natures they both require proper take care from a caregiver. In thalassemia there is weekly blood transfusion and in autism there is therapy required and sometimes medication too. So, they do have different requirements and demands but being a mother to any of them put almost equal pressure on them.

Along with that, a mother needs to distribute her attention between a child and other domains. Sometimes other children or relative might feel neglected due to this and it again build up pressure on the mother. While taking care they don't get enough time for themselves, and they don't get time to meet their relatives or friends, which leads to building up frustration. As one of the articles suggests that there is lack of social life sometimes may lead to a sense of interpersonal loss among caregivers. And this might perpetuate symptoms of psychological distress, and resentment. Because of limited social activities, there is a sense of isolation. Their caregiving role doesn't allow them to be elsewhere (Mathew & Fulton, 2018). And not having an outlet to channel their emotions build, they don't get time to talk to their close relatives and friends. Usually, there is no acknowledgment of those emotions which penetrates more distress. Social isolation doesn't allow them to express their emotion. The feeling of resentment, anger, and fear remains with them.

Moreover, in both conditions, there is proper schedule needs to be followed by the mother. There are major decision-making scenarios in both conditions, which might one of the factors to build up pressure. Both conditions need proper tracking of reports, routine checkups, hospital visits, and nutritional diet. Moreover, making their child abide by all the appointments is one of the major tasks because sometimes a child is not in the mood to go to meet a doctor or therapist. The level of consistent alertness is required in both conditions at more or less the same level so that could be the reason there was no such difference in the level of caregiver burden and psychological distress. As research suggests that feelings of helplessness and discomfort might be felt by people if they see any child with autism around them or in their families. Parents, especially mothers being primary caregivers might sense those feelings and it leads to a psycho-social burden among them (Kheir, Ghoneim, Sandridge, Hayder, Al-Ismail, & Al-Rawi, 2012).

Along with that, talking about stigma it can be seen that there is still stigma attached to both of the conditions. For thalassemia, people still don't consider it to be an illness. They still feel shy if they ask to go for a thalassemia test. It is still not in the consideration of people to for test before getting married. Moreover, due to societal pressure and taboo attached to the condition sometimes people tend to hide their child's health condition from their relatives or neighbors. As research suggests that a lack of awareness and stigma related to a child's health condition is linked with psychological distress among caregivers ((Mwale, Kauye, Gladstone, & Mathanga, 2018). Likewise in Autism, there is still a stigma attached due to its nature. Psychological health conditions are generally struggling to make their space in our society. Autism being categorized as a psychological disorder, still fails to get acknowledgment from society. They still believe that the condition has to be physically visible to get treatment or any professional help.

Efforts of caregivers and their health get neglected easily and when that frustration goes unnoticed it eventually leads to psychological distress because things get piled up. There is future anticipation about child how will look like. In thalassemia, there are very rare chances of survival, and in Autism they need continuous assistance. In a comparison of your child with another child, thinking about what a child will do without a caregiver creates a lot more distress. As their lives revolve around their child only so they lose their interest in other activities too. They don't get time to take deep breaths. Eventually, their thought pattern also goes around this environment too.

Eventually, mothers' upbringing children with thalassemia or autism might have to face a lot of questions related to the stigma attached to both conditions. And maybe that's one of the reasons there seems not much difference in their level of caregiver burden and psychological distress. Yet they both have different natures but the stigma attached to both conditions is significant. Being a primary caregiver, they have to go along with the child whether it's a school, hospital, or any other place. They are the ones who have to face all pain and hurdles along with the child.

With respect to additional findings, it is shown that caregiver burden and psychological seem high in mothers who have children between the age group of 1 to 3 years. Possible explanations for this could be:

First, mostly during this age not much time passed since the diagnosis has made. The child is too young to handle with this condition. Mother is newly introduced to this change. So, being a caregiver it's that time of the role when mother starts making amendments in her life. There is a arousal of a lot of emotions. Usually they don't understand how to go about it, and which doctor needs to be consulted for their children. Basically, they are in the process of gaining information, and adapting to this new role. Research conducted (Wang, et al., 2017) to assess caregiver among parents of children with acute lymphoblastic anemia. The study also concluded that Parents of newly diagnosed children feels more burdened. Taking care of younger child produce more distress among caregivers. Younger children tend to feel separation anxiety at a greater level as compared to adults. They also feel that they are not self-sufficient and thus their caregiver feels more burdened.

So, the caregiver has to manage the anxiety and fears of the child along with their own because, the child is too young to provide himself with self-help (Arab, Bernstein, Haghshenas, & Ranjbar, 2019)

Moreover, not only the caregiver but the whole family has to make certain changes in their lifestyles. They need to understand that one person was able to take care of all of them altogether. Now, won't be available all the time. Mother, who was dealing with all the affairs so efficiently, now might not be able to handle all those responsibilities altogether. So these are all the factors that might increase their burden and distress.

Conclusions

The present study was conducted to compare the caregiver burden and psychological distress among mothers of children with physical illness (thalassemia) and psychological illness (autism). Psychological and physical conditions have their own needs and requirements from the caregiver. Being living in a country where there is a lesser trend of trained caregivers, a lot of burdens is put onto the shoulders of mothers. Moreover, these feelings of burden then turn into distress and mothers tend to feel depression, anxiety, or stress. The findings of the study suggest that there is no such difference in the level of caregiver burden and psychological distress among mothers of children with thalassemia and autism. The reason might include the stigma attached to both conditions, the level of attention from mothers in both conditions and being a mother itself.

Implications

The present research highlighted the role of mothers a caregivers and the level of burden and psychological distress they must go through. It increases significant implications for developing proper awareness sessions firstly to make people aware of both conditions. As an organization to look after child's well-being, but at the same time it's important to organize some workshops for mothers too. Also, make them aware of all the risk factors and protective factors. This research can also be beneficial in understanding the importance of social support and community appreciation; both can play a motivational role for mothers. How they can prevent their child and how they can empathize with someone with these conditions around them.

Limitations

Data was collected during the pandemic so it was difficult to reach the maximum number of people. Hence the sample size was limited. Some of the scales were not translated into Urdu so it was difficult to search for scales in Urdu and get permission from the author. Moreover, there was a Language barrier at times as some of the mothers weren't able to understand Urdu as well. People were showing resistance as there is a taboo attached to feeling burdened when taking care of loved ones.

Recommendations

- Data should be collected from a large number of samples from various groups of organizations.
- Moreover, in future research comparison between mothers and fathers can be made.
- Those participants who have more than one child suffering from these conditions can also be included to check does this make any difference in level of caregiver burden and other variables.
- Perceived family support could be another variable to be studied.

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