

Original Research Article

Prevalence and Factors Associated with Mental Distress among Caregivers of Children with Mental Illness Attending Child and Adolescent Clinic at Muhimbili National Hospital, Dar Es Salaam

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Abstract: Background: Caregivers play an exceptionally important role in the lives of those they provide care for as well as to the healthcare system. The burden of caring for children with mental illness (CWMI) often falls on their caregivers, especially the mothers. Caregivers of CWMI experience significant challenges and are at an increased risk of experiencing mental distress than the general population. Resilience, emotion regulation, and social support are identified as protective factors against mental distress among caregivers. **Objective:** To determine the prevalence and factors associated with mental distress among caregivers of CWMI attending the child and adolescent mental health clinic at Muhimbili National Hospital (MNH) in Tanzania. **Methodology:** Hospital-based descriptive cross-sectional study was conducted at MNH Dar es Salaam, Tanzania. A purposive and convenient sample of 120 caregivers of CWMI attending the child and adolescent mental health clinic at MNH were recruited in the study. Interviewer-administered paperless questionnaire consisting of a socio-demographic questionnaire, self-reporting questionnaire (SRQ), 10-item Connor- Davidson Resilience Scale (CD-RISC), Emotion Regulation Questionnaire (ERQ), and Multidimensional Scale of Perceived Social Support (MSPSS) were used to collect data. Data were analyzed using SPSS version 28.0.1.1, where descriptive, bivariate and multivariate analyses were conducted. **Results:** Among the 120 caregivers studied, 97 (80.8%) were female, and 43 (35.8%) were aged between 35 – 44 years. Among the 120 participants 27 (22.5%) had mental distress, 35 (29.2%) had low resilience, 22 (81.7%) had low cognitive reappraisal, 27 (47.5%) had high expressive suppression, and 5% (6) had low perceived social support. All variables with a p-value of < 0.20 in the bivariate analysis were entered into the multivariate analysis model, where the independent risk of mental distress was four times higher amongst those living out of Dar es Salaam (AOR = 4.41; 95% CI 1.05-18.48; p=0.04); and four times higher amongst those with low resilience (AOR = 3.5, CI = 1.02 – 10.77; p=0.05). **Conclusion:** This study observed a less than twenty five percent prevalence of mental distress among caregivers of CWMI attending the child and adolescent mental health clinic at MNH, which was lower than that of other studies. Area of residence was significantly associated with mental distress while resilience was found to have a borderline association. **Recommendation:** Screening and early evidence- based psychosocial interventions directed towards caregivers of CWMI is required. Research to explore the effectiveness of evidenced-based interventions and further cross-sectional and longitudinal studies exploring psychosocial factors associated with mental distress among caregivers should be necessary. **Keywords:** Caregiver, Mental Distress, Children, Mental Illness, Resilience, Emotion Regulation, Perceived Social Support.

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INTRODUCTION

Mental illness affects 10-20% of children and adolescents worldwide, developing countries like Tanzania account for 85% of the 10-20% of children with disabilities worldwide [1, 2]. The burden of providing care for CWMI often falls upon their caregivers, particularly their mothers [3, 4]. In Tanzania, studies conducted among caregivers of patients with mental illness have reported experiences of mental distress as a result of their caregiving ranging

from feelings of sadness to somatic symptoms like fatigue [5-7].

Providing care for CWMI can negatively impact on the health of the caregiver regardless of their genetic vulnerabilities [8], and experiencing mental distress can affect the caregiver's ability to provide care and lead to poor prognosis in the CWMI [9]. Prevalence rates of mental distress range from 90.5% among caregivers of children with neurodevelopmental disorders to 21.1% among caregivers of adults with severe mental illness [10, 11].

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Resilience is an important adaptive process that enables one to effectively navigate through, resist, and maintain a positive outlook in the face of adversity [12]. Providing care to CWMI exposes caregivers to adversity because of the demands and challenges that are associated with caring that threaten the caregiver's capacity to adapt. High levels of resilience serves as a protective factor against mental distress by reducing perceived burden and increasing level of hope among caregivers [13-17].

Emotion regulation enhances levels of resilience by enabling adaptive psychosocial processes and increased control over emotional experiences and expressions [18, 19]. Katana *et al.*, found that cognitive reappraisal leads to higher subjective wellbeing and increased control over emotions while emotion suppression was linked to mental distress, lower wellbeing, and diminished interpersonal functioning [20].

