Vol 14, Issue 10, (2024) E-ISSN: 2222-6990

Factors Affecting Psychological Well-Being of Female Caregivers to Children with Disabilities: A Conceptual Paper

Nurin Hadirah Mohd Sufferi, Wan Arnidawati Wan Abdullah & Asmidawati Ashari

Department of Human Development and Family Studies, Faculty of Human Ecology,
Universiti Putra Malaysia
Corresponding Author Email: arnidawati@upm.edu.my

To Link this Article: http://dx.doi.org/10.6007/IJARBSS/v14-i10/23313 DOI:10.6007/IJARBSS/v14-i10/23313

Published Date: 16 October 2024

Abstract

This article focuses on the psychological well-being of female, particularly mothers, who are responsible for caring children with disabilities. Mothers frequently struggle to provide care for their children with disabilities due to overwhelming demands that exceed their ability. These challenges negatively impact every aspect of life, resulting in significant psychological stress for mothers. Therefore, this article aims to elaborate the concept of psychological wellbeing of female caregivers who provide care for children with disabilities and factors related to it. This article employed content analysis technique to describe the concepts, ideas, and issues that are relevant to the factors of psychological well-being of these female caregivers. Female caregivers who have strong psychological well-being and have children with disabilities are expected to effectively handle their caregiving tasks and enhance the mental health of their children. On the other hand, female caregivers with low psychological wellbeing may face difficulties in effectively handling the responsibilities of parenting due to heightened stress levels. The challenges may exacerbate the caregiver's psychological wellbeing, potentially leading to negative consequences for the child. Aspects associated with their children, caregiver-related characteristics, and their environment significantly influence the well-being of mothers. Consequently, prioritising one's own well-being can lead to improve quality of care, better outcomes for the child facing challenges, and enhanced wellbeing for the entire family.

Keywords: Female Caregiver, Children with Disabilities, Care Challenges, Mental Health, Organisational support

Introduction

The term "person" refers to an individual of the human species, whereas "disabled" refers to an individual who faces challenges in meeting their fundamental requirements and is unable to actively participate in society due to mental or physical limitations (Persons with Disabilities

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

Act, 2008). Sometimes, people misunderstand the difference between impairment and disability. The World Health Organization (WHO) explains that these phrases have distinct definitions. According to the WHO, "impairment" specifically refers to the loss or abnormalities of psychological, physiological, or anatomical structure. Conversely, "disability" signifies the constraint or lack of ability to perform a typical human action. Furthermore, disability is not just caused by health-related causes. It is a multifaceted occurrence that individuals with disabilities experience, resulting from the interaction between their bodily attributes and the societal conditions that give rise to a disparity in environmental and social interaction.

The broader category of individuals classified as disabled includes children with disabilities, also known as children with special needs. A sub-article of the United Nations Children's Fund (UNICEF) estimates that at least one billion individuals globally have a disability, either acquired later in life or present from birth. Out of these, approximately 240 million are under the age of 18. As mentioned in the Convention on the Rights of Persons with Disabilities (CRPD), children with disabilities are described as "individuals with long-term physical, mental, intellectual, or sensory impairments may face barriers that hinder their full and effective participation in society on an equal basis." This description elucidates the reasons why individuals with disabilities face difficulties in meeting their requirements, let alone integrating into society.

In the Malaysian context, there are seven distinct categories of disabilities: hearing, visual, speech, physical, learning disabilities, mental, and multiple disabilities, as defined by the Ministry of Women, Family, and Community Development (refer to Figure 1).



Figure 1: Types of Disabilities in Malaysia

According to the Social Welfare Department, as of January 2023, there were 637,537 individuals registered as having disabilities in Malaysia (Statistik Pendaftaran Oku.n.d.).

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

Learning disabilities and physical disabilities are the predominant types of disabilities observed in individuals with disabilities, including children. Unfortunately, due to the voluntary nature of the registration process, the exact number of children with disabilities remains unknown. Parents frequently exhibit reluctance to register their children with disabilities due to societal stigma, which then results in the denial of access to support resources.

Therefore, each type of disability entails a great array of challenges, leaving a remarkable effect on caregivers. However, executing caregiving activities such as bathing, dressing, grooming, feeding, and lifting is commonly undertaken by all caregivers, with no one excluded from these tasks. According to a mix-method study in Ireland (Casey et al.,2013), caregiving activities are described as a revolving pattern, as the consistency of being around their physically disabled child is seldom addressed as pain and hopelessness in life. This is due, even if their child has a great sense of control on wheelchair, they have ongoing worry of their child tripping. Thereby, this viewpoint led to disruption on their immune system as increasement of stress levels of worrying about their child.

