Received: 03 October 2022 Accepted: 15 January 2023

Psychological Well-being among Primary Caregivers of Children with Invisible Disabilities in Sri Lanka

Mohamed, F. W. & De Silva, I. R. R.

waahidahmohamed@gmail.com, raneesha13@gmail.com

National Institute of Business Management, Sri Lanka.

Sri Lanka Institute of Information Technology, Malabe, Sri Lanka.

Abstract

Caring for a child with invisible disabilities such as Autism Spectrum Disorder, Attention Deficit Hyperactive Disorder, speech impairments, and learning difficulties can be fulfilling whilst challenging the caregiver's psychological well-being. As these children require special support and a diligent caregiving environment to thrive, primary caregivers have to take on additional roles to provide extra support for children with invisible disabilities while accommodating their professional and personal lives through the process. This research therefore analyzed psychological well-being related depression, anxiety, and stress between primary caregivers of children with invisible disabilities and primary caregivers of typically developing children in Sri Lanka. Data was gathered through an online survey of a sample of 75 primary caregivers between the ages of 23 – 56 years, which included 38 primary caregivers of children with invisible disabilities and 37 primary caregivers of typically developing children. The DASS-21 was administered to measure depression, anxiety, and stress. The independent sample t-test was used to compare the mean between the two groups of caregivers. The results confirmed that there is no significant difference in the levels of depression, anxiety and stress between primary caregivers of children with invisible disabilities and primary caregivers of typically developing children. The implications of this study suggest, with the right support and experience, anxiety may reduce in primary caregivers. The necessity to pay attention and provide more social and family support to enhance the psychological well-being of caregivers can improve their efficiency in caregiving.

Keywords: Caregivers, Children, DASS-21 Disabilities, Psychological well-being.

Introduction

Children with invisible disabilities require special educational needs (SEN) and diligent caregiving to thrive. A caregiver of a child with an invisible disability is an individual involved in the process of identifying, treating, or supporting the disability or illness (VandenBos, 2013). Special educational needs are a highly anticipated venture towards modernized education. There were more than seven million students in America receiving special education services between the year 2019-2020 (Lewis et al., 2021).

Research shows that caregiver functioning, and wellbeing have profound effects on the wellbeing of the children under their care (Munsell et al., 2012).

Caregiving involves the process of attending to and supporting dependent individuals (Schulz et al., 2016). The role of caregiving is often adopted by family members, health professionals, social workers and even educators, who protect, supervise and directly give care for their dependent individuals (Schulz et al., 2016). Among all the caregiving roles, taking care of children is one of the most challenging tasks, especially if the child is diagnosed with an invisible disability such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), speech impairment or a learning difficulty (e.g.:Dyslexia/Dyscalculia/Dysgraphia, etc. (Andrioni et al., 2022). Caregivers of children with invisible disabilities experience increased levels of challenges in parenting, social constrictions, financial difficulties, and finding suitable treatment and support for their children (Scherer et al., 2019; Davenport & Zolnikov, 2021). The responsibilities of a caregiver, independent of their dependent's care level required, has a major impact on the caregiver's mental health such as increased levels of depression, anxiety, and stress (Masulani et al., 2016; Dhiman et al., 2020). Therefore, this causes a dysfunctional parent -child interaction and results to the reporting of poorer psychological well-being among caregivers of children with invisible disabilities (Miodrag et al., 2014). Even today, whilst curbing the spread of the COVID-19 pandemic, primary caregivers had to take on additional roles to provide extra support in order to facilitate the various needs of the children in their care, whilst accommodating their professional, home and caregiving environment into the designated role of caregiving (Zhang, 2021). It has been reported that primary caregivers of children with invisible disabilities were highly burdened (Zahaika et al., 2021). Furthermore, the parents who experience depression, anxiety and stress have characteristics of irritability, anger, negative coping behavior and exhaustion, which in turn may affect the children under their care (Cocker & Joss, 2016).

