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Social Experiences of Nurturing Persons Living With Epilepsy among Caregivers in Nairobi County, Kenya

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ABSTRACT :

Epilepsy is one of the most common non-communicable diseases (NCD) shrouded with a lot of fear and stigma due to the nature of seizures that persons living with the disease experience. While attention has been drawn to the people living with the condition, the parents and caregivers remain a forgotten group due to the perception that they are healthy and strong to handle the situation. Many people in Kenya, have little information about epilepsy and how to manage it. Many end up believing myths and misconception about the disease and suffer because of desperation and distress. The objective of this study was to explore the experiences of caregivers in nurturing persons living with epilepsy (PLWE) in the County of Nairobi. The study utilized phenomenological research design. Through purposive sampling, the study utilized a sample size of 15 participants mainly comprising parents, caregivers and family members who have raised a PLWE. Interview Guide was used to collect qualitative data and analysed using thematic analysis. The results revealed that social experiences of PLWE in Kenya were stigma and discrimination; social support; cultural beliefs and misconceptions; gender roles in caregiving; emotional stress, anxiety, and depression; and feeling of hopelessness.The study recommends to the government and the health department to initiate extensive outreach programs to debunk false beliefs and prejudices about epilepsy. Dispelling myths about epilepsy being communicable or a sin can help PLWE and their caregivers live in a more accepting community and lessen stigma.

Key Words: Social experiences; Nurturing; persons living with epilepsy; caregivers, Nairobi, Kenya

INTRODUCTION

The social experiences of individuals living with disabilities are multifaceted and influenced by various factors, including the type and severity of the disability, societal attitudes, accessibility, and available support systems. This review synthesizes empirical research on these experiences, focusing on key themes such as social inclusion and exclusion, stigma and discrimination, and the role of social support networks.Social inclusion is a critical aspect of the well-being of individuals with disabilities. Research indicates that people with disabilities often face significant barriers to full participation in social life. For instance, a study by Hall (2009) found that physical barriers, such as inaccessible public spaces, and social barriers, like negative attitudes and discrimination, significantly limit the social interactions of individuals with disabilities. Similarly, Shields et al. (2011) highlighted that child with disabilities are less likely to participate in extracurricular activities, which can lead to social isolation and hinder their social development. Also, a study conducted by Osei-Bonsu (2019) in Ghana found that traditional beliefs about disability often lead to social exclusion and marginalization of disabled individuals. Similarly, another study by Ghai (2015) in India on cultural myths and superstitions surrounding disability and contribute to the stigmatization of disabled persons and found that these negative perceptions are perpetuated by a lack of awareness and education about disabilities, reinforcing discriminatory attitudes and behaviors.

Obiakor (2018) conducted a study in Nigeria that showed traditional beliefs about disability can lead to the neglect of medical care for disabled individuals, as disabilities are sometimes perceived as spiritual or supernatural afflictions. This results to inadequate healthcare access and poorer health outcomes for disabled persons. In contrast, Western countries with more developed healthcare systems generally offer better healthcare access for persons with disabilities. However, even in these contexts, cultural biases and systemic barriers can impact the quality of care. For example, a study in the United States found that healthcare providers often have implicit biases that affect their interactions with disabled patients, leading to disparities in treatment and health outcomes (Iezzoni et al., 2019).

Another study by Yee and Schultz (2000) found that female caregivers reported higher levels of stress and depressive symptoms compared to male caregivers. This gender disparity is attributed to traditional gender roles and societal expectations, which place a greater caregiving burden on women. Similarly, Pinquart and Sörensen (2003) found that caregivers of people with disabilities reported significantly higher levels of depressive symptoms and lower levels of life satisfaction. The emotional toll of care giving can be attributed to the continuous need to provide physical and emotional support, manage medical treatments, and navigate social and financial challenges. Moreover, Smith et al. (2014) found that caregivers of individuals with severe disabilities are particularly vulnerable to experiencing high levels of stress due to the unpredictable nature of their caregiving duties. This stress can lead to burnout, characterized by emotional exhaustion, detachment, and a sense of reduced personal accomplishment.

Caregivers may experience feelings of helplessness, especially if they are unable to prevent seizures or improve the health of the person they care for. This sense of powerlessness, combined with the perception that they are not doing enough, can lead to depressive symptoms. Ekwall, Sivberg, and Hallberg (2004) found that caregivers of individuals with disabilities reported feeling socially isolated and disconnected from their social networks. This isolation can be detrimental to their mental health, as social support is crucial for coping with stress and maintaining psychological well-being. In addition to social isolation, caregiving can strain relationships within families. The allocation of caregiving responsibilities can lead to conflicts among family members, particularly if there is a lack of communication or unequal distribution of duties.

