Original Research Article

The Effect of Perceived Social Support on Psychological Distress and Equanimity among Caregivers of Thalassemia Patients

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ABSTRACT

Background: The present study aims to measure the effect of perceived social support on psychological distress and equanimity among caregivers of Thalassemia patients. Thalassemia is a chronic childhood disease which is genetically transmitted from the parents to the child. According to the World Health Organization, more than four million people in India suffer from Thalassemia. Evidently, circumstance will add to the caregiver's stress levels in several ways as the child with thalassemia requires lifetime treatment. therefore, understanding their mental health is crucial.
Methodology: A quasi-experimental design was used in the study. The data was collected from 102 caregivers who provide care to Thalassemia major patients (Male = 48 female=54) whose children are in between the age group of 1 to 20 years. Sample was derived by purposive sampling method. Multidimensional Scale of Perceived Social Support (MSPSS), the Kessler Psychological Distress Scale (K10) and the Equanimity Scale–16 (ES-16) were administered to measure Perceived Social Support, Psychological Distress and Equanimity respectively.
Results: As a statistical tool for data analysis, independent sample t test were used. The results obtained indicated that Perceived social support has an effect on Psychological Distress among caregivers of Thalassemia Patients [$t (98)= 2.56$, $p < 0.05$] however the results also stated that Equanimity was not affected by Perceived Social Support among caregivers of Thalassemia patients [$t(98) = 0.75$, $p > 0.05$] However no significant difference was obtained in Equanimity in relation to PSS.
Keywords: Thalassemia, Caregivers, Social Support, Psychological Distress, Equanimity, patients

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INTRODUCTION

Thalassemia is a genetically transmitted (i.e., passed from parents to children) blood disorder. According to the World Health Organization, more than four million people in India suffer from Thalassemia. India ranks the list when it comes to thalassemia. Over 10,000 children are born with the condition every year in the country. Of these, 50 per cent do not survive till the age of 20 due to poverty and lack of treatment. Over four million Indians are thalassemia carriers and more than 1, 00,000 are patients. [1]. The people who care for others when they are ill or in distress are known as caregivers. They play a more prominent function in relation to chronic illnesses like thalassemia. They encounter numerous difficulties in providing their children with high-quality care. Caregiver Perceived Social Support, Psychological Distress & Equanimity. Caregiver load is defined as a high degree of stress or distress one goes through while providing care for another person (typically a family member) who is sick. For instance, a person providing care for a patient with a chronic illness like thalassemia might encounter stressors like money strain, body strain, mental health issues, strain on their relationship with the patient, and levels of societal support. The caregivers of

thalassemia are heavily burdened by the cost of the illness and its complications. Additionally, it places a heavy strain on both their caregivers and society at large. [2]

Social Support

Social Support can be defined as "the existence or availability of people on whom we can rely, people who let us know that they care about, value and love us [3]. This construct has traditionally been divided into two categories: structural and functional. While received support refers to the kind and frequency of assistance transactions, perceived support refers to the perception of the support's availability when it is needed, its adequacy, and/or its quality. Several researchers have shown the positive effects of social support in psychological adjustment, health and well-being during the past three decades. Numerous studies have indicated that social support can be effective for improving the wellbeing of family caregivers. It found that higher levels of social support reduce the negative effects of caregiving and are associated with greater life satisfaction, less depression, less caregiver stress [4].

Psychological Distress

Psychological distress refers to non-specific symptoms of stress, anxiety and depression. High levels of psychological distress are indicative of impaired mental health and may reflect common mental disorders, like depressive and anxiety disorder [5]. Caregiving entails providing emotional and/or physical support to someone who has a chronic illness or disease. Some caretakers can view their job as a good challenge. Others might consider it to be a burden. The course and intensity of caregiving depend on the disease of the care recipient. Caregiver stress and burden are brought on by the demanding work of providing care, which can have a detrimental effect on their physical, psychological, and social well-being and lower their quality of life. As a result, caregivers are susceptible to psychological problems Family caregivers experience more physical and mental distress than non-caregivers in the same age group. Several studies suggest that many caregivers are at risk of experiencing clinical depression [6].

Equanimity

Equanimity is an attitude that is been recognised as a component of mindfulness [7]. One can develop equanimity by engaging in mindfulness exercises. While practising mindfulness, one can observe what is happening, yet may still find themselves drifting between overstimulated states or clinging to pleasure. The practise of mindfulness gives us the knowledge and experience necessary to eventually achieve equanimity. Equanimity is described as balanced mental state or dispositional attitude toward all experiences or things, regardless of their origin or affective valence (pleasant, painful, neutral). Acting with equanimity does not entail giving up or accepting things outside of your control that are painful or difficult for you, nor does it entail approaching daily life with a stilted indifference. Instead, it's about acknowledging that you have no control over those situations and using that knowledge to prevent yourself from wasting time and energy trying to change them. Findings from the study revealed that higher levels of perceived social support and mindfulness predicted lower levels of perceived parental stress [8].