However, there is limited research on components such as psychological wellbeing related depression, anxiety, and stress especially among family caregivers (Davenport & Zolnikov, 2021). Also, the impact caregiving has on the mental health of primary caregivers is not addressed in the Sri Lankan context. Therefore, the objective of this study is to compare the levels of psychological well-being among primary caregivers of children with invisible disabilities and primary caregivers of typically developing children in Sri Lanka. The findings will be helpful to understand how caregiving impacts the psychological wellbeing of caregivers in Sri Lankan context and also provide insight on how the community and healthcare professionals can improve caregiver well-being. This is important as the impact caregiving has on the mental health of primary caregivers is not addressed in Sri Lankan context.

Thus, in this study the mean scores of depressions, anxiety and stress are compared between primary caregivers of children with invisible disabilities and primary caregivers of typically developing children.

Materials and Methods Ethical considerations

The ethical approval for data collection was granted by the Psychology Ethics Review Committee of the National Institute of Business Management (NIBM) for a period of six months (January to July 2022) under the Project Reference Number: 8351696.

Selection of participants

Participant eligibility for primary caregivers was dependent on the following factors: age between 18 to 65 years, caring for a child between 3 to 18 years, and Sri Lankan nationality. To be considered as a caregiver of a child with invisible disabilities, the child needed to have received a formal diagnosis from a medical professional.

Study design

A quantitative approach was adopted to compare group differences in psychological well-being among primary caregivers of children with invisible disabilities and primary caregivers of typically developing children. A cross-sectional online survey, which included a demographic form and a standardized questionnaire, the depression anxiety stress scale (DASS-21) developed by Lovibond and Lovibond (1995), a scale used to measure depression, anxiety, and stress was created and shared among participants who showed interest in participating.

The survey was created on a Google Form and shared on social media platforms such as Facebook, Instagram and Email. The advertisement contained the objectives of the study and the eligibility of the participants. Prior to filling out the form, participants were provided an explanatory information sheet, and the consent form. On providing their consent, they were directed to the survey. The survey took approximately 10 minutes to complete.

Sample size

The sample size of this study is 75 consist of 38 primary caregivers of children with invisible disabilities (group 1) and 37 primary caregivers of typically developing children (group 2).

Primary data

The demographic questionnaire collected information on caregiver's age, gender, education level, civil and employment statuses, income range, and role of the primary caregiver. Further, primary diagnosis of the child such as, attention deficit hyperactivity disorder (ADHD), anxiety disorder, Autism Spectrum Disorder (ASD), deafness, epilepsy, intellectual disability, learning difficulty (e.g. Dyslexia/Dyscalculia/Dysgraphia etc.), psychiatric disability, speech impairments and if the child is typically developing the option of not applicable (if the child does not have any invisible disabilities). Furthermore, if the child was able to care for themselves, knowledge and experience of the primary caregiver were questioned in order to analyse and understand the sociodemographic profile of the recruited participants. The levels of depression, anxiety, and stress were collected through the short version of the DASS-21. Psychometric measure of DASS-21 showed high internal consistency with a Cronbach's

alpha between 0.94 to 0.97 for DASS-Depression, between 0.84 to 0.92 for DASS-Anxiety, and between 0.90 to 0.95 for DASS-Stress (Parkitny & McAuley, 2010).

Data collection

Only the demographic data listed (Table 1) was required from the participants of this study. There were no identifying markers such as participants name, therefore participation was anonymous. Only a participant code was asked which included the initial of the participant's first name, initial of the last name, birthday and birth year. Prior to participation, participants were provided with the participant information sheet to read and understand the purpose of the study, objectives of the study, confidentiality, withdrawal and potential risks of participating. The questionnaires were shared with participants only after obtaining their consent for participation, and thereafter they were informed of withdrawal from the study at any point. It was noted that there could be psychological distress in taking part in the study, therefore sources of psychological support were mentioned in the participant information sheet. Participants were requested to participate in the survey through a social media advertisement along with a web link.

Hypothesis

The study hypothesized that there was no significant difference in the mean scores of depression, anxiety and stress between primary caregivers of children with invisible disabilities and primary caregivers of typically developing children.

Statistical analysis

The data were transferred from the Google form to IBM SPSS 25 software to be analysed. The data from variable DASS-21 was computed in order to calculate total scores for depression, anxiety, and stress. Descriptive statistics reported on demographic factors within the study such as age, gender, and level of income.