In comparison, the effect of caring for a child with hearing impairment on a caregiver is profound, with communication being the biggest hurdle. Deaf children often express themselves behaviorally, leading to significant challenges in understanding their needs and emotions. In effect, a father of a deaf child, in Ghana, expressed his frustration and helpless as he struggles to interact with his child and finds it hard to develop a bond (Opoku et al.,2022). Therefore, it strained the bond and emotional well-being, resulting in heightened parental stress, and feelings of isolation. Additionally, the constants effort to break down the communication barrier, such as learning sign language or hearing aids adds as possible predictors to caregiver's burden. This issue stems from lack of required deaf resources and access.

Surprisingly, parents of children with speech impairments share similar experiences with caregivers of deaf children due to the communication barriers between them and their child. A study in Egypt (Galal Abdelrahman et al., 2022) aligns with this observation, revealing that half of the parents of mute and deaf children exhibit abnormal levels of anxiety and depression as they struggle to overcome these barriers and seek coping strategies under the burden of their children's needs. This situation not only affects the emotional well-being of the caregivers but also impacts the children, as both experience reduced mood and confidence due to the lack of effective human interaction (Keville et al., 2023). Consequently, this situation stifles the well-being of both parties, as they are unable to lead a fulfilling life.

On the other hand, caring for a child with visual impairment presents different challenges and needs. Scholars have noted that the care demands, and burden experienced by caregivers are influenced by the child's level of vision. This suggests that a child's need for physical support in daily life is directly dependent on their degree of visual impairment. A study conducted in Turkey found that caregivers of children with visual impairments often experience an imbalance in their daily life cycle, leading to a decrease in their quality of life (Yilmaz et al., 2023). This is primarily due to the constant need for support in daily activities for a child with vision loss. Consequently, caregivers must remain constantly vigilant, monitoring and protecting their child both at home and in social environments. This constant

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

vigilance leaves caregivers with little to no time for leisure activities, further impacting their overall well-being.

Previous research has gathered insights from caregivers of children with learning disabilities, highlighting their frequent encounters with challenging behaviours. Children with learning disabilities often exhibit disruptive behaviours such as repetitive and aggressive actions, driven by their difficulties and frustrations, which may occasionally escalate to self-harm. (Tathgur et al.,2021). These behaviours significantly contribute to caregivers' feelings of worried, stress and anxiety. Moreover, parents often bear the consequences of these challenging behaviors, leading to feelings of self-blame, social isolation, and a heightened burden of care. In addition, parents may experience occasional conflicts and aggression toward each other, jeopardizing their relationships when confronted with their child's disruptive behaviour that triggers worry and anxiety (Rössler, 2016). This situation often arises from their lack of knowledge about the common signs of learning disabilities, leaving them unsure of how to effectively manage or support their child.

According to various study on the effects of caring for children with mental disabilities, a common theme of "social isolation" frequently emerges where a colleague of a mother with a child with a mental disability shared her observations of the mother's tendency to isolate herself from society and avoid social activities (Mwei.K, 2015). This isolation is often driven by feelings of shame, guilt, self-blame, and societal stigma (Arasu & Shanbhag, 2021). Consequently, parents often describe their experiences of self-blame, feeling like a burden to their friends, colleagues, and family as they continually share the challenges of caring for their child. These negative feelings lead to sense of loneliness and disconnection. Additionally, they experienced strong societal and cultural stigma as having mental illness is not acceptable as it is considered a weakness and a sign of insanity (Rössler, 2016). Even worse, the stigma has projected a great impact on Swedish caregivers, as they perceive that their family members with mental disabilities would be better off dead and wish that neither the caregiver nor the patient had ever met (Ostman & Kjellin, 2002). These perceptions and experiences are possible predictor of their challenges of caring for a child with mental disability.

Evidently, caregivers of children with multiple disabilities face immense challenges that deeply impact their lives and health. Managing one disability is demanding enough, but handling multiple severe disabilities—such as intellectual, physical, communication disorders, health complications, and behavioral challenges—significantly heightens the stress and demands on caregivers. For instance, insights from a study with thematic analysis (Geuze et al.,2021) on a blog by Dutch parents shed light on the complexities of caring for a child with Profound Intellectual and Multiple Disabilities (PIMD) and fragile health. The caregivers of multiple disabilities often confront ongoing uncertainties due to sudden health deteriorations, which instill profound fears of potential loss. Consequently, caregivers find themselves in a perpetual cycle of reorganizing family life, adjusting daily activities, and navigating complex medical and caregiving routines. Despite these formidable challenges, they steadfastly provide unconditional care and love, investing immense emotional and physical energy to ensure their child's well-being. However, the relentless uncertainty exacts a heavy toll on their emotional well-being. Caregivers frequently grapple with a profound sense of loss as they witness the upheaval of their once-normal family life and contend with anticipatory grief about the potential loss of their child. These emotional strains are

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

compounded by the ongoing search for medical diagnoses and treatments throughout different stages of their child's life, adding further stress and financial strain to their lives. Therefore, Arasu & Shanbhag (2021) describe caregiving as a thankless job due to the combination of lack of emotional and financial resources.