METHODOLOGY

Hypothesis

Null Hypothesis:

1. There will be no significant difference in the levels of Psychological Distress among individuals scoring high on Perceived Social Support as compared to individuals scoring moderate on Perceived Social Support.
2. There will be no significant difference in the levels of Equanimity among individuals scoring high on Perceived Social Support as compared to individuals scoring moderate on Perceived Social Support.

Alternative Hypothesis

1. There will be a significant difference in the levels of Psychological Distress among individuals scoring high on Perceived Social Support as compared to individuals scoring moderate on Perceived Social Support.
2. There will be significant difference in the levels of Equanimity among individuals scoring high on Perceived Social Support as compared to individuals scoring moderate on Perceived Social Support.

Operational Definitions - Independent variable

Perceived Social Support Social support is the perception of being cared for by others and having a reliable network to turn to when needed, in everyday situations or specific moments of crisis [9] it can be perceived from three sources: family, friends, and significant others [9]. For the current study Perceived Social Support will be viewed with respect to high Perceived Social Support, medium Perceived Social Support and low Perceived Social Support. Scores between 12 to 35 are considered low on Perceived Social Support, scores between 36-60 are considered medium Perceived Social Support and scores between 61 to 84 are considered as high on Perceived Social Support.

Dependent Variables

1) Psychological Distress

Non-specific symptoms of stress, anxiety, and depression are referred to as Psychological Distress. High levels of psychological distress indicate poor mental health and may be indicative of common mental disorders such as depression and anxiety disorders [10]. For the current study Psychological Distress will be demarcated into no Distress, mild Distress, moderate Distress and severe Distress. Scores range will be from 10 - 19 Likely to be well, 20 - 24 Likely to have a mild disorder, 25 - 29 Likely to have a moderate disorder and 30 - 50 Likely to have a severe disorder.

2) Equanimity

Equanimity is "a balanced response to happiness and suffering, which guards against emotional disturbance" [7]. Also described as a "even-minded mental state or dispositional propensity toward all events or things, regardless of their affective valence (pleasant, unpleasant, or neutral) or source," equanimity is the capacity to remain calm under pressure. Therefore, "equanimity Perceived Social Support, Psychological Distress & Equanimity cultivation encourages one's increased capacity to control emotion and accept discomfort and distress [8]. For the current study, Equanimity will be divided into Experiential Acceptance and Non-Reactivity, where a higher score will indicate higher levels of Equanimity – that the client is immersed in experiencing acceptance and is not emotionally reacting.

Tools

Multidimensional Scale of Perceived Social Support (MSPSS)

Perceived Social Support, Psychological Distress & Equanimity. The Multidimensional Scale of Perceived Social Support was developed by Gregory, Zimet and colleagues in 1988. It is a self-report questionnaire consisting of 12 items. The scale measures perceived support from three domains: family (FA), friends (FR), a significant other (SO) and provides a global score. Participants are asked to indicate their agreement with items on a 7-point likert scale, ranging from very strongly disagree to very strongly agree. Scores ranging from 2 to 35 are considered as low support; a score of 36 to 60 are considered as moderate support, while a score from 61 to 84 is considered as high support. The test-retest reliability of the scale was very high with reliability coefficient 0.85. The reliability coefficient for three subscales i.e. family, friends and others were found out to be 0.85, 0.75 & 0.72. respectively. The MSPSS has good internal and test-retest reliability as well as moderate construct validity [11].

Kessler Psychological Distress scale (K10)

Kessler and colleagues created the Kessler psychological distress scale. It serves as a quick screening tool to determine the severity of psychological discomfort and is a straightforward measure of distress. Each response is graded on a scale of one ("none of the time") to five ("all of the time"). The ten items' scores are then added up to provide a final score that can range between 10 and 50. High scores imply high levels of

psychological distress, whereas low scores suggest low levels The scoring and interpretation range from , 10 - 19 Likely to be well , 20 - 24 Likely to have a mild disorder , 25 - 29 Likely to have a moderate disorder and 30- 50 Likely to have a severe disorder . The K10 has a good internal consistency with a Cronbach's alpha of 0.83. K10 has a two-factor solution based on results of exploratory factor analyses which accounted for approximately 66% of variance [12]**.**

Equanimity Scale-16 (ES-16)

