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**EFFECT OF CAREGIVING OF CHILDREN WITH AUTISM
SPECTRUM DISORDER ON THE CAREGIVERS' SOCIAL
WELLBEING IN SELECTED INTEGRATED PRIMARY
SCHOOLS IN NAIROBI COUNTY, KENYA**

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Abstract:

Social wellbeing is an essential part of general wellbeing of human beings because it shields individuals from social isolation by promoting positive relations. However, social challenges associated with the caregiving of children with Autism spectrum disorder (ASD) are likely to impede the caregivers' of children with ASD from achieving their social well-being. ASD is a neurodevelopmental childhood disorder that has no physical marker. It is characterized by peculiar behaviors that are socially intolerable. The purpose of this study was to examine how caregiving of children with ASD affect the caregivers' social wellbeing. Social Ecological System Theory (SEST) and Cognitive Behavioral Theory (CBT) guided the study. The study used a qualitative phenomenological approach and purposive sampling method to select 24 informal caregivers and four formal caregivers from selected integrated primary schools in Nairobi County, Kenya. The study used in-depth interviews and focus group discussions (FGDs) to collect data from the caregivers of children with ASD. Data was captured using tape recording and field notes. Verbatim transcription was employed. QSRN N'vivo 10 data software was used to simplify and analyze the data. The findings revealed that caregiving of children with ASD affect the caregivers' social wellbeing in the selected integrated primary schools in Nairobi County. The study recommends creation of public awareness about ASD, training for the caregivers to equip them with skills to manage the difficult behaviors exhibited by the children with ASD, availability of affordable therapies and mental health support to the caregivers.

Keywords:

Caregiving, Relations, Isolation, ASD, Social – Wellbeing.

Introduction

ASD is a childhood disorder that encompasses conditions previously known as infantile, childhood, Kanner's high-functioning and atypical autisms, childhood disintegrative and Asperger's disorders and thus the name spectrum (DSM -5, 2013; Matson & Williams, 2013). Besides, it is common for a child with ASD to be diagnosed comorbidity with other disorders (DSM -5, 2013). ASD is a hidden disorder because it has no physical marker unlike other disabilities for example Down syndrome and cerebral palsy. Its symptoms are exhibited through odd behaviours for instance hyperactivity, repetitive behaviours such as hand flapping, body rocking, running around in circles and demandness, especially in early stages Unumb (as cited by Mthombeni and Nwoye, 2018). Although ASD can be managed through therapy and behaviour management it persists across the entire life span of an effected individual (Dziegielewski, 2015). A study by Ludlow and Rohleder (2012) established that caregivers find it difficult to control the unpredictable behaviours displayed by the children with ASD. Moreover, some of the behaviours are socially unacceptable and may cause the caregivers' to be communally alienated thereby affecting their social wellbeing. This study examined how the caregivers' social wellbeing is affected by caregiving of children with ASD in selected integrated primary schools in Nairobi County.

Background

Social wellbeing is an important construct of the general wellbeing. It has five dimensions that are divided into three broad areas namely an individual's self-appraisal in relation to social setting (social integration, social contribution), individual's appraisal of other people including family members, friends neighbours (social, acceptance), and an individual's evaluation of the society at large (social coherence, social actualisation) (Keyes, 1998). According to Ryff and Keyes as cited by Medvedev and Landhuis (2018) these constructs determine whether an individual can achieve their social well-being or not. Csikszentmihalyi (2021) asserts that individuals who achieve their social wellbeing tend to flourish in life. However, caregivers of children with ASD are likely to encounter several social challenges such as lack of awareness about ASD, lack of information about available resources and lack of skills to manage difficult behaviours exhibited by children with ASD. This may impede their ability to achieve their social wellbeing.

The cause of ASD is yet to be documented (DSM-5, 2013) as such ASD is laden with myths as people try to make meaning of it. For instances, in most African countries there are myths that ASD is caused by supernatural causes such as witchcraft, evil forces and ancestral curses (Bakare & Munir, 2018). Such myths are likely to prevent the caregivers' from achieving their social coherence. This is because of the inferences that the caregivers of children with ASD or their families practice or had something to do with the evil forces which cause their children to have the disorder. In this regard the relationship between the caregivers and other family members and the community members may be affected. Individuals who have negative relationship with significant others may find it hard to achieve social coherence. According to