On the other hand, social inclusion has been found to be significant in handling persons with disabilities. For instance, a study by McConkey and Collins (2010) found that inclusive education settings can foster meaningful friendships between children with and without disabilities. These friendships, in turn, promote greater understanding and acceptance, reducing social exclusion. Stigma and discrimination are pervasive issues that affect the social experiences of individuals with disabilities. Goffman’s (1963) seminal work on stigma provides a theoretical foundation for understanding how individuals with disabilities are often labeled as "different" and subjected to negative stereotypes. Empirical studies support this theory, showing that stigma leads to social marginalization and reduced opportunities for social engagement (Werner & Shulman, 2013).

A qualitative study by Paterson et al. (2017) explored the experiences of adults with physical disabilities and found that many participants reported experiencing overt discrimination, such as being treated unfairly at work or in social settings, and more subtle forms of prejudice, such as patronizing attitudes. These experiences can lead to internalized stigma, where individuals with disabilities start to believe the negative stereotypes about themselves, further hindering their social participation (Corrigan & Watson, 2002). Social support networks play a crucial role in the lives of individuals with disabilities, providing emotional, informational, and practical support that can enhance their quality of life and social experiences. Research by Heller et al. (2007) indicates that strong family support is associated with better psychological well-being and increased social participation among individuals with intellectual disabilities.

Furthermore, a study by Bigby and Fyffe (2012) found that community-based programs that promote social interaction and inclusion can significantly improve the social experiences of individuals with disabilities. These programs often involve peer support groups, community outings, and skill-building activities that help individuals with disabilities form meaningful relationships and participate more fully in society. The social experiences of individuals with disabilities are not monolithic; they are influenced by intersecting factors such as gender, race, and socioeconomic status. For instance, a study by Emerson and Hatton (2008) found that individuals with disabilities from minority ethnic backgrounds face compounded discrimination, leading to even greater social exclusion. Similarly, women with disabilities often experience unique challenges related to gender-based discrimination in addition to disability-related stigma (Nosek et al., 2001).

Despite the challenges, many individuals with disabilities demonstrate remarkable resilience and have positive social experiences. Research by Lindsay and McPherson (2012) highlights that participation in adaptive sports and recreational activities can significantly enhance the social well-being of individuals with disabilities, providing opportunities for socialization, skill development, and empowerment. Moreover, personal agency and self-advocacy are important factors that contribute to positive social experiences. A study by Test et al. (2005) emphasizes the importance of self-determination and empowerment for individuals with disabilities, suggesting that those who are able to advocate for themselves and make their own decisions are more likely to experience social inclusion and improved quality of life.

Technological advancements have also played a significant role in improving the social experiences of individuals with disabilities. The rise of social media and communication technologies has provided new avenues for social interaction and community building. A study by Shpigelman and Gill (2014) found that social media platforms can serve as important tools for individuals with disabilities to connect with others, share experiences, and access support networks. Assistive technologies, such as communication devices and mobility aids, have also been shown to enhance social participation. For example, a study by Hammel et al. (2015) demonstrated that the use of advanced mobility devices significantly improved the ability of individuals with physical disabilities to engage in social activities and navigate public spaces. The aim of the current study was to explore the experiences of caregivers in nurturing persons living with epilepsy (PLWE) in the County of Nairobi, Kenya.

METHODOLOGY

The study employed phenomenological research design to explore the lived experiences of nurturing persons living epilepsy. The location of the study was Lang’ata, Dagoretti and Kamukunji constituencies. This was because the issues under study were unique and people do not share about it openly thus identifying respondents may necessitate data collection over a wider area. The study drew participants form three epilepsy clinics within Lang’ata, Dagoretti and Kamukunji constituencies in Nairobi County. The population of the study consisted of parents and caregivers who bring their people living with epilepsy to the clinics for on -going medical consultation. Through purposive sampling,a sample size of 21 participants was selected to participate in the study.