Perceived social support has the ability to reduce harmful effects of stress that are associated with caregiving as it enhances caregiver adjustment and ability to cope [21]. Studies have found that caregivers with low social support were more likely to have mental distress compared to those with high social support [11, 22, 23].

The aim of this study was to ascertain the prevalence of mental distress among caregivers of CWMI in Dar es Salaam and to find the factors associated with mental distress.

MATERIALS AND METHODS

Participants and Procedure

This cross-sectional study was purposively conducted at the child and adolescent mental health clinic at MNH and conveniently recruited 120 caregivers aged 18 – 68 years providing care for CWMI attending the clinic at MNH. Those included in the study were: caregivers aged 18 years or above; caregiver, of child receiving care at MNH child and adolescent mental health clinic; and caregiver who has been living and providing care for CWMI for at least six months. Caregiver was defined as usually a family member, who is primarily involved and responsible for providing care, often unpaid, to the child with mental illness with whom they have a personal relationship [24].

Data were collected through interviewer-administered questionnaire, administered by trained research assistants who were fourth year medical students. The structured questionnaire consisted of: A self-developed Socio-Demographic Questionnaire, 10-item Connor-Davidson Resilience Scale (CD-RISC), Emotion Regulation Questionnaire (ERQ), Self-

Reporting Questionnaire (SRQ) and Multidimensional Scale of Perceived Social Support (MSPSS).

Ethical approval was given by the MUHAS Senate Research and Publications Committee, reference No.DA.282/298/01.C/1182, and permission to conduct the study were obtained from the office of the Executive Director of MNH and the Head of Department of Psychiatry at MNH. The research assistants were trained in administering the paperless version of the questionnaire, and the ERQ was piloted on caregivers of people with mental illness. During the interview the questions were read out loud and filled in by the research assistants, providing clarification and explanation to ensure caregivers understood the questions when required.

Data Analysis

The researcher analyzed the data by using the Statistical Package for Social Sciences (SPSS) for MacBook version 28.0.1.1.

Descriptive statistics were used to characterize the participants (mean, range, frequency, percentage, and standard deviation). The prevalence of mental distress (outcome variable) was a dichotomous variable and was determined using descriptive statistics. Participants who scored 8 or above were categorized as having mental distress (Yes) and those who scored below 8 as not having mental distress (No). During analysis of socio-demographic variables, participant's age in years was categorized in three groups; 34 years and below, 35 – 44 years, and 45 years and above. The age of CWMI was grouped into 3 categories; early childhood (0 – 5), middle childhood (6 – 11), and adolescents (12 – 17). The relationship of caregiver to CWMI was grouped into three categories. Educational level was categorized into four groups; primary & below, secondary 'O' & 'A' level, post-secondary training, and university level. Employment status was categorized into three groups; employed, unemployed, and self-employed. Perceived social support (PSS) was categorized into three groups; those having high PSS, medium PSS, and low PSS.

The following variables were dichotomized; participant sex was dichotomized as male or female, marital status was split into in relationship or not in relationship, relationship to CWMI was dichotomized as mother or others (denotes someone other than mother of CWMI), residence was split into living in Dar es Salaam or Out of Dar es Salaam, monthly income was dichotomized as 250,000 or less or more than 250,000, resilience and emotion regulation were both dichotomized as high or low.

Regression analyses were done to determine the presence and strength of associations between the independent variables and outcome variable. All variables with p-value of less than 0.2 in bivariate

analysis were included in the final multivariate analysis model to determine independent association of each variable to mental distress (outcome of interest) after controlling for confounders. The p-value of ≤ 0.05 and a confidence interval of 95% were used to determine statistical significance.

RESULTS

Socio-Demographic Characteristics of Participants

A total of 120 caregivers were interviewed, the caregivers were aged 18 – 68 years with a mean age of 36.2 ± 9.04 . From the 120 caregivers, 97 (80.8%) were female, 89 (74.2%) were mothers and majority of them

105 (87.4%) live in Dar es Salaam. The majority of the caregivers (87.5%) were in a relationship. Half had primary level education and below 37 (30.8%) had secondary level education, 11 (9.2%) had post-secondary training, and 12 (10%) had university level education. The majority 68 (56.6%) were unemployed. Also a majority 72 (60%) reported a monthly income of 250,000 Tanzanian shillings or less. About sixty-one (50.8%) of the CWMI were aged between 6 - 11 years with a mean age of 9.15 ± 3.76 , and majority of the participants 68 (56.7%) reported providing care for 3 or more children mean 2.97 ± 1.73 (Table 1).