An independent sample t- tests was conducted separately for each variable to compare means in two groups. Correlation analysis was carried out to find the significant association between age and three main variables namely depression, anxiety, and stress. Simple linear regression analysis was used to find the relationship between age and anxiety.

Results and Discussion Distribution of demographics factors

The percentage distribution of the numbers among the levels within demographic factors with respect to the total sample size (75): group 1: "38 primary caregivers of children with invisible disabilities" and group 2: "37 primary caregivers of typically developing children" are shown in Table 1.

Table 1.

Percentages of each level with respect to totals in both groups within each factor.

Levels & Factors	Perce	ntages
	Group 1	Group 2
Gender		
Male	9.3	5.3
Female	40.0	42.8
Prefer not to say	1.3	1.3

Table 1. (Continued)		
Age		
(18 - 25) years	1.3	1.3
(26 - 64) years	49.4	48.0
Civil status		
Single	8.0	10.7
In a relationship	1.3	5.3
Married	37.3	30.7
Divorced/ Separated	4.0	2.7
The role		
Parent	42.7	46.6
Legal guardian	8.0	2.7
Education level		
Passed GCE O/L	8.0	9.3
Passed GCE A/L	16.0	9.3
Graduate	12.0	2.0
Postgraduate /	14.7	10.7
Doctorate		
Occupation		
Unemployed	13.3	13.3
Student	1.3	1.3
Employed (full-time)	13.3	18.8
Employed (part-time)	10.7	9.3
Self-employed	8.0	6.7
Others	4.0	0.0
Nr. 41.		
Monthly income	5.2	0.2
<rs. 15,000<="" td=""><td>5.3</td><td>9.3</td></rs.>	5.3	9.3
Rs.15,000-50,000	9.3 10.7	6.7 16.0
Rs. 50,000-150,000		
>Rs.150,000	14.7	10.6
Not applicable	10.7	6.7
Any systems of home		
care therapy?		
Yes	30.7	12.0
No	20.0	37.3

The majority of primary caregivers of this study constituted of mothers. Thirty-eight

(50.6%) primary caregivers reported to care for a child with invisible disabilities and 37 (459.4%) participants reported to care for a typically developing child. The majority of participants (97.47%) were middle-aged group (26-64 years) with mean of 37.2 years and standard deviation of 7.8. Among both groups, 32.0% participants were employed fulltime, but 17.3% of the participants did not receive a monthly income whereas, 50% of the participants reported receiving a monthly income of Rs. 50,000 and above.

Depression, anxiety, and stress among primary caregivers

The mean prevalence of depression, anxiety, and stress were 15.42, 14.21, and 17.32 respectively for primary caregivers of children with invisible disabilities. For primary caregivers of typically developing children, the mean prevalence was reported comparatively lower as the corresponding values for depression, anxiety and stress were 12.92, 12.16 and 14.7 respectively (Table 2).

Table 2.

Mean scores of depressions, anxiety and stress between two groups.

Variables	Group 1		Group 2	
	Mean	SD	Mean	SD
Depression	15.42	12.51	12.92	10.42
Anxiety	14.21	12.07	12.16	8.37
Stress	17.32	11.60	14.70	8.80

Both groups reported mild levels of stress, mild to moderate levels of depression, and moderate levels of anxiety. Therefore, it can be speculated that caring for a child with invisible disabilities may not be the primary reason impacting their mental health, but the influence of other environmental factors such as the COVID-19 pandemic and the current economic crisis could be major contributing factors (Dhiman et al., 2020; Zahaika et al., 2021).

Group differences in levels of depression, anxiety and stress

A pairwise t-test found that there is no significant difference for depression, anxiety and stress between two groups of caregivers as the corresponding p-values are greater than 5%. This implies that independent of the child's diagnosis, there was no significant difference, and the findings are in contrast with previous studies (Cocker & Joss, 2016; Masulani et al., 2016).

Impact of demographic factors on depression, anxiety, and stress

The correlation coefficients were computed in order to find the corresponding impact (Table3).

Table 3.

Status of significance of the correlation coefficients (r) between age and three variables in group 1 (primary caregivers of children with invisible disabilities).