This study employed Interview Guide. An interview guide was designed for in depth interviews with caregivers of PLWE. By use of open-ended questions, the researcher intended to gather a wide range of views and opinions regarding experiences of nurturing PLWE. The first part of the interview guide had demographic information of the participants. The demographics included age, gender, religion, education level, number of years taken in nurturing PLWE and the relationship with the PLWE. The second part of the Interview Guide collected data among the caregivers on their social experiences of nurturing people living epilepsy.

Before the actual data collection, the researchers visited epilepsy clinics in the target areas to identify and inform concerned parties that were to be engaged in the study on a separate day and provided an explanation to them regarding the general purpose of the study. The interviews took up to 45 minutes.The data collected was transcribed and analyzed using thematic analysis. The initial steps of analyzing data collected included transcribing recorded information, then in depth reading and re-listening to the recordings. Initial ideas were noted down and reference codes, open codes and axial codes assigned. The codes assisted the researchers to link narratives with participants, synthesize the entire data to comprehensible set of data and interpretive analysis of the data. Obtained data was then was organized into themes.

RESULTS AND DISCUSSION

The study aimed to explore the social experiences of nurturing persons living with epilepsy among caregivers in Nairobi County, Kenya. The section started by presenting the demographic information of the participants followed by the key findings of the study.

Demographic Details of the Participants

The study captured several demographic of the participants including the age, gender, religion, educational level, relationship with the person living with epilepsy and period of nurturing the person living epilepsy. The demographic details are presented in table 1.

Table 1: Description of Participants for the Interviews

Respondent No.	Gender	Age	Religion	Highest Education Level	Relationship with PLWE	Period of Nurturing PLWE(Years)
R/001	Male	84	Christian	VTC	Father	22
R/002	Female	51	Christian	Primary	Aunt	10
R/003	Female	49	Christian	Secondary	Mother	5
R/004	Female	63	Christian	VTC	Mother	19
R/005	Female	40	Muslim	VTC	Mother	4
R/006	Male	70	Christian	VTC	Uncle	14
R/007	Female	36	Christian	Primary	Mother	1
R/008	Male	79	Christian	VTC	Father	1
R/009	Male	50	Christian	VTC	Foster Father	1
R/0010.	Female	32	Christian	Secondary	Mother	4
R/0011	Female	54	Christian	Secondary	Mother	4
R/0012	Female	50	Christian	VTC	Mother	2
R/0013	Female	42	Christian	VTC	Mother	12
R/0014	Female	47	Christian	Undergraduate	Mother	12
R/0015	Female	41	Christian	Secondary	Mother	25

Results in table 1 indicate that the youngest participant was 32 years old while the oldest participant was 84 years old. The study showed that the majority of the respondents were above 50 years. In terms of gender, majority of the participants were female compared to their male counterparts. This shows that women are mostly involved in taking care of persons living with epilepsy. All the participants were Christians except one of them who were a Muslim. Majority of the participants had a primary and secondary education. Majority of the participants taking care of the persons living with epilepsy were mothers while the rest were an Uncle, Aunt or Foster Father. The period of taking care of persons living with epilepsy ranged from 1 year to 25 years.

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Stigma and Discrimination

Majority of the Caregivers of people with epilepsy often face social stigma due to widespread myths and misconceptions about epilepsy in Kenya. Many people view epilepsy as contagious or a curse. This creates social isolation for both caregivers and the individuals they care for, leading to emotional distress, exclusion from social gatherings, and challenges in accessing community support as expressed by one of the respondents who said,

It was a curse. People believe that it was a curse, a witch, or all sorts of bad things, that's what the people out there would talk about. Even today, culturally, even today, they will not believe anything else other than a witch. Yeah. What have you not done to the diseased? That you should do. Slaughter a goat. Offer this (R001).

Most of the respondents reported feeling discriminated against in their social settings because others are reluctant to associate with those who have epilepsy as respondent reported,

They don't even want to shake her hand even to come close to her. They don't even want to share anything they eat with my daughter even to come, to me in my house because they will get that epilepsy (R003).

The findings of this study was consistent with findings of Osei-Bonsu (2019) who conducted study conducted in Ghana found that traditional beliefs about disability often lead to social exclusion and marginalization of disabled individuals. Similarly, the findings were supported by the findings of

Ghai (2015) who conducted a study in India on cultural myths and superstitions surrounding disability and contribute to the stigmatization of disabled persons and found that these negative perceptions are perpetuated by a lack of awareness and education about disabilities, reinforcing discriminatory attitudes and behaviors. Furthermore, the findings are in alignment with findings of Werner and Shulman (2013) who found that stigma leads to social marginalization and reduced opportunities for social engagement.