Diener and Scollon (2014) individuals who fail to achieve social coherence look at the world as disorderly and unpredictable, subsequently affecting their social well-being (Gao & McLellan, 2018; Ryff and Keyes as cited by Medvedev and Landhuis, 2018). Nonetheless, contending with the social challenges associated with caregiving of children with ASD is likely to hinder the caregivers from achieving their social wellbeing. Similarly a study by Diener, and Chan (2011) established that individuals with positive relationships are able to form trusting, meaningful and long lasting relations with other people such as family, friends, neighbours, and community members. According Plumb (2011) a family that maintain positive relations adjusted well and is able to meet the extra needs of a child with an ASD. Similarly, studies by Gao and McLellan, (2018) and Gouin et al (2014) revealed that caregivers who maintain meaningful relationships with significant others are likely to enhances their social well-being because positive relations shield them from social isolation and increase their community of support, thus, lessen the burden of caregiving.

Limited empirical information about the causes of ASD is also likely to affect the caregivers' of children with ASD ability to socially integrate. With no known cause of the disorder family members and the community may read sinister motives on the part of the caregivers in regard to their children having ASD and this may affect their social wellbeing. Studies have established that caregivers of children with disabilities are blamed or blame themselves for contributing to their children's disabilities (Gona,et al, 2017; Kocabıyık & Fazlıoğlu, 2018). As a result, the caregivers may find it difficult to socially integrate and this may cause them to experience social alienation. Social integration is important because individuals who demonstrate it, have a sense of belonging in the family and the community at large. Conversely, lack of social integration may cause an individual to feel discontented with others. As a result, this may affect their social support system where the caregivers bear the burden of raising their children with ASD alone. According to Wang (2021) where family members work together the burden of caregiving of children with ASD is made lighter thereby enabling the caregivers to achieve their social well-being.

Culture plays an important role in shaping how people comprehend themselves, other people, and the world around them (Bernier et al, 2010). Through cultural narrative values, attitudes and beliefs about aspects of life are learnt (WHO, 2013). From cultural perspectives, most disabilities are seen as a way of paying the price for the past wrongs committed by the caregivers or their family members (John 9:1-2, New International Version, 1984). Cultural beliefs about the causes of ASD are likely to hinder the caregivers of children with ASD from integrating socially. This is because the caregivers may realize that they do not share the same values with other community members in regard to children with ASD. A socially integrated individual experiences a sense of commonness and belonging to their community, however, an individual who is not integrated socially is likely to feel estranged from others and may lack a sense of belonging. For example, a study by conducted by Bunning et al (2017) in Kilifi, Kenya established that caregivers of children with disabilities were alienated in their own community because of the nature of the children's condition. In such situation the caregivers' social well-being is likely to be compromised since they experience social discrimination and exclusion. This study sought to investigate how caregiving of children with ASD is likely to affect the caregivers' social integration thereby affect their social well-being.

Most African communities have no names for mental illnesses and disabilities without known cause. They are all lumped together and referred to as “madness”, or *Wazimu* in Swahili (Ambikile & Outwater, 2012). In this context children with ASD may be perceived as having mental illness where people may avoid interacting with such families because of stigma associated with “madness”. This may affect the caregivers’ positive relationship with others where they are socially discriminated for supposedly attracting the wrath of the gods against their children (Gona et al., 2016; Mthombeni & Nwoye, 2018; Nwoye, 2017). According to (Abosi and Koay, as cited by Ndadzungira, 2016) caregivers of children with disabilities in Uganda are alienated from significant others because they are presumed to be under ancestral curses. Similarly, a study carried out by Haihambo and Lightfoot (2010) based on cultural beliefs about disabilities in Namibia established that the caregivers of children with disabilities are socially isolated for purportedly associating themselves with witchcraft. In Ghana and Tanzania, the caregivers of children with ASD are socially excluded because siring children with disabilities is considered a taboo or a bad omen (Aldersey, 2012; Oti-Boadi, 2017). Just like other African communities, most Kenyan communities also attribute causes of unexplainable disorders such as ASD to the wrath of gods, evil spirits, ancestral curses, and witchcraft, (Gona et al., 2015). Based on the above information, it can be concluded that caregivers of children with ASD in most African countries experience lack of social acceptance which in turn affects their social well-being. A study by Cicognani (2014) established that self or social-isolation prevent individuals from establishing positive relationships with other people subsequently affecting their social wellbeing. Yet it is within positive relations for instance caregivers are supported, affirmed, and validated. For this reason, lack of establishing positive relationship with significant others may impede the caregivers from achieving social well-being.