Variable	r	p value
Stress	29	0.08
Anxiety	37*	0.02
Depression	32	0.06

Results in Table 3 indicate that there was no significant relationship between age and depression and age and stress among the caregivers of children with invisible disabilities as the corresponding correlations are not significant (p>0.05). A significant moderate negative correlation was reported between age and anxiety (r = -.37, p < .05). This finding reveals that age has a negative linear relationship with anxiety and could be contributing to the significant relationship between age and total DASS-21 score as well. The simple linear regression analysis between these two variables revealed that age predicted anxiety as F (1, 36) = 8.47, p< .05 and =-0.44, p< .05. Therefore, it implies that when age increases by 1 unit, anxiety decreases by 0.44 units. This finding emphasizes on the impact of age as a protective factor to decrease levels of anxiety when caring for children with invisible disabilities. This finding is supported by past research as anxiety may reduce due to the increased amount of knowledge and experience into caregiving. However, this is challenged by Scherer et al. (2019) where they reported that anxiety increased with age because of long-term caregiving and deterioration of primary caregivers' mental health. However, over the years of caregiving, age has shown to be a protective factor in reducing the impact of caregiving on mental health (Tentorio et al., 2020). This may be due to the fact that primary caregivers are more aware and educated on the knowledge of the child's condition and over time, resilience grows (Tentorio et al., 2020). They also learnt to prioritize and pay attention towards their emotional support and individual needs. (Therefore, providing necessary support by promoting awareness on early intervention and the importance of well-being can positively impact the psychological wellbeing of caregivers of children.

Through the findings that have been brought forward through the analysis of this study, some conclusion can be drawn in regard to understanding the background of primary of children with invisible caregivers disabilities and how this impacts their psychological well-being by giving rise to depression, anxiety and stress. Usually, a child with invisible disabilities needs more support and assistance comparative to a typically developing child, and past research has concluded that in the context of caring for the child, the role is predominantly taken over by mothers (Naghavi & Zamani-Forooshani, 2019). Based on the current study, it is made evident that the majority of primary caregivers of children with invisible disabilities were females. These findings are similar to the findings of previous studies where majority of caregivers have been females (Chafouleas & Iovino, 2021). Further, the demographics of the sample indicate that majority of the sample involves middle aged female married parents in regard to both groups of caregivers (children with invisible disabilities and typically developing children). This can be further supported as the law in Sri Lanka does not allow adoption by a single parent and only married individuals are allowed to do so following several guidelines (Ministry of Justice, 2022). Only 32% of caregivers in the total sample of 75 caregivers stated that they were single, divorced, separated, where caregivers who were single may indicate individuals who have legal guardian rights over a child. It can therefore be deduced that in Sri Lanka, a majority of caregivers are females.

In observing the levels of anxiety, depression, and stress among the two groups of primary caregivers, both groups experienced an impact on their mental health. Comparing the mean scores of depressions, anxiety, and stress of both groups, it is made evident that caregivers of children with invisible disabilities did experience a slight increase in each of the scores though they were not significant. Since the scores indicated that overall, both groups experienced mild levels of stress, mild to moderate levels of depression and moderate levels of anxiety, it can be understood that caring for a child with invisible disabilities may not necessarily be the sole reason for the impact on their wellbeing rather other environmental factors such as COVID-19 and the current economic crisis could be major contributing factors as well. This, therefore, is not consistent with findings of past research.

Moreover, 60% of the caregivers of children with invisible disabilities had trained for home care therapy such as educational therapy, speech therapy, occupational therapy, physiotherapy and behavior therapy, which means they have the potential and efficiency to take care of their children well through the skills they developed through training. As a result, the findings of this study can also indicate that both groups had similar factors that were influencing the overall increased levels of depression, anxiety, and stress, and may not necessarily be the role of caregiving itself. However, this would also require further investigation.

In this study, the primary caregivers of children with invisible disabilities showed a significant impact of age on their anxiety levels. The findings show that as age increased the levels of anxiety lessened. This finding contradicted with past research where most studies found

that anxiety increased with age because of long-term caregiving and deterioration of primary caregivers' mental health (Bujnowska et al., 2019; Scherer et al., 2019). However, this finding remains consistent with the findings of a past study conducted by Tentorio et al. (2020). They stated that the impact age has on anxiety levels may be due to that fact that over the years of caregiving, primary caregivers are more aware and educated on various interventions focusing on the knowledge of the child's strengths and weaknesses, and over time, resilience grows. They are also more accepting of and are experienced towards the needs of the child. Further, the research article also stated that this relationship maybe because with time the caregivers also learn to prioritize and pay attention towards their emotional support and individual needs (Tentorio et al., 2020).