Therefore, a wide range of caring issues are associated with various disabilities, which have a significant impact on caregivers. This is likely to explain the ongoing debate between caregivers with different disabilities. This unsatisfaction stems from the perception that resources, support, and recognition are unequally distributed. It is often claimed that assistance and resources are more readily available for caregivers of children with visible disabilities, such as physical or visual impairments, leaving those caring for children with less visible disabilities, such as ASD or ADHD, feeling unfairly treated (McLeod., 2023). Thereby, each group advocates for their specific needs and fair treatment. Thus, the health of caregiver caring for a child with a disability therefore requires research attention to help us better understand the implications of caring for a child with special needs.

Female Caregivers

Caregiving can be an overwhelming and demanding task for caregivers due to the unforeseen problems associated with the registration process. Thus, caregiving is a noble task that requires a significant amount of patience and compassion. Being a caregiver demands a unique combination of qualities that only a few people possess, making them exceptional individuals. Therefore, a caregiver is a comprehensive term that includes all those who provide support to people requiring assistance in managing their day-to-day activities. Moreover, it is assumed that the responsibility of a caregiver is a significant undertaking that entails a great array of difficulties. Delivering care 24/7 requires steadfast commitment and altruism.

A caregiver may receive an employment contract to care for a patient, or they may choose to provide their services unpaid. The unpaid caregiver is typically presumed to be the parents, family members, or relatives. We alternatively refer to this approach as informal caregiving. Informal caregiving is primarily carried out by female and is generally perceived as unpaid labour (Rodríguez-Madrid et al., 2018). These females are usually daughters, moms, or other family relatives who have the responsibility of providing care for their loved ones. This inquiry frequently seeks to understand the reasons behind the disproportionate burden of caregiving that female bear in comparison to male. The study conducted by Ali et al. (2018) in Besut, Terengganu, demonstrates that spouses, children, and daughters-in-law are the main caregivers for older adults because they are entrusted with a significant level of responsibility.

In line with Ali et al (2018), female caregivers believe that caregiving is not just a duty but a crucial part of their identity and societal role, as indicated by Ruiz et al. (2018). As a result, numerous relevant aspects of the caregiving setting influence an individual's perception of choosing to provide care. Additionally, this viewpoint is consistent with the theory of gender role socialisation, which argues that female caregiver assumes caregiving responsibilities as a result of cultural norms, societal expectations, and the inherent caring characteristics associated with femininity (Kim et al., 2018). As a result, there is often an expectation for female caregiver to take on the role of primary caregiver, in contrast to men

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

(Cohen et al., 2019; Kim et al., 2018). This idea also stems from their emotional attachment to the patients, which motivates them to engage in personal care tasks like bathing, dressing, and feeding.

Challenges of Female Caring for Children with Disabilities

In a world with a high standard of living, female is not marginalised from the workforce, as they too require financial sustenance. Undoubtedly, mothers of children with disabilities, particularly single mothers, face a tough task. The immediate assignment of caregiver duties to employed mothers led to years of hardship as they struggled to balance work and childcare responsibilities. Evidently, people rarely viewed this as a straightforward task. According to a study, working female had to adjust in order to balance their professional responsibilities with their role as mothers Dizaho et al (2016), On the other hand, unemployed mothers who decided to quit their jobs did so because they wanted to fully dedicate themselves to caring for their children in need (Scott et al., 2010). This situation could be that, despite the difficulty and challenges, rather than viewing employment as a strain pulling at their well-being, one must make sacrifices for the sake of their child.

Furthermore, despite the seemingly improbable nature of a female caregiver, research revealed that the mother experienced higher levels of psychological discomfort than the father. While both fathers and mothers face similar obstacles, mothers are more susceptible to stress and depression because of the demanding caregiving tasks involved in raising a child with a disability, which may exceed their capabilities (Papadopoulos et al., 2024). In Ababa, Ethiopia, a study revealed that the proportion of female caregivers for children and adolescents with mental illness was 2.4 times higher than that of male caregivers. Researchers have found that sex hormones significantly influence depression, which likely explains this situation (Minichil et al., 2019).

