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

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Abstract:

The psychological well-being of an individual is important for them to flourish in life. However, the demands associated with taking care of children with Autism Spectrum Disorder (ASD) may derange the caregivers from achieving their psychological well-being. ASD is a neurodevelopmental childhood disorder that persists into adulthood. It impairs an individual's social, cognitive, and behavioural domains, causing most of the children to be dependent on caregivers throughout their lives. The objective of this study was to investigate the effects of caregiving of children with ASD on the caregivers' psychological wellbeing. The study's objective explored how caregiving of children with ASD affects the caregivers' psychological wellbeing. The study employed the Social Ecological System Theory to explain the importance of a supportive environment in facilitating the caregivers to achieve their psychological well-being. The Cognitive Behavioural Theory was used to discuss the interventions to mitigate the effects of caregiving on caregivers' psychological well-being. The study used a qualitative descriptive phenomenological approach and purposive sampling method to select 24 informal caregivers and four formal caregivers from selected integrated primary schools in Nairobi. The study used in-depth interviews and focus group discussions (FGDs) to collect data from the caregivers. Data was captured using video tape recordings and field notes. Verbatim transcription was employed. QSRN N'vivo 10 data software was used to simplify and analyse data. The result revealed that caregiving of children with ASD affect the caregivers' psychological wellbeing in the selected integrated primary

schools in Nairobi County. The study recommends creation of public awareness about ASD, availing authentic information about ASD symptoms to help the caregivers to seek early interventions for their children with ASD, making therapies accessible and affordable, equal distribution of the available resources among children with ASD and availing psychological support to the caregivers as measures of mitigating the effects of caregiving of children with ASD.

Keywords:

Caregivers, Caregiving, Autism Spectrum Disorder, Lack Of Awareness.

Introduction

ASD is a global health concern classified under the umbrella of neurodevelopmental disorder that is commonly diagnosed in early childhood, and persists into adulthood (Diagnostic and Statistical Manual of Mental Disorder (DSM-5), 2013). It is characterized by deficits in three basic areas: social skills, communication (verbal and nonverbal), and behavioural acts (restrictive, repetitive, and ritualistic). These deficits significantly impair the child's ability to perform Activities of Daily Living (ADL). Due to the nature of these impairments, children with severe symptoms of ASD depend on the caregivers to manage their ADLs throughout their lives (Black, & Andreasen, 2014, Diagnostic and Statistical Manual of Mental Disorders, (DSM-5), 2013). Unfortunately, the aetiology and cure for ASD are yet to be established (Dziegielewski, 2015; Morrison, 2014). Contending with a disorder that is not well understood is likely to affect the caregivers' psychological well-being. This study sought to explore how caregivers' psychological well-being is affected by giving care to children with ASD.

The psychological well-being of caregivers is important because besides giving quality care to the children with autism, it enables the caregivers to flourish and to optimize their full human potential (Cicognani 2014, WHO, 2017). However, a plethora of challenges associated with the demands of meeting the needs of these children is likely to derail the caregivers from maintaining their psychological well-being. This study focused on how caregiving of children with ASD affect the caregivers' personal growth, autonomy and their purpose in life. These are some of the Psychological well-being constructs identified by Ryff and Keyes as cited by Medvedev and Landhuis, (2018). Each of these constructs is important in stabilizing an individual's psychological wellbeing. According to Cooper (n.d) daily experiences determine how an individual attains their psychological wellbeing. For instance when an individual has positive experiences they are likely to achieve their psychological wellbeing while the opposite is true. This study sought to explore how caregiving of children with ASD affect the caregivers' psychological wellbeing.

According to WHO (2017) lack of knowledge and understanding about ASD is a global concern. This is because the level of awareness and knowledge about ASD is low compared to the level of prevalence rise. On the same matter a study by Woodgate et al (2014) established that a significant number of caregivers globally have low knowledge and awareness about ASD prior to their children being diagnosed with ASD. In Australia, for example, a study by Farmer and Reupert (2013) established that most parents had little knowledge about ASD prior to their children being diagnosed. In Canada a study by Gentle et al (2020) had similar findings that most caregivers cited lack of information about ASD as one of the difficulties they contend

with before, during, and after their children are diagnosed with ASD. Studies by Adib et al, (2019) and Bahry et al (2019) established that caregivers in Malaysia also experienced lack of awareness about ASD. Similarly a study by Zaki and Ahmed (2016) established that most of the parents and guardians of children with autism had poor knowledge about ASD. While Gona et al., (2015) had similar finding in Nigeria. Similarly a study by Muhoho (2017) reported low levels of ASD awareness in Kenya among the caregivers of children with ASD.