Limitations in the study

It should be noted that there were limitations in this study. The COVID-19 pandemic and the economic crisis in Sri Lanka may have influenced the caregiver reporting in addition to the challenges of caregiving, at the time of data collection. The majority of the respondents were recruited through social media platforms with English research material. Further the use of convenient sampling in a limited population greatly limited the generalizability of the findings. Though the results cannot be generalized, this was done to overcome restrictions imposed by the pandemic followed by the economic crisis and civil unrest in recent history. Therefore, if the study was to be replicated, as it is taking place in Sri Lanka, conducting it in all three languages spoken in Sri Lanka: that is Sinhala, Tamil and English, would help to yield a better sample as participants can be then recruited beyond the social media audience. Further, incorporating paper-pencil data collection method would be an added advantage.

Conclusions

This paper provides an understanding on the psychological well-being related depression, anxiety, and stress among primary caregivers of children with invisible disabilities and typically developing children. Findings revealed that depression, anxiety, and stress were reported by both groups of primary caregivers, but without a significant difference between groups. Therefore, it can be suggested that depression, anxiety, and stress in primary caregivers of children with invisible disabilities do- not primarily stem from having to care for a child requiring additional care. However, the level of anxiety in primary caregivers of children with invisible disabilities was reported to decrease with increasing years of age. Through the results of the study, it can be implied that the impact of caring for a child with an invisible disability may be reduced if the caregiver receives the necessary support.

This support would primarily involve gaining the skills of caregiving needed to take care of the specific disability of their child. Gaining the necessary skills will increase their efficiency in taking care of their child. Further encouraging caretakers to take care of themselves and prioritize their mental health should also be an important factor to be considered and addressed by the health care professionals such as a psychologist who maybe attending to the child as the primary health care provider. This could be mediated

through educating the caregivers regarding the diagnosis of the child, creating awareness and advocating for inclusion in order to reduce the social stigma in schools and society. Further providing them with access to professional care to receive holistic support for their various needs would also strengthen caretaking. Since parents in both groups showed symptoms of depression, anxiety and stress, the health ministries or hospitals can conduct workshops for new parents to help them understand parenthood and identify their children's developing milestones so as to be able to identify symptoms at an earlier stage and get the immediate professional help as needed. Being exposed to such services with time will increase their efficiency in caretaking and improve their overall psychological wellbeing, and also support the significant finding of this study that with age anxiety levels related to caregiving reduced.

Acknowledgement

I wish to extend my sincere gratitude to Mariam and Sarah for their guidance, and to my supervisor Ms. Raneesha De Silva for her invaluable advice and knowledge.

Reference

Andrioni, F., Coman, C., Ghita, R. C., Bularca, M. C., Motoi, G., & Fulger, I. V. (2022). Anxiety, Stress, and Resilience Strategies in Parents of Children with Typical and Late Psychosocial Development: Comparative Analysis. International Journal of Environmental Research and Public Health, 19(4), 2161. https://doi.org/10.3390/ijerph19042161.

Aththidiye, R. (2012). Adaptation and Validation of the Depression Anxiety and Stress Scale (DASS21) among Student in the University of Colombo.

Annual ResearchSymposium, University of Colombo.**

Bujnowska, A., Rodríguez, C., García, T., Areces, D., & Marsh, N. (2019). Parentingand future anxiety: The impact of having a child with developmental disabilities. *International Journal of Environmental Research and Public Health*, 16(4), 668. https://doi.org/10.3390/ijerph16040668.

Chafouleas, S. M., & Iovino, E. A. (2021). Comparing the initial impact of covid-19 on burden and psychological distress among family caregivers of children with and without developmental disabilities. *School Psychology*, *36*(5), 358-366. https://doi.org/10.1037/spq0000426.