In addition, the findings were in agreement with findings of Paterson et al. (2017) who explored the experiences of adults with physical disabilities and found that many participants reported experiencing overt discrimination, such as being treated unfairly at work or in social settings, and more subtle forms of prejudice, such as patronizing attitudes. These experiences can lead to internalized stigma, where individuals with disabilities start to believe the negative stereotypes about themselves, further hindering their social participation (Corrigan & Watson, 2002). Moreover, the findings are in agreement with the findings of Hall (2009) found that physical barriers, such as inaccessible public spaces, and social barriers, like negative attitudes and discrimination, significantly limit the social interactions of individuals with disabilities. Also the findings are supported by findings of Shields et al. (2011) who highlighted that child with disabilities are less likely to participate in extracurricular activities, which can lead to social isolation and hinder their social development.

Social Support

Some caregivers are very lucky as they receive support from their family members which is very helpful for them in terms of their spiritual practices and general well-being as one of the respondents said,

Definitely. That's why I do it. Why do I leave women to go and mix with people only one day probably the whole month? Also, you know, my daughters, some come over the weekend. So, I'm able to attend my mass. They make sure I attend my mass every Sunday. Yeah, and it is also very, very good for me. You know, many times, you find that we are so much focused on this person who is, as you say, having some challenge but we forget about ourselves, yet we are going through a lot. Yeah, and sometimes we don't realize (R008).

The findings were in alignment with the findings of Heller et al. (2007) who found that strong family support is associated with better psychological well-being and increased social participation among individuals with intellectual disabilities. The findings are also consistent with the findings of Bigby and Fyffe (2012) who found that community-based programs that promote social interaction and inclusion can significantly improve the social experiences of individuals with disabilities. These programs often involve peer support groups, community outings, and skill-building activities that help individuals with disabilities form meaningful relationships and participate more fully in society.

Cultural Beliefs and Misconceptions

In many communities in Kenya, including Nairobi, epilepsy is often misunderstood. Some traditional beliefs attribute epilepsy to many people, especially in rural areas or informal settlements in Nairobi, who may view epilepsy as a result of curses, sorcery, or punishment from ancestors and family members. One of the respondents said,

Particularly like myths and misconceptions. Curses, generational curses. There must be something you did to an unfortunate person somewhere that is why you are being paid back. Maybe there are things you did when you were expectant that you did not, have you gone out of your matrimonial bed… (R014).

These beliefs heavily influence the care giving process, as caregivers may seek traditional healers or spiritual intervention instead of medical treatment. Some communities believe that seizures are caused by evil spirits or demons as expressed by one of the respondents; *"...to witchcraft, pastors, to remove these demons so that my nephew can become normal as other people but it was in vain, all was in vain*" (R002).

The findings were consistent with the findings of Obiakor (2018) who conducted a study in Nigeria that showed traditional beliefs about disability can lead to the neglect of medical care for disabled individuals, as disabilities are sometimes perceived as spiritual or supernatural afflictions. This results in inadequate healthcare access and poorer health outcomes for disabled persons. In contrast, Western countries with more developed healthcare systems generally offer better healthcare access for persons with disabilities. However, even in these contexts, cultural biases and systemic barriers can impact the quality of care. For example, a study in the United States found that healthcare providers often have implicit biases that affect their interactions with disabled patients, leading to disparities in treatment and health outcomes (Iezzoni et al., 2019).

Gender Roles in Care giving

Cultural norms about gender also play a role in who becomes the primary caregiver for a person with epilepsy. In Nairobi, as in many other parts of Kenya, women are often expected to take on care giving responsibilities, especially for family members. This reinforces traditional gender roles and can lead to the caregiverburden on women as one of therespondents said,

A daunting task and mothers are nurtures while fathers provide money for medication and upkeep(laughing) but the nurturing is the mother, the mother is the nurturer so you know you feel you are the one who is carrying this burden, you know a mother being a nurturer you, I don't know you just feel it is your responsibility to help this child transition from this stage to this stage (R004).

The findings were supported by findings of Yee and Schultz (2000) found that female caregivers reported higher levels of stress and depressive symptoms compared to male caregivers. This gender disparity is attributed to traditional gender roles and societal expectations, which place a greater caregiving burden on women.