The Equanimity Scale-16 (ES-16) is a 16-item self-report mindfulness scale which is developed by Rogers and colleagues, and it used to assess a client's level of non-reactivity to thoughts, feelings, and experiences. The ES-16 is intended for adults 18 and older and can be used in the therapeutic setting to assess experiential Perceived Social Support, Psychological Distress & Equanimity 37 avoidance and emotional reactivity - two factors that increase suffering. It is divided into two subscales:

1. **Experiential Acceptance:** This is an attitude in which the client does not seek to resist or attach to the experience and accepts all internal experiences (thoughts, feelings, body sensations, etc.).
2. **Non-Reactivity:** the client demonstrates non-reactivity to experiences, preventing attachment or aversion to these experiences (e.g., thoughts, feelings), or the ability to do so.

A total score is calculated in addition to subscale scores for experiencing Acceptance and Non-reactivity, where a higher score implies higher degrees of equanimity—indicating that a client is engaged in experiencing acceptance and is non-emotionally reactive. This scale showed good internal consistency (Cronbach's alpha = 0.88), test-retest reliability (n =73; r = 0.87, p < .001) over 2–6 weeks and convergent and divergent validity, illustrated by significant correlations in the expected direction with the Nonattachment Scale, Depression Anxiety and Stress Scale, Satisfaction with Life Scale and Distress Tolerance Scale [13-14].

Participants

A sample of 102 caregivers who provide care to Thalassemia major patients (of all genders) whose children are in between the age group of 1 to 20 years and were undergoing blood transfusion participated in the study. The data was collected from various blood banks and day care centers which have blood transfusion facilities for Thalassemia patients across Mumbai and Thane City. Caregivers of Patients who are below or above the age of 20 years were excluded from the study. Caregivers of Thalassemia minor patients were excluded from the study.

Procedure

The current study used a quasi-experimental design. Participants were chosen using the purposive sampling approach. Permission was taken from the blood bank and day care centres. Before taking part in this study participants were briefed about the aims and objective of the study, confidentiality of the data obtained and voluntary participation in the study. Consent form was given to each caregiver along with demographic sheet and questionnaire, participants were also informed that they are free to withdraw from the study at any point. Any doubts or queries related to the demographic sheet or questionnaire were cleared. Towards the end each participant was debriefed about the study. And the relevant data was collected, the scales were scored, and raw scores were obtained. As a statistical tool for data analysis, the Independent Samples t-test was administered in Statistical Package for Social Sciences (SPSS) version 28. Total three Independent Samples t-test was administered to draw inferences. The entire research study was reviewed and approved by the College Ethical Board

RESULTS

With respect to the above table, the means of the scores of high Perceived Social Support and medium Perceived Social Support on Psychological Distress are compared. The obtain t value is 2.56, significant at 0.05 level. Number of participants, categorised as high Perceived Social Support on Psychological Distress were 52, had a mean of 16.21 and standard deviation of 6.40. 50 participants were categorized as medium

Perceived Social Support on Psychological Distress with mean and standard deviation of 19.64 and 7.06 respectively.

Table 1: Inferential statistics of the mean differences between the scores of Perceived Social Support on Psychological Distress

Perceived social support	N	Mean	SD	t value	df	p value
High	52	16.21	6.40	2.56	100	0.05
Medium	50	19.64	7.06			

Table 2: Inferential statistics of the mean differences between the scores of Perceived Social Support on Equanimity

Perceived social support	N	Mean	SD	t value	df	p value
High	52	52.59	10.36	0.75	100	0.05
Medium	50	50.98	11.27			

With respect to the above table, the means of the scores of high Perceived Social Support and medium Perceived Social Support on Equanimity are compared. The obtain t value is 0.75 significant at 0.05 level. Number of participants, categorized as high Perceived Social Support on Equanimity were 52, had a mean of 52.59 and standard deviation of 10.36 .50 participants were categorized as medium Perceived Social Support on Equanimity with mean and standard deviation of 50.98 and 11.27 respectively.