Moreover, it is worth noting that females exhibit lower physical strength in comparison to males, which underscores the inherent differences in gender. This is due to anthropometric and physiological characteristics. Females possess lower levels of muscular strength compared to males (Nestler et al., 2017). As a result, females are more susceptible to experiencing excessive physical exertion. These findings suggest that female often endure significant physical discomfort and agony as a result of engaging in caregiving tasks such as carrying, lifting, and cleaning the child. This implies a significant impact on the mental and physical health of female.

Furthermore, regardless of their exceptional and extraordinary performance in their caring responsibilities, female caregivers tend to disregard their own health and well-being. Although they are eager and selflessly dedicated to offering the highest quality care for their child, they struggle with significant obstacles. Simultaneously managing caregiving tasks alongside other roles places an excessive and burdensome load on individuals, pushing their abilities to their maximum capacity. According to Chen et al. (2019), their study found that the Chinese participants experienced negative effects on their health and well-being because of informal care. As a result, their requests frequently outweigh their ability to handle them efficiently.

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

Methodology

The methodology of this article uses content analysis approach which is common and mainly used by researcher as it is helpful in analysing and evaluating the occurrence, relationships, and interpretations of specific words, themes, or concepts. This approach is flexible in both quantitative and qualitative designs, allows researchers to interpret data subjectively to reveal the answers.

This article, a qualitative design was implemented using content analysis technique to review secondary data. Therefore, this article concept, psychological well-being of female caregiver to children with disabilities are selected by applying content analysis, to identify the existence of key concepts such as "psychological well-being", "caregiver stress", and "social support" to illustrate an example of these concepts. This analysis provides a clear illustration of how these concepts manifest in the context of caregiving for children with disabilities.

Factors Affecting Psychological Well-being (PWB) of Female Caregivers

Previous research has reported that the psychological well-being of female caregivers tends to decrease despite their serious devotion and hard work in their profession. Thus, empirical data on disability indicates that caregiving has detrimental effects on the psychological well-being of caregivers. While it is commonly recognised that the responsibilities of caregiving can have negative effects on a caregiver's overall well-being, it is important to note that psychological well-being encompasses more than simply carrying out tasks. The factors encompassed in the study were holistic well-being, psychological resilience, interpersonal skills, and personal growth. Thus, the obligations of caregiving may oversimplify the intricate interaction of elements that affect well-being by simply causing a decrease in psychological well-being. In addition, ecological theory suggests that a multitude of social elements and interconnected environmental interactions have an intricate role in influencing psychological well-being (Soga et al.,2020).

However, the sole responsibility of caregiving does not exclusively lead to the deterioration of psychological well-being. Previous research has supported this finding, pointing to factors related to children (Marquis et al., 2019), carers (Kim et al., 2023), and the environment (Mei-Hui Tseng et al., 2016) as possible predictors of this drop. Many literary works frequently fail to acknowledge the complex nature of delivering care. This overlook has resulted in a disregard for the intricate interplay among individual, familial, and environmental influences.

Hence, child-related factors encompass attributes such as the child's age, gender, specific disabilities, the severity of disabilities (Gates et al., 2019), behaviour (Harrison et al., 2002), and diagnosis. Parents may face harsh views from others and endure unpleasant emotions when it comes to their child's diagnosis and behaviour. This phenomenon frequently links to stigma, which refers to external attitudes. Stigma can directly affect the mental well-being of parents by subjecting them to discrimination, labelling, stereotyping, and emotional reactions (Salleh et al., 2020). This phenomenon may arise from societal attitudes towards individual physical attributes, resulting in discrimination against parents who feel excluded from the community and face psychosocial difficulties (Vadivelan et al., 2020). Furthermore, parents characterised the time of their child's diagnosis as a sudden surge of anger, guilt, grief, and a sense of unfairness. Guimaraes et al. (2023) attribute this to

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

the demanding and startling nature of accepting the diagnosis, compounded by the apprehension regarding their child's future. The scenarios lead to mental difficulties and contribute to the already existing psychological challenges faced by caregivers.

Furthermore, caregiver psychological discomfort is frequently linked to behaviour and specific types of disabilities. Studies suggest that individuals who provide care for children with invisible disabilities encounter comparable levels of stress, depression, and anxiety. Caregivers of children with neurodevelopmental disorders, including autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), and oppositional defiant disorder (ODD), primarily observe this phenomenon. Individuals with neurodevelopmental problems have restricted capacities for emotional regulation, communication, and adaptation. Papadopoulos et al (2024), found that caregivers of children with ASD have elevated levels of psychological distress in comparison to parents of children with ADHD or intellectual disability (ID). The burden experienced by parents with ASD may be attributed to the behavioural difficulties and communication skills commonly observed in children with ASD. This load can lead to increased mental health distress and diminished well-being in parents. Additionally, parents of individuals with ASD often feel a sense of shame in relation to their child's inappropriate behaviour, such as screaming, being aggressive, or being misunderstood by society.