Lack of awareness of ASD infer that most of the caregivers will be contending with a pervasive phenomenon (ASD) with less understanding from family, community, and government levels. Besides lack of information and understanding about ASD reduces the caregivers' autonomy to make informed decision regarding the health care of their children. This is likely to affect the caregivers' psychological wellbeing because they may not be aware of where to seek for interventions.

After the children are diagnosed with ASD the caregivers self-teach themselves how to navigate through a maze of health care providers. Besides they glean through volumes of unverified information available in the internet about ASD (Alderson, 2010, Gentles et al, 2020). The caregivers have to familiarize themselves with various interventions measures available that they need to choose from (Gentles et al, 2020). Moreover, most of the information available in books, journal and internet is from the developed countries where there are supportive policies, advanced affordable health care and established ASD assessment protocols. (Pilapil, et al, 2017). There is paucity of local available authentic information about ASD that the caregivers of children with ASD can identify with. This is in accordance with Uweazuoke (2016), findings that there are a few studies that have focused on ASD in the Sub-Saharan Africa region. Therefore the findings of this study will strive to minimize this gap. Availing correct information and increasing level of awareness about ASD is likely to lessen the negative emotions experienced by the caregivers and increase the caregivers' autonomy in making informed decisions about the health of the children thereby increasing their psychological wellbeing.

A body of studies have established that caregivers of children with autism experience physical health problems such as somatic pains, psychological disorders such stress, anxiety, and depression, and financial challenges four times more compared to caregivers of children without ASD or the general population (Eapen & Guan 2016; Falk et al., 2014; Hoopen, et al, 2020). These psychological disorders are debilitating and may increase the caregivers' sense of being overwhelmed and this is likely to reduce their sense of life purpose consequently hindering them from achieving their psychological wellbeing. Beside, these negative emotions are associated with lack of sleep and cause caregivers to experience physical and emotional fatigue which reduces their ability to perform other roles for example self -care (Gentle et al., 2020). Physical and emotional fatigue could result in a serious downward spiral on caregivers' health and this may impact their purpose in life and as a result affect their psychological wellbeing.

The caregivers and the children with ASD do not live in isolation but live in a family set up. According to the systems theories a family is seen as a mutually dependent, and reactive organisms and as such a problem with one part affects the whole system (Seligman & Darling, 2017). The family is then viewed as a functioning unit that is more than the sum of the roles of its various members. According to Seligman and Darling (2017) it is not possible to accurately

understand an individual's psychological wellbeing in isolation of other family members. In the same way, a family member with challenges will affect all the others in the family. Similarly, a study by Chu, et al (2018) established that bringing up a child with ASD overwhelms not only the caregivers but also all other family members. According to the principle of family system, a problem with one part affects the whole system (Seligman & Darling 2017) as such, problems of the child with ASD not only affect the caregivers' psychological, wellbeing but also other family members as well. On the same page Anderson (2014) pointed out that a family with child (ren) with ASD is a family living with ASD, therefore, a family living with ASD is compelled to reorganize itself to accommodate the needs of one of its member(s). The caregivers need support from all other family members in caregiving activities in order to maintain their psychological well-being.

A belief can be a personal or collective view of how a group or individuals make meaning out of a common or a rare occurrence such as ASD. Beliefs are mostly founded on the cultural discourses and do not always represent reality (Kishore et al., 2011). The caregivers' subjective belief or world view about the causes of ASD is very important because it determines how the caregivers' psychological wellbeing will be affected by their role of caregiving for their children with ASD. In some cases the caregivers' of children with ASD self- acceptance is determined by the family and community beliefs about the cause of ASD. For example, the cold mothering theory where mothers were accused of being the cause of their children having ASD (Feinstein 2010). Even today mothers are blamed for being the cause of ASD (Alderson, 2010; Anderson 2014). Some mothers blame themselves for causing their children to have ASD because they did something wrong (Kishore et al., 2011). In such circumstances the caregiver may experience self-rejection, shame and guilt which consequently affect their self- acceptance and their psychological wellbeing.