Studies by Werner and Shulman (2015) and Mitte et al (2018) established that, caregivers of children with ASD experience public, institutional, self, and affiliate stigma associated with ASD. According to Ali et al (2012) stigma is a subjective internalization of strong feeling of unfairness or social disgrace that a person experience based on their personal attributes such a gender, ethnicity, social class, occupation, disabilities, mental disorders, or religion. In this regard studies have established that raising children with disabilities cause the caregivers to experience, shame and embarrassment because of stigma associated with the condition of the children (Dababnah, & Parish, 2014; Broady et al, 2018). Some of the idiosyncratic behaviours displayed by the children with ASD attract public stigma because they are socially unacceptable, and this is likely to affect the caregivers’ capacity for social contribution.

An example of such idiosyncratic behaviours is Extra-personal Challenging Behaviours (ECBs) (Bauminger, et al 2017). ECBs are acts of aggression directed to other people by children with ASD, including physical and verbal aggression (Autism Speaks, 2018; Miranda et al, 2019). Intra-personal Challenging Behaviours (ICBs) are self-directed harmful behaviours that are self-injurious. ICBs include self-biting, head-banging on hard surfaces, and self-stimulation behaviours such as disrobing in public and touching themselves inappropriately (Miranda et al., 2019). These behaviours cause the caregivers of children with ASD to experience social ridicule and harsh judgment as bad parents who have lost control over their children (Alderson, 2011, Bennett et al., 2018). As a result, the caregivers may isolate themselves and their children to escape the public criticism and harsh judgment directed at them (Mitter et al., 2018; Werner & Shulman, 2015) consequently, this hinders their social contribution. Social contribution includes an individual’s belief that they are valued members

of the community (Westerhof, & Keyes, 2010). The caregivers' lack of social contribution is likely to delay them from achieving their social well-being.

Studies by Ting et al. (2018) and Wong et al (2016) established that most families with children with disabilities experience negative emotions such as shame, frustrations, fear and mental disorders such as depression and anxiety. These negative emotions and mental disorders are likely to compromise the positive relationship of caregivers of children with ASD with others, their self-acceptance, social cohesion, and social integration which ultimately affects their social well-being (Diener, & Scollon, 2014). For example where the caregiver is depressed, they are unlikely to have meaningful relationships with others, and may fail to socially integrate, hence, affecting their social well-being. Depression in itself is a debilitating mental mood disorder that incapacitates an individual's ability to function effectively (DSM- 5, 2013) conversely affect their social wellbeing.

The overarching question the study sought to answer was in which ways raising a child(ren) with ASD affect the caregivers' social well-being.

The specific objective of this study was to investigate how caregiving of child(ren) with ASD affect the caregivers' social wellbeing.

Research Methodology

The study used qualitative descriptive phenomenological method Moustakas, (as cited by Neubauer et al., 2019). The study conducted nine in-depth interviews and two Focus Group Discussions (FGDs) with the caregivers and four in depth interviews with key informants. Phenomenological approach enabled the respondents to share their individual experience and to tell of the challenges encountered in raising up child(ren) with ASD. This enabled the study to have an insights of the intricate nature of the caregiving of children with ASD (Bryan 2016). The phenomenology approach was considered suitable for this study because it permitted flexible investigation to broaden the understanding of the research problem to meet the study's objectives, provided modalities to identify the essence of human experiences about the phenomenon as described by participants (Moustakas as cited Neubauer et al., 2019), and lastly, provided strategies for analysing and interpreting data (Creswell, 2017; Bryman, 2016; Englander, 2016; Merriam& Grenier, 2019).

The population of the study comprised 21 mothers, two grandmothers, and a father who are caregivers of children with ASD, four key informants' namely, two special needs education teachers and two occupational therapists in selected integrated primary schools in Nairobi County.

Nairobi County was chosen for the study because of the availability of integrated primary schools. This is based on the findings by Kamau (2017) study which established that most of the integrated primary schools that admit children with ASD are located in Nairobi County. Beside Nairobi being a cosmopolitan city, it is home to communities of diverse ethnical, cultural, and social-economic backgrounds that gave rich data to inform the study.

Purposive sampling technique was used to select 24 caregivers of children with ASD and four key informants as respondents of the study in total the study had 28 respondents. According to Bryan (2016) the criterion for sample size is reliant on data saturation as opposed to focusing

on the number of the sample size. The 28 respondents of the study sufficiently generated enough data to the point of information saturation. The study chose purposive method to gain an in-depth understanding of the variables under study. The strength of purposive sampling technique according to Creswell (2017) is that it allows the researcher to intentionally select respondents and settings to provide information that cannot be gathered using other sampling techniques. Purposive sampling is valuable for ensuring a unique and a quality sample.