Emotional Stress, Anxiety, and Depression

Caregivers of persons with epilepsy frequently experience high levels of stress and anxiety due to the unpredictable nature of seizuresas respondent said, *"And what they would do was just as the seizures increased so did the medication… the medication increased and the seizures increased and you can imagine how scary that was" (R004).* The unpredictability of when or where seizures will occur can be highly distressing. Caregivers may fear that they won't be able to respond effectively during a seizure or that the PWE could injure themselves during an episode. The fear of sudden seizures can lead to constant vigilance, making it difficult for caregivers to relax as one respondent said,

You fear for the worst because you fear anything can come up. One, if you don't do it, the children normally have a way of trying to rebel. And in the process of rebelling, sometimes they can even rebel against care. So, you must try to stamp your authority and make it really help, because they will try to rebel. And if they rebel, the other children may not understand. And they see they want to be like any other person. So that's why the rebellion will come here (R009).

They also are concerned about the conditions of those they take care of and of not knowing what to do as expressed by one of the respondents,who said,

Yeah, I was depressed because me myself I need money and also the kid needs money to support and sometimes you find there is no that money, you find she needs medicine, she needs this with her condition, so sometime you will work hard to being with the condition, so thereafter money goes no money for medicine, so you feel what is this now (R015).

Caregivers often worry about the long-term well-being of the person with epilepsy, particularly if they experience frequent or severe seizures which can make them injure themselves as one of the respondents *"The first time she got seizures, yeah, we got worried. We were sure that when she got near the fire, she could have seizures and fall into the fire and then she could be burnt. So, we were worried"* (R011). This uncertainty about the future can result in chronic anxiety and depression for PLWE and affects their functioning.

The findings were in agreement with findings of Pinquart and Sörensen (2003) found that caregivers of people with disabilities reported significantly higher levels of depressive symptoms and lower levels of life satisfaction. The emotional toll of care giving can be attributed to the continuous need to provide physical and emotional support, manage medical treatments, and navigate social and financial challenges. In addition, the findings were supported by findings of Smith et al. (2014) who indicated that caregivers of individuals with severe disabilities are particularly vulnerable to experiencing high levels of stress due to the unpredictable nature of their caregiving duties. This stress can lead to burnout, characterized by emotional exhaustion, detachment, and a sense of reduced personal accomplishment.

Feelings of Hopelessness

Hopelessness is a common psychological experience among caregivers of persons with epilepsy, especially when they feel overwhelmed by the caregiving responsibilities as one of the respondents said,

Anything that affects your child affects you directly. Anything that makes a child feel unhappy, you equally become unhappy. If it is a kind of frustration, if people mistreat him in any way, you feel it even more. Because you feel that you need to give that protection. So, if it cannot come from you, you feel hopeless. That is what brings in hopelessness in the parent. You feel that they could have had this one. And you see now when they are disappointed because of these frustrations coming from this, always it comes back to you. It has to come back to you as a parent (R009).

The stigma surrounding epilepsy can lead caregivers to isolate themselves socially, which can increase feelings of loneliness and depression. Some may withdraw from social interactions out of fear of judgment or due to the demands of caregiving, leaving them with little emotional support as expressed by one of the respondents saying; *"Withdrawing from people. Because they don't want me, and the condition also is severe. And I don't know how to do it. I am confused. No one to come to help me, So I have to stand by myself"* (R015).

Caregivers may experience feelings of helplessness, especially if they are unable to prevent seizures or improve the health of the person they care for. This sense of powerlessness, combined with the perception that they are not doing enough, can lead to depressive symptoms.The findings were supported by findings of Ekwall, Sivberg, and Hallberg (2004) who found that caregivers of individuals with disabilities reported feeling socially isolated and disconnected from their social networks. This isolation can be detrimental to their mental health, as social support is crucial for coping with stress and maintaining psychological well-being. In addition to social isolation, caregiving can strain relationships within families. The allocation of caregiving responsibilities can lead to conflicts among family members, particularly if there is a lack of communication or unequal distribution of duties.