Table 1: Socio-demographic characteristics of participants (N=120).

Characteristic	N (%)	Mean (SD)
Sex		
Female	97 (80.8%)	
Male	23 (19.2%)	
Age Range 18 - 68		36.2 (9.4)
≤ 34	39 (32.5%)	
35 – 44	43 (35.8%)	
≥ 45	38 (31.7%)	
Relationship to CWMI		
Mother	89 (74.2%)	
Other caregivers	31 (25.8%)	
Residence		
Dar Es Salaam	105 (87.5%)	
Outside Dar Es Salaam	15 (12.5%)	
Marital Status		
In Relationship	105 (87.5%)	
Not in Relationship	15 (12.5%)	
Education Level		
Primary & Below	60 (50%)	
Secondary ‘O’ & ‘A’ level	37 (30.8%)	
Post-secondary training	11 (9.2%)	
University	12 (10%)	
Employment Status		
Unemployed	68 (56.7%)	
Self-Employed	12 (10%)	
Employed	40 (33.3%)	
Monthly Income (TZS)		
250,000 or Less	72 (60%)	
More than 250,000	48 (40%)	
Age of CWMI		9.15 (3.76)
Early childhood (0 – 5)	20 (16.7%)	
Middle childhood (6 – 11)	61 (50.8%)	
Adolescents (12 – 17)	39 (32.5%)	
No. Children Providing Care for		2.97 (1.73)
1	22 (.3%)	
2	30 (25%)	
3 or more	68 (.7%)	

Psychosocial Characteristics of Participants

Using the cut-off point of 25 on the CD-RISC scale, 85 (70.8%) of the participants reported high resilience while 35 (29.2%) reported low resilience. ERQ scores were divided into two subscales, cognitive reappraisal and expressive suppression. The cut-off

point for ERQ subscales was calculated using the median. The median score for cognitive reappraisal was 4.92 and that of expressive suppression was 5.75. Ninety-eight (81.7%) scored low while the rest 22 (18.3%) scored high in cognitive reappraisal. Sixty-three (52.5%) scored low while 57 (47.5%) scored high

in expressive suppression. The cut-off point for the MSPSS was 1 – 2.9 for low PSS, 3 – 5 for moderate PSS, and 5.1 – 7 for high PSS. Among the participants

77 (64.2%) reported to have high PSS, 37 (30.8%) reported to have moderate PSS, and 6 (5%) reported to have low PSS (Table 2).

Table 2: Psychosocial characteristics of participants (N=120)

Characteristic	N (%)
Resilience	
High ≥ 25	85 (70.8%)
Low ≤ 25	35 (29.2%)
Emotion Regulation	
Cognitive Reappraisal (Median 4.92)	
High > 4.92	22 (18.3%)
Low < 4.92	22 (81.7%)
Expressive Suppression (Median 5.75)	
High > 5.75	57 (47.5%)
Low < 5.75	63 (52.5%)
Perceived Social Support	
High 5.1 - 7	77 (64.2%)
Moderate 3 – 5	37 (30.8%)
Low 1 – 2.9	6 (5%)

Prevalence of Mental Distress

The prevalence of mental distress among caregivers of CWMI attending the child and adolescent

mental health clinic at MNH who participated in this study was 27 (22.5%) using the SRQ-20 scores with a cut-off point of 8 or above (Figure 1).

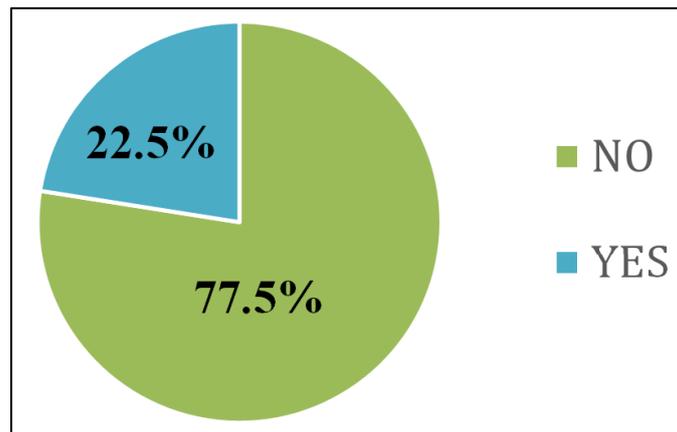


Figure 1: Prevalence of mental distress

Factors Associated with Mental Distress

To explore the association of independent variables with mental distress, bivariate and multivariate analysis were conducted. In the bivariate analysis, factors including residing outside of Dar es Salaam, being self-employed, having high expressive suppression, having low resilience, and being mother were found to be significantly associated with mental distress at p-value less than 0.2. These factors were entered into the multivariate analysis model to control for confounding effects.