Nine in depth interviews were conducted in different locations including the caregiver's homes, the researcher's home and in selected integrated primary schools in Nairobi County. The interviews with the key informants were done over the phone. The key informants provided information regarding their expert knowledge of the effect of caregiving of children with ASD on the caregiver's social wellbeing. Semi structured interview schedules for one on one in-depth interviews were used to guide the study.

The study conducted a twenty five minutes follow up interview session with each respondents. The purpose of the second interview was to accord the caregivers of children with ASD an opportunity to add any important information that they might have left out during the initial in depth interview. Additionally, to clarify and validate whether the recorded information is a true presentation of their views (Bryman, 2016). The second interview sessions with participants occurred between June and July 2021. The Follow-up interviews were conducted over the phone. All the respondents confirmed that their views were well captured clear and an accurate picture of their experiences.

The study also conducted two focus group discussions (FGDs). Out of the two FGDs one consisted of eight caregivers and the other one compromised of seven caregivers. The FGDs were conducted in two different integrated primary schools in Nairobi County. The two FGD were considered large enough to provoke healthy discussion (Creswell, 2017). An interview schedule consisting of open ended semi-structured questions was used to guide the FGDs (Leedy & Ormrod, 2010). The semi-structured open ended questions were short, precise; non-threatening and worded in a way the respondents could easily comprehend (Bryman, 2016; Creswell, 2017). Questions that guided FGDs were structured to probe the respondents their personal appraisals of their social acceptance, their social contribution and social coherence /actualisation) as they raise their children with ASD.

Accuracy of information was obtained by employing rigor and trustworthiness of the study through inclusion of credibility, transferability, dependability, conformability and peer debriefing, as well as member checking.

The FGD sessions, and in depth interviews were tape recorded and handwritten notes of the discussion were taken in order to enhance the dependability of the content shared by participants during the discussion.

The principles of ethical considerations were observed including providing, information about the study to the respondents, obtaining the respondent's consent confidentiality and anonymity was maintained by assigning pseudonyms to the respondents. Also respondents consented to tape recording and to note taking of the discussions (Bhattacharjee, 2012).

Data, was transcribed verbatim. Intelligent transcription which entails transcription with minimal editing and minor paraphrasing to make a sensible read was employed. Transcription took about eight hours to complete. The hand written notes were typed in a word document. A twenty minutes individual respondent checking sessions was carried out with all the respondents to confirm whether the captured information reflected their true views. The accuracy of the transcribed data was ascertained by listening to the audio tape recordings of the interviews and by matching the transcripts with the recorded interview. The total number of hours taken for focus group data collection process was about sixteen. The rationale for using two focus groups was to get more information that might have been overlooked during the in depth interviews.

The interview schedule guide was crucial in organizing and summarizing data. Verified data was imported into NVivo software package for ease of data coding, searching for patterns and generating themes (Creswell, 2017).

Findings and Discussion of the Study

The study established that caregiving of children with ASD affected the caregivers' relationship with significant others including spouses. This affected the caregivers' social acceptance and subsequently their social well-being. According to Westerhof and Keyes, (2010) an individual who is not socially accepted may find it difficult to trust other people. The study established that the caregivers were alienated by their spouses after their children were diagnosed with ASD. This meant that the caregivers of children with ASD were left to bear the burden of caregiving of the child (ren) with ASD alone. These findings concurred with Tathgur and Kang (2021) findings which established that ASD caused strain in the spousal relationships. The study established that some caregivers were falsely accused by significant others as being responsible for their children predicament. They were accused of exchanging their children spirits for wealth, practicing witchcraft and eating forbidden food while pregnant. These findings are consistent with the findings from Abosi and Koay as cited by Ndadzungira (2016) which established that in Uganda the caregivers of children with disabilities were secluded by their significant others because they were alleged to have been involved with witchcraft or to be under ancestral curses. Similarly, a study conducted in Ghana by Oti-Boadi (2017) revealed that caregivers of children with ASD were rejected by their family members because of having a child with disabilities was considered as a bad omen. The findings of this study revealed that the caregivers experienced rejection and abandonment by their family members when they most needed their support. These findings are consistent with the findings by Kocabıyık and Fazlıoğlu (2018) study which was conducted in Turkey concerning lived experiences of parents raising children with ASD, it established that majority of parents raising children with ASD hardly receive any support from their immediate family members after their children were diagnosed with ASD. This caused the caregivers' to experience social - rejection and consequently low social wellbeing.