Ellis as cited by (Corey, 2014) maintains that self –blame is the main cause of the common emotional disorders. Such as stress, anxiety and depression. He further explains that people maintain their emotional problems by the way they continuously interpret their situations. Additionally, according to Proverbs 23:7 (New International Version, 1984) individuals feels the way they think. When an individual has negative beliefs about themselves, they are likely to experience low self-acceptance. According to García-Alandete, (2015) a person who has low self-acceptance lack capacity to regulate negative emotions for example fear, worry stress, anxiety, and depression. These negative emotions are commonly associated with the caregiving of children with ASD and are attributed to the fact that ASD is a debilitating developmental disorder that limits the children functionality thus caregivers of children with ASD give them intensive specialized care. Ryff and Keyes as cited by Medvedev, and Landhuis (2018), assert that self- acceptance is an important aspect of psychological well-being and when it is not achieved, the caregivers of children with ASD are likely to fall short of achieving psychological wellbeing, thereby affecting their potential to flourish in life.

Caregiving of children with ASD is said to be more costly than caregiving of other childhood onset disorders (WHO, 2013). Caregiving for children with ASD cost the caregivers their time, energy, finances, health and career consequently hindering them from attaining their personal growth. This is because most of the available resources including finances and time are channelled towards meeting the high needs of the children with ASD. Caregiving of children with ASD depletes the caregivers' time, finances, and emotions (Kamaralzamana, et al, 2018). A study by Clasquin-Johnson and Clasquin-Johnson, (2018) established that the diagnosis

process for ASD is intensive, expensive, long and tedious. Studies by Crane, et al., (2016) had similar findings that appointments with various health professionals including paediatricians, psychologists, psychiatrists, speech, and occupation therapists, for assessments, follow ups and therapies is time and financial consuming. Most of the available resources is channelled to meeting the child with ASD expenses the caregivers' personal development is likely to be put on hold consequently affecting their psychological wellbeing. Lack of resources may also minimize the chances of the caregivers' career advancement or business expansion (Olin et al., 2019). The personal development of caregivers of children with ASD is likely to be slowed down by time and financial constrains associated with the high cost of managing it. This is because one needs time, finances, and emotional stability to improve their self-development and meet their personal needs.

Ensuring safety of their children is every parent's priority. More so for the parents of children with ASD. This is because most children with ASD are always on a fright mode and are prone to straying away from the presence of their caregivers (Autism Speaks, 2018). A study by Clasquin-Johnson and Clasquin-Johnson (2018) established that most caregivers of children with ASD practice vigilant parenting to ensure safety of their children. Since the social and communication skills (verbal and nonverbal) of children with ASD are impaired, it is usually an uphill task to trace them when they stray away from their caregivers. Some of the children are nonverbal and they may not even respond to their names or know the caregivers' name (Autism Speaks, 2018; 2014; Klinger, et al 2013). The caregivers' energies are mostly channelled to ensuring that their children are safe. As a result the caregivers are left emotionally and physically exhausted to do other meaningful activities. This may hinder the caregivers from attaining their psychological wellbeing. This study sought to explore how the caregivers' psychological well-being is affected by these challenges of caregiving of children with ASD.

Theoretical Framework

Social-Ecological System Theory

The Social-Ecological System Theory (SEST) was founded by Urie Bronfenbrenner in the 1970s (Rosa & Tudge, 2013). He coined the terms microsystem, mesosystem, and macrosystem as constructs of the social-ecological system to explain how an individual influences and is influenced by their environment. These systems have a reciprocal relationship and are embedded within each other (Eriksson et al., 2018). Microsystem is the first level of SEST, and it represents where the caregivers of children with ASD and the immediate family subsystems (couple, parental, siblings), extended family members, friends, and neighbours reside, and their relationships (Rosa & Tudge, 2013; Seligman & Darling, 2017). The next level of the SEST is the mesosystem which consists of various settings within which the caregivers directly relate with such as schools, hospitals, and the peer groups, as well as the relationships within the settings. The largest level of the SEST is the macro which consists of social norms, cultural beliefs, attitudes, and policies that guide the community (Berns, 2015). This study was guided by SEST in investigating how these specific areas of the environment (micro, meso, and macro systems) contribute towards the caregivers of children with ASD self-growth, autonomy, purpose in life hence enhancing their psychosocial well-being. This is so because it is only within the environment that individuals are able to maintain or have their psychological well-being compromised.