Cocker, F., & Joss, N. (2016). Compassion Fatigue among Healthcare, Emergency and Community Service Workers: A Systematic Review. *International Journal of Environmental Research and Public Health*, 13(6), 618. https://doi.org/10.3390/ijerph13060618.

Davenport, S., & Zolnikov, T. R. (2021).

Understanding Mental Health
Outcomes Related to Compassion
Fatigue in Parents of Children
Diagnosed with Intellectual Disability.

Journal of Intellectual Disabilities,
174462952110136. https://doi.
org/10.1177/17446295211013600.

- Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of covid-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in Developmental Disabilities*, 107, 103790. https://doi.org/10.1016/j.ridd.2020.103790.
- Lewis, M. M., Burke, M. M., & Decker, J. R. (2021). The relation between The Individuals with Disabilities Education Act and Special Education Research: A systematic review. *American Journal of Education*, 127(3), 345-368.
- Lovibond, S. H., & Lovibond, P. F. (1995). Depression anxiety stress scales. *PsycTESTS Dataset*. https://doi.org/10.1037/t01004-000.
- Masulani-Mwale, C., Mathanga, D., Silungwe, D., Kauye, F., & Gladstone, M. (2016). Parenting children with intellectual disabilities in Malawi: The impact that reaches beyond coping? *Child: Care, Health and Development, 42*(6), 871-880. https://doi.org/10.1111/cch.12368.
- Ministry of Justice (2022). *Adoption of Children*. LawNet. (2022). Retrieved 30 April 022, from https://www.lawnet.gov.lk/adoption-of-children-3/
- Miodrag, N., Burke, M., Turner-Smith, & Hpdapp, R. M. (2014). Adverse health in parents of children with disabilities

- and chronic health conditions: A meta-analysis using the Parenting Stress Index's Health Sub-domain, *Journal of Intellectual Disability Research*, 59(3), 257-271. https://doi.org/10.1111/jir.12135.
- Munsell, P. E., Kilmer, R., Cook, J., & Reeve, C. (2012). The effects of caregiver social connections on caregiver, child, and family well-being. *American Journal of Orthopsychiatry*, 82(1), 137-145. https://doi.org/10.1111/j.1939-0025.2011.01129.x.
- Naghavi, A., Zamani-Forooshani, F. (2019).

 Fatigue and Satisfaction due to Compassion: the Experiences of Mother Caregivers of a Child with Disability. *Journal of Applied Sociology*, 30(4), 21-34. doi: 10.22108/jas.2019.114021.1557.
- Parkitny, L., & McAuley, J. (2010). The Depression Anxiety Stress Scale (DASS). *Journal of Physiotherapy*, 56(3), 204. https://doi.org/10.1016/s1836-9553(10)70030-8.
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and Anxiety in Parents of Children with Intellectual and Developmental Disabilities: Α Review **Systematic** and Meta-**PLOS** Analysis. ONE, 14(7). https://doi.org/10.1371/journal. pone.0219888.
- Schulz, R., & Eden, J., (2016). Family Caregiving Roles and Impacts. In Families Caring for an Aging America.

National Academies Press (US). https://doi.org/10.17226/23606.

- Tentorio, T., Dentali, S., Moioli, C., Zuffi, M., Marzullo, R., Castiglioni, Franceschi, M. S., (2020).Anxiety and Depression are Not Related to Increasing Levels of Burden and Stress in Caregivers of Patients with Alzheimer's Disease. American Journal of Alzheimer's Disease & Other Dementias, 35, 153331751989954. https://doi. org/10.1177/1533317519899544.
- VandenBos, G. R. (Ed.). (2013). APA dictionary of clinical psychology. *American Psychological Association*. https://doi.org/10.1037/13945-000.
- Zahaika, D., Daraweesh, D., Shqerat, S., Arameen, D., & Halaweh, H. (2021). Challenges Facing Family Caregivers of Children with Disabilities During COVID-19 Pandemic in Palestine. *Journal of Primary Care & Community Health*, 12, 215013272110430. https://doi.org/10.1177/21501327211043039.
- Zhang, X. (2021). Barriers and benefits of primary caregivers' involvement in children's education during COVID-19 school closures. *International Journal of Disaster Risk Reduction*, 66, 102570. https://doi.org/10.1016/j.ijdrr.2021.102570.