Conversely, the parents of individuals without neurological disorders (referred to as neurotypical or NT) did not experience feelings of shame, as indicated by Marcinechová et al. (2023). Additionally, caregivers of children with ADHD exhibited a significant level of affiliate stigma. This stigma arises from a sense of embarrassment caused by the children's behaviour, leading caregivers to avoid socialising with the child, limit their interactions with friends and family, and even withhold information about the child's ASD diagnosis from others (Werner et al., 2015). The experience of guilt, coupled with the burden of caregiver stress, can be demoralising and have a detrimental impact on the emotional well-being of parents. In addition, mothers of children with ADHD who felt they had little control over their child's behaviour reported higher levels of stress and depression, according to a study by (Harrison et al., 2005). This may be due to the caregiver's incapacity to bring about changes in the child's behaviour, despite their attempts, resulting in a connection between psychological suffering and a sense of helplessness.

Surprisingly, the caregiver's demographic and psychosocial features are the least anticipated factors that contribute to the unfavourable implications for their psychological well-being. The misconception that caregivers consistently exhibit exceptional physical well-being makes them ideal candidates for caregiving. Unfortunately, caregivers are not sufficiently equipped for their responsibilities, as researchers would not have to inquire about their psychological state if they were. Furthermore, we assume that psychological distress, including anxiety, depression, stress, and physical strain, is a result of both demographic and psychosocial features. These include being female, being older, having a low income, and lacking education and expertise.

Caregiver-related factors and caregiver traits, such as caregiving knowledge and abilities, serve as predictors of psychological well-being. The possession of a substantial amount of caregiving knowledge and skills by caregivers has the potential to decrease

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

psychological distress, including stress, anxiety, and depression (Zhou et al., 2021). Conversely, an inadequate level of knowledge results in a sense of despair and powerlessness, which reduces the amount of stress (Vadivelan et al., 2020). Therefore, in the absence of adequate information and skills, caregivers may experience confusion in delivering appropriate care that is specifically customised to the specific type of disability. Insufficient knowledge and skills can lead to a decline in the quality of care and pose a risk of injury to those with disabilities. Furthermore, the absence of knowledge and abilities required to assist their children is referred to as subjective guilt (Marcinechová et al., 2023), which is frequently linked to mothers attributing blame to themselves for their perceived inability to adequately provide care for their children and for being the cause of their child's condition.

In addition, education is considered a vital factor in enabling caregivers to properly manage and overcome obstacles and stress. Additionally, possessing the benefit of education will grant access to a wide range of resources, such as support services, professional networks, and programmes. Accessing these tools improves the caregiver's perception of their ability and satisfaction, leading to improved psychological well-being. Undoubtedly, exposure to intervention skills is necessary for caregivers of children with disabilities to effectively carry out their responsibilities and promote the well-being of those under their care while also ensuring long-term sustainability in their caregiving practices. For instance, a mother of children with cerebral palsy experienced a sense of relief after participating in parent support training programmes, while facing challenges of self-blame and difficulty caring for her children (Zuurmond et al., 2019). Nevertheless, according to de Lorient (nd), the education level of mothers of children with ADHD does not have a substantial impact on their capacity to effectively handle the responsibility of caregiving. Hence, it is imperative for the government to establish a community training programme specifically designed for caregivers of children with disabilities in order to effectively address this issue.

Furthermore, caregiver attributes, such as their monthly income, have a crucial role in predicting the level of psychological distress they experience. This is likely because a family with disabled children requires a consistent source of income to minimise the occurrence of mental health issues. In a cross-sectional study, Yakubu et al. (2018) found that African female caregivers with higher earnings exhibit better physical health than those with lower incomes. This is because a higher salary affords individuals financial stability, enabling them to fulfil their basic needs in terms of medical treatment, medications, and improved healthcare. Having financial stability enables caregivers to avoid the financial hardships that come with the substantial costs of caring for children with disabilities. Additionally, high-income caregivers could allocate funds into educational and enrichment endeavours for their children, thereby enhancing their overall growth and progress.

Irrespective of caregivers' personal desires, they must prioritise their child's needs. For instance, the financial burden prevents caregivers of disabled children in Terengganu from engaging in leisure activities. According to Ismail et al (2023), they were identified as the primary factor responsible for the lower score in the psychological well-being domain. This suggests that individuals require leisure time as a respite from extended periods of caring for their children. However, the act of spending money on leisure activities might elicit feelings of guilt, stress, and anxiety.