CONCLUSION

Pervasive stigma and insufficient support networks provide serious social, economic, and emotional difficulties for Kenyan caregivers of people with epilepsy. Due to persistent misconceptions that epilepsy is contagious or a curse, caregivers frequently face prejudice and social exclusion. As a result, they are frequently excluded from social events and people are reluctant to engage with them or their loved ones. Financial strains are also typical, especially for low-income families, since caregivers frequently find it difficult to pay for necessary prescription drugs and medical care.There is insufficient support from family members; while some caregivers receive help, others are left to handle caring alone. Both the person who has epilepsy and the person providing care are impacted by the stigma surrounding the condition, which can cause isolation and restrict their participation in daily activities.The unpredictable nature of seizures presents psychological issues for caregivers as well, which heightens anxiety and stress. These feelings are exacerbated by financial difficulty, which makes caregivers feel overworked and overwhelmed by their dual responsibilities of providing care and managing finances. Despite the psychological strain, many caregivers eventually become resilient, taking up coping mechanisms such as therapy, personal growth, emotional support, and finding meaning in their caregiving roles.

RECOMMENDATIONS

The findings from this empirical research on the social experiences of individuals with disabilities have important policy implications. Ensuring accessibility, combating stigma, and promoting inclusive practices are essential for improving the social well-being of individuals with disabilities. Policymakers should focus on creating inclusive environments in schools, workplaces, and communities to facilitate greater social participation. Future research should continue to explore the diverse experiences of individuals with disabilities, taking into account the intersection of various social factors. Longitudinal studies could provide deeper insights into how social experiences evolve and the long-term impact of social inclusion initiatives. By addressing barriers to inclusion and fostering supportive environments, society can enhance the social well-being and overall quality of life for individuals with disabilities.

REFERENCES

1. Bigby, C., & Fyffe, C. (2012). Making mainstream services accessible and responsive to people with intellectual disability: what is the equivalent of lifts and Labradors? Proceedings of the Seventh Annual Roundtable on Intellectual Disability Policy.
2. Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical psychology: Science and practice*, *9*(1), 35.
3. Ekwall, A., Sivberg, B., & Hallberg, I. R. (2004). Dimensions of informal care and quality of life among elderly family caregivers. *Scandinavian journal of caring sciences*, *18*(3), 239-248.
4. Hall, P. et al. (2009). Successful Societies: How Institutions and Culture Affect Health. Cambridge: Cambridge University Press.
5. Hammel, J., Magasi, S., Heinemann, A., Gray, D. B., Stark, S., Kisala, P., ... & Hahn, E. A. (2015). Environmental barriers and supports to everyday participation: A qualitative insider perspective from people with disabilities. *Archives of physical medicine and rehabilitation*, *96*(4), 578-588.
6. Heller, D., Watson, D., Komar, J., Min, J. A., &Perunovic, W. Q. E. (2007). Contextualized personality: Traditional and new assessment procedures. *Journal of personality*, *75*(6), 1229-1254.
7. Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Lagu, T., ... & Campbell, E. G. (2022). US Physicians' Knowledge About The Americans With Disabilities Act And Accommodation Of Patients With Disability: Study examines what physicians know about the Americans With Disabilities Act and what is done to accommodate patients with a disability. *Health Affairs*, *41*(1), 96-104.
8. Lindsay, S., & McPherson, A. C. (2012). Strategies for improving disability awareness and social inclusion of children and young people with cerebral palsy. *Child: care, health and development*, *38*(6), 809-816.
9. McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, *54*(8), 691-700.
10. Osei-Bonsu, K., Masroor, N., Cooper, K., Doern, C., Jefferson, K. K., Major, Y., ... & Doll, M. (2019). Alternative doffing strategies of personal protective equipment to prevent self-contamination in the health care setting. *American journal of infection control*, *47*(5), 534-539.
11. Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *58*(2), P112-P128.
12. Shields N, Synnot AJ, Barr M. (2011). Perceived barriers and facilitators to physical activity for children with disability: a systematic review.;46(14):989-97.
13. Shields, C. L., Markowitz, J. S., Belinsky, I., Schwartzstein, H., George, N. S., Lally, S. E., ... & Shields, J. A. (2011). Conjunctival melanoma: outcomes based on tumor origin in 382 consecutive cases. *Ophthalmology*, *118*(2), 389-395.
14. Shpigelman, C. N., & Gill, C. J. (2014). How do adults with intellectual disabilities use Facebook?. *Disability & Society*, *29*(10), 1601-1616.
15. Test, D. W., Fowler, C. H., Brewer, D. M., & Wood, W. M. (2005). A content and methodological review of self-advocacy intervention studies. *Exceptional Children*, *72*(1), 101-125.
16. Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in developmental disabilities*, *34*(11), 4103-4114.
17. Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in developmental disabilities*, *34*(11), 4103-4114.
18. Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, *40*(2), 147-164.