The study also established that the caregivers were blamed by their significant others for being the cause of ASD. This is a demonstration of how lack of knowledge and awareness affect family relationships. The study established that lack of correct information about the cause of ASD validated the traditional held beliefs about the causes of ASD or how disabilities with no known causes were conceptualized by individual and the family members. This affected the caregivers' social integration because they did not share the same values about their children with ASD with their family members and the community at a large. These findings agree with

Rainia et al (2016) whose study established that mothers who take care of their children without the support of family members reported experiencing depression and loneliness. Similarly a study by Tathgur and Kang (2021) revealed that lack of information and understanding about ASD caused misunderstanding among the caregivers and their family members causing the caregivers to be socially discriminated. This caused the caregivers to experience social isolation thereby reducing their ability to integrate socially, thus affecting their social wellbeing.

The study further established that child (ren) with ASD affected not only the caregivers' relationship with immediate and extended family members but also the relationship with the community members. Family social relations were also affected subsequently the family as a unit experienced social seclusion. Equally a study by McKechanie et al as cited by Pratesi et al (2021) established that a family with a child (ren) with ASD experiences family dysfunction and lack social integration. According to Keyes as cited by Medvedev and Landhuis (2018) social integration is the extent to which an individual experience commonness with others who constitute their social realities. In this regard the caregivers did not experience a sense of belonging because they did not share the same values when it came to their children's condition. This is unfortunate because it is within the family context that caregivers are able to achieve their social wellbeing because this is where supportive factors are found for example, emotional and hands on support in providing the necessary care to the children with ASD.

On a positive note the study established that there were some caregivers of children with ASD who had supportive relations with their family members and with other caregivers of children with ASD. These caregivers were able to experience a certain level of social acceptance, self-acceptance and had sense of belonging for they shared same values with their significant others in raising children with ASD. These findings are similar with Henderson and Vandenberg study as by cited plumb (2011) findings which established that a family that maintain positive relations adjusted well to meeting the extra needs of a child with ASD. Similarly, studies by Gao and McLellan, 2018 and Gouin et al, (2014) revealed that caregivers who maintain meaningful relationships with significant others enhances their social well-being. In this regard positive relations with others shield the caregivers from social isolation and it increase their community of support, thus, lessening the burden of caregiving and increasing their social wellbeing.

The study established that some caregivers had established their own support groups. Working together with each other raised the caregivers hope and encouragement as they realized that they were not alone but there are other caregivers facing the same challenges. This enhanced the caregivers' self- acceptance and it also increased their wellbeing. These findings concur with Clifford and Minnes as cited by Catalano et al (2018) findings that the caregivers within a support group give each other moral support, affirmation, validated each and increased their social support system. This validation enhanced the caregivers' ability to integrate socially thereby achieving their social wellbeing. On the same note Wang (2021) reported that the burden of caregiving of a child with ASD was made lighter when the caregivers were given support by their family members, friends, neighbours and community members. This made the caregivers to experience a sense of belonging to a community thereby achieving their social wellbeing. These findings are in agreement with Hoopen et al (2020) findings which established that most of the caregivers of children with ASD experience satisfaction with the support accorded to them by significant others, this enabled them to increase their social wellbeing.

The study established that the caregivers failed to social actualize because family members, friends, and neighbours avoided relating with them purporting they lacked control over their children with ASD problematic behaviours. In any case most of these behaviours are socially unacceptable for instance, lack of courtesy, demandness, impulsivity and aggressiveness. These findings concur with Ludlow and Rohleder (2012) study which established that caregivers reported that they found it difficult to control unpredictable behaviour exhibited by their children with ASD. On the same page studies by Mitter et al., (2018) and Werner and Shulman (2015) established that caregivers of children with ASD experience social stigma associated with the children with ASD extra-personal problematic behaviours (ECBs). Similarly a study by Broad et al (2018) revealed that ECBs caused caregivers to experience shame, and embarrassment. As a result, the caregivers reported that they preferred to keep to themselves as a way of controlling their children and also to escape from the public criticism and harsh judgment directed at them. This hindered the caregivers from social actualizing because they felt their neighbours cannot be trusted. According to Cicognani (2014) individuals who failed to demonstrate social actualization do not believe that people can be trusted, have no hope of the society's future improvement. Based on this caregivers may estrange themselves from others thereby fail to achieve their social wellbeing. This study found that lack of understanding that the children with ASD are not *spoiled brats* and are not wilfully acting out caused the caregivers to disassociate themselves from the families, friends and neighbours. These findings concur with Bauminger, et al (2017) findings which established that the aggressiveness and lack of social skills for the children with ASD as one of the reasons caregivers' experience social isolation. This resulted in the caregivers experiencing negative emotions such as stress and loneliness, thus, reducing the caregivers' ability to achieve their social wellbeing.