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

Moreover, ensuring financial stability may require caregivers to have employment to acquire resources and benefits such as income, bonuses, and leaves to cover their living expenses and healthcare expenses. However, due to the inflexibility of the job nature, certain caregivers opt to leave their positions and engage in part-time employment that better aligns with their caregiving schedule (Cantero-Garlito et al., 2020). A Kenyan study found a strong correlation between unemployment and depression among family caregivers of individuals with intellectual disabilities (Mbugua et al., 2011). It suggests that even though the caregivers have minimal or non-existent income, it still leads to their feeling of despair. Nevertheless, caregivers from Indonesia expressed their worries and concerns regarding their inadequate income despite engaging in various occupations. This insufficiency hinders their ability to save for the future, as they are compelled to allocate their earnings towards their daily expenses and the needs of their disabled children (Asa Ga et al., 2020). This persistent concern can result in long-term stress, which can have adverse effects on both mental and physical well-being.

Previous research has seldom addressed the potential impact of the caregiver's age on their psychological well-being. A Kelantan study revealed that the quality of life of older caregivers of children with special needs was lower (Isa et al., 2021). This is because elderly individuals are vulnerable to physical stressors. Therefore, advancing in age can present hazards, particularly when caring for children who heavily rely on others. Caregivers of children with developmental disabilities specifically face this challenge, as they often shoulder a substantial physical workload. Therefore, elder caregivers find it challenging to do caregiving tasks that demand physical prowess, such as lifting, playing, moving, and cleaning the child. This assumption is based on the premise that their inability to meet these physical requirements results in emotions of frustration, inadequacy, and guilt.

In addition to the aforementioned factors, social support from a life partner, family, colleague, friend, or professional services can serve as a potential safeguard against parental stress. We refer to this as an interpersonal relationship. Nevertheless, it is crucial to acknowledge that the support dynamics can be complex, and occasionally, assistance aimed at relieving stress may unintentionally exacerbate it. Thus, it is anticipated to recognise a recurring pattern documented in previous research: the lack of sufficient assistance mitigates stress among caregivers. Furthermore, there are various types of assistance, and each one affects the caregiver's psychological distress differently. According to Asa Ga et al. (2020), the government can provide psychological support to parents or caregivers of individuals with disabilities through counselling programmes. This assistance can be considered successful in helping them manage the challenges associated with caregiving. In addition, parents of children with cerebral palsy reported that their community was unsupportive. The community's negative behavioural consequences contribute to the blame placed on parents for their child's health, further intensifying the feeling of isolation felt by caregivers (Vadivelan et al., 2020). The community's attitude exacerbates the already heavy burden that parents of a child with cerebral palsy bear, rather than providing them with compassion and support. This lack of understanding and support perpetuates a cycle of distress for caregivers, making it difficult for them to find solace and acceptance within their community.

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

Conclusion

In conclusion, public awareness initiatives play a vital role in diminishing societal stigma and promoting an inclusive atmosphere for families with children who have impairments. In addition, prioritising the welfare of caregivers not only increases their overall life happiness but also boosts the quality of care provided to children with disabilities. Caregivers with psychological stability and empowerment are more proficient in managing caregiving responsibilities, which benefits them as well as the children under their care. Therefore, this paper proposes more investigation into the interaction between many factors affecting well-being, as well as creating evidence-based approaches to support female caregivers in enhancing their coping mechanisms and effectiveness. Therefore, it is imperative for governments and healthcare systems to have a comprehensive support package that encompasses caregiver training, psychological counselling, and community-based support networks in order to mitigate the detrimental impact on caregivers' mental health.