The results of the multivariate analysis showed that living out of Dar es Salaam and having low resilience were significantly associated with mental

distress, with p-value of ≤ 0.05. Caregivers living out of Dar Es Salaam were four times more likely to have mental distress (AOR = 4.41, CI = 1.05 – 18.48; p = 0.04). Caregivers who reported low resilience were four times more likely to have mental distress (AOR = 3.51, CI = 1.02 – 10.77; p = 0.05), showing a borderline association with mental distress.

Conversely, age, sex, monthly income, employment status, relationship to CWMI, emotion regulation strategy of expressive suppression, and PSS were not statistically significant with mental distress in multivariate analysis model (Table 3).

Table 3: Independent strength of association between socio-demographic characteristics, psychosocial factors and mental distress

Variable	N	AOR (CI)	p-value
Sex			
Female	97	ref	
Male	23	40.00 (0.00)	1.00
Age			
Below 34	39	ref	
35 – 44	43	0.72 (0.20-2.60)	0.61
45 & Above	38	0.37 (0.08-1/64)	0.19
Employment Status			
Unemployed	68	1.30 (0.32-5.27)	0.71
Self-employed	12	5.67 (0.91-35.12)	0.06
Employed	40	ref	
Monthly Income			
250,000 or Less	72	1.68 (0.50-5.69)	0.40
More than 250,000	48	ref	
Residence			
Dar es Salaam	105		
Out of Dar es Salaam	15	4.41 (1.05-18.48)	0.04†
Relationship to CWMI			
Mother	89	ref	
Other	31	9.5 (0.46-18.73)	1.49
Resilience			
Low	35	3.505 (1.02-10.77)	0.05†
High	85	ref	
Emotion Regulation			
Cognitive Reappraisal			
Low	98	1.13 (0.26-4.89)	0.87
High	22	ref	
Expressive Suppression			
Low	63	ref	
High	57	2.75 (0.84-8.99)	0.09
Perceived Social Support			
Low	6	4.37 (0.94-20.34)	0.06
Moderate	37	0.77 (0.19-3.13)	0.71
High	77	ref	

AOR: Adjusted Odds Ratio. Key: † = p-value ≤ 0.05

DISCUSSION

In Tanzania there are no studies conducted on mental distress among caregivers of children with mental illness, and those conducted in other countries are limited, with the bulk focusing mainly on caregiver burden. Thus, very little is known about mental distress and associated factors among caregivers of CWMI in Tanzania. This study aimed to determine the prevalence and factors associated with mental distress among caregivers of CWMI attending child and adolescent mental health clinic at Muhimbili National Hospital in Tanzania. This study was conducted among 120 caregivers of CWMI attending the child and adolescent mental health clinic at MNH to determine the magnitude of mental distress and factors that are associated with it using a cross-sectional study design and proposed tools. This chapter discusses the findings of this study and how they compare to the literature regarding caregiver mental distress and its associated

factors. The discussions are based on the specific research objectives.

Prevalence of Mental Distress

This study found that 22.5% of caregivers of CWMI to have mental distress as assessed in the past month. This is not different from the prevalence rates seen in the general population, and could be due to various factors. It could potentially be a result of underreporting of symptoms or lack of understanding of the questions. Alternatively it could be due to the fact that caregivers receive support from other members in the household hence, reducing the burden associated with caregiving as it is shared within the household.

Out of all the significant socio-demographic factors only one was seen to be significantly associated with mental distress, this was caregiver residence (living out of Dar es Salaam). The caregivers in this study were primarily female (80.8%), most were mothers (74.2%) of the CWMI, were between 35 – 44

years of age (35.8%), and were in a relationship (87.5%). Caregiving in Tanzania is traditionally regarded as the role of the female caregivers predominantly mothers who often are in their early and middle adulthood. These demographic factors seen in the study are similar to those found in other studies [25-27, 23, 10, 11].