Cognitive Behavioural Theory

The Cognitive Behavioural Theory (CBT) is an eclectic model that combines both the cognitive and behavioural principles (Goldenberg & Goldenberg, 2008). CBT, focuses on the tenets of 'thinking, judging, deciding, analyzing, and doing (Goldenberg & Goldenberg, 2008). It is based on the assumption that thoughts, feelings, and behaviours have a reciprocal relationship (Corey, 2014 Goldenberg & Goldenberg, 2008. The ABC model posits that an individual's emotions and behaviour are not caused by the event, situation, circumstance, or the consequences, but by the way one perceives, believes, or evaluates the event or the problem. Since an event cannot be manipulated to get the desired outcome CBT is concerned with modifying beliefs to create positive outcomes and work on the negative emotions, cognitions, feelings, associated with caregiving of children with ASD so as to resolve emotional and behavioural problems (Corey, 2014). The study employed the ABC model to come up with need-based intervention measures to alleviate the effects of caregiving to children with ASD on the caregivers' personal growth, autonomy, purpose in life, to improve their psychological well-being.

Research Design

This study adopted transcendental phenomenology which is also known as a descriptive approach Moustakas, (as cited Neubauer et al., 2019). Specifically the Phenomenological inquiry was considered suitable for this study because it guided the study to collect rich data on the intricate nature associated with the caregiving of children with ASD which could not be achieved using other approaches. Phenomenological approach permitted flexible investigation to broaden the understanding of the phenomenal under research. It also provide modalities to identify the essence of the caregivers' experiences about their phenomenon Moustakas as cited Neubauer et al (2019). Lastly it provided strategies for analysing and interpreting data (Creswell, 2017)

The Population of the Study

The population of the study consisted of mothers, grandmothers, and a father who are informal caregivers of children with ASD in selected integrated primary schools in Nairobi County. In addition key informants who included special needs class teachers and occupational therapists as formal caregivers were also included. Nairobi County was chosen for the study because of the availability of integrated primary schools. This is based on the findings by Kamau (2017) he established that most of the integrated primary schools that admit children with ASD are located in Nairobi. Besides, 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 (2012) 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 of selecting the respondents with the intention of gaining an in-depth understanding of the phenomenal under study. The rationale for using purposive sampling for this study was not to generalize the outcome of the study but to have an in depth understanding of phenomenon under study. The strength of purposive sampling technique according to Creswell (2017) 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 (Creswell, 2017). The unique sample for this sample included mothers, a father, and grandparents from different economic and cultural backgrounds as informal caregivers and special needs teachers and occupation therapists as the formal caregivers. The diversity of respondents gave rich data that aided the study to achieve its objectives. The inclusion criteria for this study was that the respondents must be a caregiver of children with ASD enrolled in the selected integrated primary schools in Nairobi. The study also excluded caregivers of children with any other form of disability enrolled in these schools.

The 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. Three in depth interviews took place in respective schools, one took place at the researcher's compound, and the remaining five were conducted at the caregivers' homes. The in-depth interview with the key informants were done through the phone. The role of the key informants in this study was to provide information regarding their expert knowledge of the effect of caregiving of children with ASD on the caregiver's psychological wellbeing in selected integrated primary schools in Nairobi County. The interviews were conducted through the phone and took about forty to fifty minutes to complete. The two focus group discussions were held in two different integrated primary schools in Nairobi County. Interviewing the caregivers in their own environment gave the researcher an opportunity to be immersed in their phenomena and to see where the caregivers lived, to meet other family members including siblings, the child with autism, increased the researcher's understanding of the essence of caregiving of children with ASD. During the data collection the researcher applied the 'Epoche' process so as to prevent their own subjective view and knowledge about the phenomena under study to influence the respondents' subjective experience of the phenomenon.

The study conducted a twenty five minutes follow up interview session with each respondents to accord them an opportunity to further elaborate on any thought, ideas or to add on any important information that they might have left out. Additionally, checking sessions of twenty minutes were conducted with each of the nine respondents to enable the caregivers to clarify and validate whether the recorded information is a true presentation of their views (Bryman, 2012). The second interview sessions with participants occurred between June and July 2021. All the respondents reported that their views were well captured clear and an accurate picture of their experience.