References

- Ali, S. B., & Aziz, R. A. (2018). Penjagaan Tidak Formal Warga Tua: Antara Tanggungjawab dan Beban. e-BANGI Journal, 13(3).
- Arasu, S., & Shanbhag, D. (2021). Quality of life and burden of caregiving among the primary caregivers of children with disability in rural Karnataka. *Journal of Family Medicine and Primary Care*, 10(8), 2804-2809.
- Asa, G. A., Fauk, N. K., Ward, P. R., & Mwanri, L. (2020). The psychosocial and economic impacts on female caregivers and families caring for children with a disability in Belu District, Indonesia. PloS one, 15(11), e0240921.
- Cantero-Garlito, P. A., Moruno-Miralles, P., & Flores-Martos, J. A. (2020). Mothers who take care of children with disabilities in rural areas of a Spanish region. *International journal of environmental research and public health*, 17(8), 2920.
- Casey, J., Gittins, L., & McDonald, R. (2016). Impact of wheelchair provision upon parent caregivers: A qualitative study. In Wheelchairs: Perceptions, Technology Advances and Barriers (pp. 51-80). Nova Science Publishers, Inc.
- Chen, L., Fan, H., & Chu, L. (2019). The hidden cost of informal care: An empirical study on female caregivers' subjective well-being. Social Science & Medicine, 224, 85-93.
- Cohen, S. A., Sabik, N. J., Cook, S. K., Azzoli, A. B., & Mendez-Luck, C. A. (2019). Differences within differences: Gender inequalities in caregiving intensity vary by race and ethnicity in informal caregivers. *Journal of Cross-Cultural Gerontology*, 34, 245-263.
- De Lorient, S. R., Setiawati, Y., Hidayati, H. B., & Rejeki, P. S.(nd). Relationship between Sociodemographic Factors and Caregiver Burden Among Mothers of Elementary School Students with ADHD Symptoms in Surabaya: A Cross-sectional Study. Age, 8(9), 10
- Dizaho, E. K., Salleh, R., & Abdullah, A. (2016). The impact of work-family conflict on working mothers' career development: A review of literature. *Australian Journal of Basic and Applied Sciences*, 10(11), 328-334.
- Galal Abdelrahman, R., Ibrahim El-Malky, M., & Mohamed Barakat, M. (2022). Psychological Distress and Coping Strategies among Parents with Deaf and Mute Children. *Journal of Nursing Science Benha University*, 3(1), 637-651.
- Gates, L. B., & Akabas, S. H. (2012). Meeting the Demands of Work and Responsibilities of Caring for a Child with Asthma: Consequences for Caregiver Well-being. *Journal of Social Service Research*, 38(5), 656–671. doi:10.1080/01488376.2012.709481

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

- Geuze, L., & Goossensen, A. (2021). Exploring the experiences of Dutch parents caring for children with profound intellectual and multiple disabilities: A thematic analysis of their blogs. Global Qualitative Nursing Research, 8, 23333936211028170.
- Guimarães, A., Pereira, A., Oliveira, A., Lopes, S., Nunes, A. R., Zanatta, C., & Rosário, P. (2023). Parenting in cerebral palsy: understanding the perceived challenges and needs of parents of elementary school children. *International Journal of Environmental Research and Public Health*, 20(5), 3811.
- Isa, S. N. I., Ishak, I., Ab Rahman, A., Saat, N. Z. M., Din, N. C., Lubis, S. H., ... & Suradi, N. R. M. (2021). Quality of life among caregivers of children with special needs in Kelantan, Malaysia: The importance of psychosocial mediators. *The Malaysian Journal of Medical Sciences: MJMS*, 28(2), 128.
- Ismail, K. F., Martine, S. E., Ahmad, A., Harith, S., Lua, P. L., & Ibrahim, W. P. W. (2023). Association of Sociodemographic, clinical and feeding characteristics with quality of life among caregivers of disabled children in Terengganu, Malaysia. *Malaysian Journal of Public Health Medicine*, 23(1), 207–217.
- Keville, S., Zormati, P., Shahid, A., Osborne, C., & Ludlow, A. K. (2023). Parent perspectives of children with selective mutism and co-occurring autism. *International Journal of Developmental Disabilities*, 1-11.
- Kim, H. K., & Park, C. H. (2023). Effects of General Characteristics, Emotional Labor, Empathy Ability, and Wisdom on the Psychological Well-being of Female Caregivers Visiting the Homes of Vulnerable Care Recipients and the Elderly. Behavioral Sciences, 13(5), 360.
- Kim, Y., Mitchell, H. R., & Ting, A. (2019). Application of psychological theories on the role of gender in caregiving to psycho-oncology research. Psycho-Oncology, 28(2), 228–254.
- Marcinechová, D., Záhorcová, L., & Lohazerová, K. (2024). Self-forgiveness, guilt, shame, and parental stress among parents of children with autism spectrum disorder. Current Psychology, 43(3), 2277-2292.
- Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors Affecting the Health of Caregivers of Children with an Intellectual/Developmental Disability. *Journal of Policy and Practice in Intellectual Disabilities*. Doi:10.1111/jppi.12283
- Mbugua, M. N., Kuria, M. W., & Ndetei, D. M. (2011). The prevalence of depression among family caregivers of children with intellectual disability in a rural setting in Kenya. *International journal of family medicine*, 2011(1), 534513.
- McLeod, J. D. (2023). Invisible disabilities and inequality. Social Psychology Quarterly, 86(1), 6-29.
- Minichil, W., Getinet, W., Derajew, H., & Seid, S. (2019). Depression and associated factors among primary caregivers of children and adolescents with mental illness in Addis Ababa, Ethiopia. BMC Psychiatry, 19, 1-9.
- Mwei, K. (2015). The caregiver experience: Raising a child with a mental health condition.
- Nestler, K., Witzki, A., Rohde, U., Rüther, T., Tofaute, K. A., & Leyk, D. (2017). Strength Training for Women as a Vehicle for Health Promotion at Work: A Systematic Literature Review. Deutsches Aerzteblatt International, 114(26), 439.
- Opoku, M. P., Nketsia, W., Benefo, E. B., & Mprah, W. K. (2022). Understanding the parental experiences of raising deaf children in Ghana. *Journal of Family Studies*, 28(4), 1235-1254.
- Ostman, M., Kjellin, L. (2002) Stigma by association: psychological factors in relatives of people with mental illness. Br J Psychiatry 181: 494 498