Majority of the caregivers resided in Dar es Salaam (87.5%) which is an urban area, had primary education or below (50%), and are providing care for 3 or more children (82.4%). Many people relocate from rural areas in pursuit of better opportunities often these individuals do not have secondary or tertiary levels of education and often take up domestic work or other low paying jobs, this could explain why majority of the caregivers in the study were found to reside in Dar es Salaam. Having more children in the household could serve as a protective factor for caregivers, as the provision of care is distributed among those within the household and often caregivers receive support from their children with care and/or household chores. These findings are in-keeping with other studies [27, 23, 28, 11].

The participant area of residence was found to be significantly associated with mental distress, this could be explained by the limited access to specialist healthcare services available outside of Dar es Salaam and most caregivers require traveling to the major cities such as Dar es Salaam to gain access to specialist services for the CWMI. Traveling long distance can be costly and challenging for most caregivers. This association is seen in other studies as well, for example a study conducted in Nigeria found that 80% of caregivers living in areas outside the main city had higher mental distress [26].

The prevalence of mental distress found in this study is almost similar to the findings from a study conducted in Addis Ababa, Ethiopia among 409 caregivers of patients with epilepsy which had a prevalence of 27.1% of mental distress in the study that was assessed using the Kessler Psychological Distress Scale (K10) [22]. In another study conducted using the Composite International Diagnostic Interview (CIDI) to assess the prevalence and factors associated with family caregiver burden worldwide had a prevalence of 23.3 – 27.1% of psychological distress as measured by the family burden section [29]. The present study appears to have a higher prevalence of mental distress when compared to a study done in the United States which reported 12.4% of psychological distress among caregivers of people with acute illnesses, chronic illnesses, and other types of illnesses that was assessed using the Mental Component Survey, the Brief Symptom Inventory-A, and Patient Health Questionnaire-2 [30].

Using a different instrument in Nepal, the General Health Questionnaire (GHQ), the prevalence of mental distress was 90.5% which is higher than that of this present study [10]. Two studies conducted in Nigeria both utilizing the GHQ had prevalence rates of 43.8% and 49% respectively [31, 32]. In a separate Nigerian study the prevalence of emotional distress among caregivers of patients with epilepsy using the Hospital Anxiety and Depression Scale (HADS) was 65.7% [26]. In Malaysia, in a research using the K10 among caregivers of patients with schizophrenia the prevalence of mental distress was 31.5% [27]. In a study using SRQ-20, a tool also used in the present study, in Ethiopia the prevalence of mental distress among caregivers of patients with severe mental illness was 56.7% [33]. The differences observed may have been contributed by the varying sample sizes, the use of different screening tools, as well as different types of illnesses that the care recipients have.

Association between Resilience and Mental Distress

In this study caregivers' resilience was found to have a borderline significance with mental distress, whereby having low levels of resilience was found to be associated with higher mental distress. Resilience is an adaptive skill that helps to facilitate an individual's ability to withstand and navigate through various stressors whereas people with low resilience might dwell on negatives, adopt a victim mentality and become overwhelmed or engage in risky unhealthy coping mechanisms.

This is seen in similar studies conducted in China whereby high resilience was seen to be negatively correlated with symptoms of depression among primary caregivers of CWMI [34]. Another Chinese study that looked at the moderating effects of resilience on psychological distress among caregivers revealed that caregivers having high levels of resilience had greater ability to overcome adversity protecting them from experience psychological distress [14].

A study conducted in Iran among family caregivers of patients with mental disorders found that having high resilience was associated with positive mental health, physical health and quality of life outcomes [35]. In a systematic review of 23 qualitative and quantitative studies reviewing resilience among caregivers it was concluded that there is an association between resilience and distress where by low resilience led to higher levels of distress and vice versa [16]. These findings posit that having low resilience was associated with mental distress.

Association between Emotion Regulation and Mental Distress

This study utilized the Emotion Regulation Questionnaire (ERQ) to assess emotional regulation among caregivers of CWMI. The tool divides emotion regulation into two strategies, cognitive reappraisal and

expressive suppression both of which were not significantly associated with mental distress in the final multivariate analysis model. However, this was not the case in other studies which found associations between emotion regulation and caregiver subjective wellbeing [18-20]. Majority of these studies looked at how emotion regulation enhances resilience which then positively impacted on mental health and wellbeing. Furthermore, differences observed in this study could be due to cultural differences that are evident between the present study population and that of the above reviewed literature.