The study established that majority of caregivers were not able to contribute socially or to be involved with other activities apart from taking care of their children with ASD. This was attributed to the child(ren) with ASD resistance or difficulties in adjusting to minimal change. This limited both the caregiver and the child(ren)'s involvement in social activities, for instance attending birthday parties, weddings in some cases attending church. This study revealed that managing the children's erratic behaviours hindered the caregivers from getting involved in social activities. The caregivers expressed their frustrations in controlling their children behaviours which seemed to get worse when the caregivers and their children were away from home. These findings concur with Ludlow and Rohleder (2012) study which established that caregivers reported that they found it difficult to control unpredictable behaviours displayed by their children with ASD especially in public. Similarly Miranda et al (2018) study established that caregivers of children with ASD experienced challenges in controlling their children's behaviours. The caregivers reported that they did not feel competent to manage their children's peculiar behaviours in public so they avoided going out with or without their children with ASD. This reduced the caregivers' opportunities to participate in social activities and consequently affecting their social wellbeing.

The study further, established that majority of caregivers were not involved with social contribution because they were exclusively involved in meeting the multitude needs of their children with ASD. According to DSM – 5 (2013) ASD symptoms markedly impair the child (ren) functioning domains such that they require daily assistance with activities of daily living (ADL). These findings concur with Manyara and Mwarari (2020) findings which established that continuously assisting children with ADLs for instance dressing, grooming, feeding and using the toilet without help from family members left the caregivers exhausted. Similarly, a

study by Paget as cited by Chabeda-Barthe et al (2019) established that meeting the demands of children with ASD limit the caregivers' involvement in other activities unrelated to caregiving. This conversely impede the caregivers' sense of relatedness and belonging with their family members, neighbours and the society at large as a result affect their social wellbeing.

The caregivers concern for the safety of their children with ASD affected their ability to integrate socially thus affecting their social wellbeing. The study established that majority of the caregivers were worried because of their children with ASD tendency to wander away. This was exacerbated by the children's lack of sense of danger, and communication impairments. This caused the caregivers to experience anxiety and fear because it would be difficult to trace their children with ASD if they wandered away from safety. These findings concur with a report by Autism Speaks (2018) that wandering behaviour by the children with ASD was stressful to the caregivers. These findings are supported by Manyara and Mwarari (2020) findings that the caregivers are always worried because their children with ASD are prone to wandering away and getting lost which would increases chances of them to being hurt. Equally a study by McIlwain et al as cited by Anderson (2014) established that caregivers struggle to ensure their children with ASD safety because these children love running away and lack ability to sense danger. Likewise, a study by Clasquin-Johnson and Clasquin-Johnson (2018) established that most caregivers of children with ASD eyes are constantly on their children for fear of them getting lost. The caregivers reported that apart from their children with ASD wondering away they also feared to be judged as careless parents if their children managed to wonder away. This cause caregivers to ensure that they are with their children around the clock and as a result this reduce caregivers' ability to achieve social wellbeing.

The study established that caregivers were also concerned about their children with ASD tendency to self-harm. These finding are similar to Unumb report as cited by Mthombeni and Nwoye (2017) that the caregivers protect the children with ASD from self-harm because some them are prone to self-injurious behaviours such as head bunting on hard surfaces, self-pinching and hair pulling. These findings were confirmed by Autism Speaks (2018) report that some children with ASD are prone to harm more than other children with special needs. Children with ASD are predisposed to self-injuries, injured by others or being bullied partly because of their peculiar behaviours and partly because they lack capacity to report the abuse to their caregivers. Furthermore, some children with ASD can harm others or destroy properties because of their defiant behaviours. Similarly, a study by Aldersen (2010) established that children with ASD require constant supervision to ensure their safety. This study established that ensuring the safety for the children is a time demanding exercise and it affect the caregivers other life domains for example socializing thereby affecting their social wellbeing. The study noted that caregivers' self-isolated themselves as way of coping with their children tendencies to wander away. These findings concur with Oti-Boadi (2017) that most mothers of children with ASD isolated themselves to keep their children safe and to protect them from public stares. According to Westerhof and Keyes (2010) social alienation destroys relationships that provides an individual with support system. In this regard social alienation deprived the caregivers the support and validation from their family members, friends and neighbours consequently affecting their social wellbeing.