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

- Papadopoulos, D. (2023). Impact of Child and Family Factors on Caregivers' Mental Health and Psychological Distress during the COVID-19 Pandemic in Greece. Children, 11(1), 7.
- Rodríguez-Madrid, M. N., del Río-Lozano, M., Fernandez-Peña, R., Jiménez-Pernett, J., García-Mochón, L., Lupiañez-Castillo, A., & García-Calvente, M. D. M. (2019). Gender differences in social support received by informal caregivers: A personal network analysis approach. *International Journal of Environmental Research and Public Health*, 16(1), 91.
- Rössler, W. (2016). The stigma of mental disorders: A millennia-long history of social exclusion and prejudices. *EMBO reports*, *17*(9), 1250-1253.
- Ruiz, I. J., & Nicolás, M. M. (2018). The family caregiver: The naturalised sense of obligation in women to be caregivers. Enfermería Global, 17(49), 434-447.
- Salleh, N. S., Abdullah, K. L., Yoong, T. L., Jayanath, S., & Husain, M. (2020). Parents' experiences of affiliate stigma when caring for a child with autism spectrum disorder (ASD): A meta-synthesis of qualitative studies. *Journal of Pediatric Nursing*, 55, 174–183. https://doi.org/10.1016/j.pedn.2020.09.002
- Scott, E. K. (2010). "I Feel as if I Am the One Who Is Disabled" The Emotional Impact of Changed Employment Trajectories of Mothers Caring for Children with Disabilities. Gender & Society, 24(5), 672–696.
- Soga, M., & Gaston, K. J. (2020). The ecology of human–nature interactions. Proceedings of the Royal Society B, 287(1918), 20191882.
- Statistik Pendaftaran Oku. (n.d.). Jabatan Kebajikan Masyarakat. https://www.jkm.gov.my/jkm/index.php?r=portal/full&id=ZUFHVTB1NnJWM0EreGtw NC9Vb1hvdz09
- Tathgur, M. K., & Kang, H. K. (2021). Challenges of the Caregivers in Managing a Child with autism Spectrum Disorder—a Qualitative analysis. *Indian journal of psychological medicine*, 43(5), 416-421.
- Tseng, M. H., Chen, K. L., Shieh, J. Y., Lu, L., Huang, C. Y., & Simeonsson, R. J. (2016). Child characteristics, caregiver characteristics, and environmental factors affecting the quality of life of caregivers of children with cerebral palsy. Disability and rehabilitation, 38(24), 2374-2382.
- Werner, S., & Shulman, C. (2014). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research*, 59(3), 272–283. doi:10.1111/jir.12136
- Yakubu, Y. A., & Schutte, D. W. (2018). Caregiver attributes and sociodemographic determinants of caregiving burden in selected low-income Cape Town, South Africa communities. *Journal of Compassionate Health Care*, 5, 1-10.
- Yılmaz, G. G., Abaoğlu, H., Demirok, T., & Akı, E. Caregiving Children with Visually Impairments: Occupational Balance and Quality of Life Perspective. *International Journal of Disabilities Sports and Health Sciences*, 6(2), 111-118.
- Zhou, Z., Wang, Y., Feng, P., Li, T., Tebes, J. K., Luan, R., & Yu, Y. (2021). Associations of caregiving knowledge and skills with caregiver burden, psychological well-being, and coping styles among primary family caregivers of people living with schizophrenia in China. Frontiers in psychiatry, 12, 631420.
- Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T., ... & Bernays, S. (2019). A support programme for caregivers of children with disabilities in Ghana:

Vol. 14, No. 10, 2024, E-ISSN: 2222-6990 © 2024

Understanding the impact on the well-being of caregivers. Child: Care, Health and Development, 45(1), 45–53.