DISCUSSION

The first hypothesis was, 'There will be a significant difference in the level of Psychological Distress among individuals scoring medium on Perceived Social Support as compared to individuals scoring high on Perceived Social Support'. To test this hypothesis, a t test was done to compare the means of medium and high Perceived Social Support on Psychological Distress. The obtained t value 2.56, is significant at 0.05 level. So, the hypothesis 'There will be no significant difference in the level of Psychological Distress on individuals scoring medium on Perceived Social Support as compared to individuals scoring high on Perceived Social Support' was rejected as the obtained t value was significant at 0.05 level. [$t(98) = 2.56$, $p < 0.05$]. The aim of this research was to understand the effect of Perceived Social Support, Psychological Distress & Equanimity among caregivers of Thalassemia patients. There exists research evidence to support the above, the obtained results were like the results in the study conducted by George and colleagues, they evaluated psychological distress among part-time and full-time caregivers in people who are 45 years of age or older [15]. The aim of the study was to identify psychological distress among caregivers and the moderating effects of social support. The sample for this study comprised of 2,670,41 participants. Results of this study revealed that perception of social support reduced the strength of the relationship between caregivers' status and psychological distress by 40% for full-time caregivers and 60% for part-time caregivers. Similar study was conducted by Long and his colleagues [16], it aimed at finding correlates of self-reported psychological distress among caregivers of cancer patients in Vietnam. The results revealed that educational level and type of support were significantly associated with having psychological distress among caregivers. Psychological distress is also referred to as stress or emotional distress, these terms are used interchangeably to refer to negative emotional states. In a related study, Hazlina and colleagues [17] aimed to understand the role of perceived social support in relation to stress in mothers of thalassemia patients. It was a cross-sectional study involving 372 mothers whose children suffer from Thalassemia with routine monthly blood transfusions treatment government hospitals in Malaysia. Findings of the study indicated significant negative direction in relationships between stress and social support. The findings from our study highlight the importance of social support perceived by mothers in buffering the effect of stress. The importance of

social support as perceived by mothers in mitigating the effects of stress. According to the data gathered, most caregivers with education levels below graduation experience higher levels of distress. Other factors that may have an impact on the study's findings include the caregiver's perceived sources of support, such as friends, family, support groups, or none. Most caregivers who have only one or no support systems experience high levels of discomfort.

It was hypothesized that – 'There will be a significant difference in the level of Equanimity on individuals scoring medium on Perceived Social Support as compared to individuals scoring high on Perceived Social Support'. To test this hypothesis, a t test was done to compare the means of medium and high Perceived Social Support on Equanimity. The Perceived Social Support, Psychological Distress & Equanimity 44 obtained t value, was found to be insignificant at 0.05 level. So, the hypothesis 'There will be no significant difference in the level of Equanimity on individuals scoring medium on Perceived Social Support as compared to individuals scoring high on Perceived Social Support' was rejected as the obtained t value was significant at 0.05 level. [$t(98) = 0.75$, $p > 0.05$]

Though there have not been researchers studying the relationship between these two variables, equanimity as a concept is related to mindfulness and there has been research done on mindfulness which are not in line with the results. One such study was conducted by Padhy and colleagues [18], the aim of the study was to look at how well-being, social support, and mindfulness relate to one another in the Indian community. The results revealed a positive correlation between mindfulness and social support. It was concluded that both social support and mindfulness are significant indices of wellbeing. Similar study was conducted by Wang and colleagues [19], the main aim of the study was to look at the role that perceived social support played in modulating the link between burnout and mindfulness in Chinese special education teachers. According to the findings, mindfulness and perceived social support were positively correlated. The findings show that combining mindfulness with perceived social support may be effective in preventing and alleviating burnout.

The factors affecting the results of the study were that almost all the participants in the study were married and it didn't have an impact on their levels of Equanimity. Secondly most of the caregivers who participated in the study were involved in the decision-making process of the treatment from the start, they were informed about the condition of the child, and this would have an effect of them accepting the situation and dealing with it in an effective way.

Limitations

In the above study, there could be a few limitations. One of the major limitations could be that the study is confined only to caregivers of thalassemia patients residing in Mumbai and Thane district, the data may not be applicable to other areas of the state or nation. Also, this study was carried out using survey forms, in depth interviews with parents would have been more useful for collecting data from the parents. This study was confined to caregivers whose children are in between 1-20 years, which could be extended by increasing the age range of the population and obtaining information from those excluding this age-group. Another limitation could be that the linguistic barrier in the study as only the participants having basic proficiency in English language and the ability to understand and fill the questionnaires were included. All the questionnaires administered in the research were in English language and thus, it was necessary to only include participants who had basic understanding and proficiency in the language.

CONCLUSION

Thalassemia, which is prevalent in India, poses significant challenges for caregivers. Caregivers face stressors such as financial strain and mental health issues. Social support, essential for caregivers, has been linked to improved well-being. Psychological distress, which is common among caregivers, can lead to impaired mental health. Equanimity, a component of mindfulness, is crucial for maintaining emotional balance. Previous research indicates the importance of social support in mitigating stress and highlights the importance of perceived social support in reducing psychological distress among caregivers of thalassemia patients. While equanimity was not significantly influenced by social support, psychological distress had a significant impacted based on the levels of Social Support in this study. Further research exploring the relationship between mindfulness, social support, and equanimity is required among caregivers.

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