This study revealed that the caregivers of children with ASD benefited greatly from integrated primary schools. Firstly, it was through the schools that the caregivers realized that their children had ASD. These findings are supported by Bakare and Munir (2018) study that established that, in most African countries ASD diagnosis is done when children start going to school. Moreover, schools helped caregivers balance between the responsibilities of giving care to the children with ASD and other family responsibilities thereby enhancing their wellbeing. This study established that caregivers use the schools as respite care. In that when the children are in school the caregivers take that time to pursue other chores unrelated to caregiving of child(ren) with ASD. For example the caregivers did house responsibilities, went to the market; did casual job such cleaning other people's houses to earn a living; others used that time to have a restful nap. These activities enhanced the caregivers' wellbeing. These findings are similar to Gona et al (2017) findings which established that the caregivers viewed respite care as a way of helping them manage other aspects of their lives unrelated to caregiving responsibilities. For example taking a child with ASD to a boarding school enabled the caregiver to have time to engage in income generating projects and other family responsibilities as long as the child was in school. This increased the caregivers' capacity for social acceptance and as a result enhance their social wellbeing.

Secondly, the study realized that the integrated primary schools supported the caregivers in establishing and maintaining a firm routine for their children with ASD. According to DSM-5 (2013) children with ASD exhibit ritualistic and repeated behaviours and they like to follow an established routine. The study established that if anything interfered with the integrated primary schools for example the abrupt closer of schools due to covid-19 the caregivers found it hard to manage their children's behaviour. A previous study by Morrison (2014) established that one of the characteristics of children with ASD is exhibition of inflexibility or rigid behaviours which is caused by marked difficulties for these children to adjust to new routines. With disruption of their routine the children with ASD became easily irritable and at the slightest provocation they would throw violent tantrums and it would take a long time to calm them down. Similarly a study by Parenteau et al (2020) established that children with ASD were negatively impacted by interruption of the school routine. This is because change in routine aggravated the children with ASD mood and behaviour causing them to exhibit anger and agitation. This increased the caregiving demands because it took time for the children to establish staying home routine. Similarly a study Ghosh et al (2020) confirmed that abrupt changes in routine aggravated the children with ASD behaviours by increasing aggressiveness. Managing such behaviours restrict the caregivers from participating in social life. Furthermore, controlling the children's increased behavioural problems caused the caregiver to be fatigued. On the same token Durkheim as cited by Westerhof, and Keyes, (2010) established that social life or social participation improves an individual's social wellbeing through experiencing a sense of belonging to a community. In this regard the caregivers were not able experience social participation which according Keyes (2010) is a foundation for social integration and cohesion consequently they failed to achieve their social wellbeing.

Thirdly the study established that the selected integrated primary schools helped the caregivers to overcome social challenges for instance social isolation or self-isolation. The caregivers used the schools as a socialization platform where they interacted with other caregivers of children with and without ASD. Similarly a study by Gona et al. (2017) established that caregivers used schools as respite care also caregivers interacted with other parents as they take their children to school. This increased the caregivers' opportunity for socially contribution and social

acceptance especially during parents meetings. According to Cicognani (2014) an individual who experiences social contribution feels a valued member of the community or a group with something of value to give to their community and subsequently increase their social wellbeing. The study established the schools reduced the caregivers' anxiety or concern over their children's safety. When the children are in school the caregivers were not overly worried over their safety, they took a break from vigilante parenting this improved their wellbeing because they could focus on other issues.

Fourthly, integrated primary school helped to regulate the children with ASD behaviour and enhanced their personal skills for instance using the toilet without help. This increased the children's independent thereby lessening the demands on the caregiver's time. However, the study established that the children with ASD require continuously practice the life skills they learnt because without practice they can easily loose them. For instance the study established that the prolonged school closure due to Covid 19 Pandemics caused the children to regress as a result some children lost some of the skills they had learnt when attending school. These findings are in line with Stankovic et al (2020) findings which indicated that the discontinuation of school routines due to Covid 19 pandemic caused the children with ASD to lose some abilities they had learned before the pandemic.