Association between Perceived Social Support and Mental Distress

In this present study Perceived Social Support (PSS) as measured by the Multidimensional Scale of Perceived Social Support (MSPSS) was not seen to have a significant association with mental distress in both the bivariate or multivariable analyses. In Tanzania caregiving is not limited to the parents alone however; a child is brought and up cared for by the community in which they live. Furthermore, there could be the issue of high stigma surrounding mental illnesses, caregivers might refrain from seeking social support in fear of being ostracized or judged by others in their circles and/or community. Thus, having more social support/involvement exposes them to stigma which is detrimental to their social, emotional and mental wellbeing. Hence having low PSS might potentially be protective among this population.

This was inconsistent with findings from previous research done in other countries which found significant associations between PSS and presence or absence of mental distress among caregivers. A study conducted in Chile among caregivers found that having high PSS is associated with lower levels of mental distress [21]. Two separate studies conducted in Ethiopia both using MSPSS found that caregivers reporting low social support were more likely to have mental distress compared to those with high PSS [22, 23]. In a different study in Ethiopia using the Oslo-3 Social Support Scale (OSS-3) it was found that having low social support put the caregiver at a 9 times increased risk of mental distress [33]. In a study conducted in Tanzania among caregivers of adult patients with severe mental illness low PSS was found to be highly associated with mental distress, whereby caregivers with low PSS had 5 times higher odds of developing depression compared to those with high PSS [11].

With the exception of the present study all the other studies referenced above have findings that align with a review done to assess psychological distress among caregivers of people with mental illness which found that the lack of social support put the caregiver at increased risk of depression and vice versa [25]. The differences observed may be due to cultural and

population differences between the present study and the above referenced studies. Although, the study by Rwiza was conducted in a similar setting it explored PSS among caregivers of adults with severe mental illness, which arguably is associated with more stigma and increased level of burden as adults are expected to be independent and self-reliant compared to children [11].

Study Limitations

The use of interviewer-administered questionnaire may have resulted in bias due to desirable responses from participants and may have influenced the quality of data collected. This was mitigated by encouraging participants to not overthink their responses, assuring them of the anonymity of data, and maintaining a neutral stance as interviewers.

Some of the CWMI attended clinic with a person other than their primary caregiver, thus those individuals were not eligible to participate in the study. To mitigate this and achieve a desired sample size the list of caregivers phone numbers was requested from the nurses and the caregiver was called and informed of the study, asked to volunteer to participate in the study and those who agreed were requested to arrive at the child and adolescent mental health clinic to complete the face-to-face interviewer administered questionnaire.

The Emotion Regulation Questionnaire (ERQ) has not been validated for use in Tanzania, this was mitigated by conducting a pilot study to determine the internal consistency of the tool within the Tanzanian context prior to commencing data collection.

Difficulties in remembering while answering the time-framed questions such as in the past month for mental distress may have led to recall bias and was mitigated by interviewing participants in a comfortable and quiet room which had very limited distractions. This created an environment where they could recall more easily.

There was very limited research available on the prevalence of mental distress and association with resilience, emotion regulation, and perceived social support among caregivers of CWMI which limited discussion of the study findings. Although this was difficult to mitigate, data from other research exploring caregivers of people with mental illnesses were utilized to facilitate discussion.

CONCLUSION

Findings from this study conclude that the prevalence of mental distress among caregivers of CWMI attending the child and adolescent mental health clinic at MNH is low especially when compared to other studies. Majority of the caregivers had high resilience and perceived social support, but reported low emotion regulation.

This study found a borderline association between resilience and mental distress among caregivers of CWMI, whereby those with low resilience appeared to have high mental distress compared to those with high resilience. Only one socio-demographic factor, the caregivers' area of residence was seen to be significantly associated with mental distress, while the rest had no association with mental distress.

RECOMMENDATIONS

The following recommendations are made from the findings obtained from this study:

- Regular screening of mental distress among caregivers of CWMI when they accompany the CWMI at the child and adolescent mental health clinic for follow-up sessions, this can be done by nurses or interns while waiting to enter for the CWMI's doctors' consultation.
- Initiation of psychosocial interventions directed towards caregivers, with the aim of increasing their understanding of the CWMI's illness, psychoeducation regarding signs and symptoms of mental distress, and teaching adaptive emotion regulation skills like cognitive reappraisal (utilizing the skills outlined in dialectical behavior therapy).
- Research needs to be done on the implementation of effective evidence-based interventions directed towards caregivers of CWMI.
- More research studies to assess factors such as resilience and emotion regulation among caregivers of CWMI are encouraged.
- Further longitudinal studies to ascertain the directionality of the causation between resilience and mental distress among caregivers of CWMI are needed.

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