Fifthly, the study established that despite serving as respite care the integrated primary schools also serve as life line for the caregivers. The study established that the government recognize the caregivers and their children with ASD through these schools. It was through these schools that the government channels any form of assistance for the caregivers and their children with ASD. For example, the study established that during the Covid 19 lockdown the government channelled its support to the caregivers through the integrated primary schools. These findings are contrary to Pavlopoulou, et al (2020) study which established that many families of children with special needs did not receive any form of support from their government during the lockdown caused by Covid-19. These support systems improved the caregivers' social wellbeing.

The study established that the caregivers felt judged by their family members, friends and the community members as careless parents who were not able to control their children. These finding are supported by Tathgur and Kang (2021) who found that caregivers of children with ASD experienced stress and anxiety arising from the family friends, and the general public's negative attitudes toward them and their children with ASD. Children with ASD look perfectly normal because they have no physical marker like other disabilities for instance Down syndrome to warn people that a child has special needs. It is difficult to know that a child has ASD by just looking at them. This is made complicated by the fact that the aetiology of ASD is yet to be established DSM-5 (2013). This study established that the caregivers found it hard to explain to other people including their family members, friends and neighbours why their children exhibited problematic behaviours which are socially unacceptable. This caused the caregiver to be condemned and judged by their significant others instead of being given empathy and support. To avoid being judged the caregivers opted to social isolate themselves and this affected the caregiver's ability to attain their social wellbeing. These findings concurred with findings from several other countries. For instance, a study by Dababnah and Parish (2013) established the majority of the caregivers in Palestine avoided going out with children for fear of being judged. Similarly, a study carried out by Werner and Shulman (2013)

in Israel established that the caregivers of children with ASD were socially alienated due to the condition of their children thus they experience low social wellbeing.

The study established that the caregivers of children with ASD were judged by their family members, friends and the community members as careless parents whose children were out of control. The caregivers attributed this to lack knowledge and awareness about ASD at family and community levels consequently affecting their social wellbeing. These findings are similar to Uweazuoke (2016) to findings which revealed that there is lack of awareness and knowledge about ASD as demonstrated by paucity of published journals about ASD in Sub Saharan Africa countries. Lack of awareness about ASD only confirmed the cultural beliefs about the cause of ASD. This was demonstrated by the way people were quick to blame and judge the caregivers about the condition of their children. These findings are consistent with findings from Gona et al as cited by Ndirangu and Midigo (2018) study which found that the majority of caregivers of children with special needs frequently experienced feelings of being judged stigmatized and rejected in various contexts including home, schools and health care institutions. This study found that ASD was not recognized traditionally as a result children with ASD were referred to as “children out of control”. These findings concur with Ambikile and Outwater (2012) findings that disorders and mental illnesses without identified cause were lumped together and referred to as “madness” or *Wazimu* in Swahili.

Lack of awareness about ASD also validated myths and stigma as people try to make sense of ASD is about. Similarly, studies by Broady et al, (2018) and Dababnah and Parish, (2014) established that myth and stigma about ASD predisposed the caregivers of children with disabilities to experience rejection, shame and embarrassment from their community. Such emotions included shame, fear, and associated with the condition of the children. Some caregivers internalize these challenges and perceive themselves as bad parents. These findings are similar to Manyara and Mwarari (2020) study which established that owing to alleged stigma and discrimination towards the caregivers’ they experienced low self-esteem, and this caused them to isolate themselves from the community consequently affecting their social wellbeing.

Conclusion

The caregivers’ social well-being of is affected by the caregiving of children with ASD. This is majorly caused by a lack of awareness and information at the community level. This study established that lack of information validates irrational cultural beliefs about the causes of disabilities. As such, diagnosis of ASD creates tension and suspicion among the family members. Sometimes, this ends in separation, predisposing the caregivers to social isolation, thereby forcing them to bear the burden of caregiving alone. Without support from the family members, the caregivers find it difficult to balance caregiving and other family responsibilities. This study confirmed that the caregivers were not equipped to manage the impulsive, compulsive, and aggressive behaviours that are normally exhibited by their children with ASD. In most cases, these behaviours are socially unacceptable, and consequently, the caregivers are condemned and judged by the family and community members as parents who had lost control of their children, notwithstanding the shame and embarrassment they have to bear. This causes the caregivers to be socially isolated. Creating awareness will inform family members, neighbours, and the community, hence reducing the criticism and blame on caregivers for being the cause of their children's condition. This would also increase support and promote

compassion to the caregivers of children with ASD in various settings. As a result, this will improve their social well-being.

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