Qualitative data was collected using a descriptive phenomenological inquiry enveloped in focus group discussions and in depth or one on one interviews. This was done using open ended semi-structured questions that gave the respondents the autonomy to express themselves (Leedy & Ormrod, 2010). The research instruments were tested through piloting before the commencement of the study. The study used the following instruments: semi structured interview schedules for one on one in-depth interviews; semi structured guiding questions for focus group discussions. The researcher, as the main instrument of the study guided and controlled the Focus Group discussions and conducted the in depth interviews.

Findings and Discussion of the Study

This study investigated how caregiving of children with ASD affects the caregivers' psychological wellbeing in selected integrated primary schools in Nairobi. Findings from this study established that majority of the caregivers had not known about ASD prior to their

children being diagnosed. Only 2(8.30%) of the caregivers reported to having heard of the word ASD before their children were diagnosed. This was attributed to lack of awareness and information about ASD at individual and the community level. Low level of ASD awareness and knowledge was not confined to Kenya alone but it is prevalent in other countries also. These findings are similar to what has been established elsewhere in the world. For example, a study by Woodgate et al (2014) established that there is a significant number of caregivers who have no knowledge about ASD globally. Similarly in Australia, a study by Farmer and Reupert (2013) established that most parents had little knowledge about ASD prior to their children being diagnosed. A study by Chu et al (2018) had similar findings that caregivers in Malaysia reported low awareness and knowledge about ASD to be among the challenges they encountered. These findings concur with WHO (2017) concern that although ASD prevalence is increasing globally the level of awareness is very low.

This study established that lack of information about ASD caused the caregivers to experience anxiety because they knew something was not right with their children but did not know what was ailing them. The findings of this study concurred with a study by Kheir et al., (2012) study conducted in Qatar which established that low level of awareness about ASD is connected to caregivers' poor mental wellbeing. Poor knowledge about ASD at the individual, family and community level affects the caregivers' autonomy in making informed decisions concerning their children's health and consequently impede their psychological wellbeing.

The diagnosis of the children with ASD caught the caregivers unaware. Despite the fact that the caregivers had noticed early symptoms of ASD. However, they were not aware that it was ASD. Majority of the caregivers reported being overwhelmed with emotions when they first learnt that their children had ASD. Majority of the caregivers reported that they experienced a plethora of negative emotions after receiving the diagnosis: fear, horror, shock, denial, depression, sadness, grief and anxiety some felt let down by God. The realization that their children had disabilities affected the caregivers psychological wellbeing because they could not predict the reaction of their significant others and the community members toward their children. The time the caregivers were receiving the ASD diagnoses coincided with the time their children had started exhibiting the idiosyncratic behaviours or what caregivers called weird behaviours caused by ASD symptoms which are socially unacceptable. This was also the time the majority of the caregivers were experiencing marital and family discords related to the child's condition. The caregivers reported that they were overwhelmed by the unexpected and multiple transitions in their lives. These findings concurred with Tathgur et al (2021) study which established that caregivers of children with ASD experience plethora of psychological and psychiatric disorders in the process of adjusting to meeting the needs of their children with ASD.

This study established that caregiving of children with ASD affect the caregivers' personal development and consequently their psychological wellbeing. This was attributed to the fact after the diagnosis most of the caregivers had to make decisions, and adjustments that had long time implications on their lives. One of major decision the caregivers made that affected their personal development was to resign from their employment so as to take full charge of taking care of their children. The caregivers reported that work demands conflicted with the demands of caregiving so most of the times they found themselves in a dilemma to choose between work and their children's wellbeing. The caregivers acknowledged that resigning from work was a painful decision they were compelled to make by the demands and needs of their children with

ASD. Resigning from work was attributed to the demands of both the child and place of work responsibilities. The finding of this study revealed that none of the caregivers were in any form of employment, 18(62.52%) of the caregivers of children with ASD in selected integrated primary schools had no meaningful employment. While 5(20%) caregivers work, have small businesses or are self-employed.

Interestingly, regardless of the caregivers' social economic status, level of education or marital status the caregivers experienced the anguish of making difficult decisions about meeting the needs of their child(ren). This is consistent with findings from other studies done in the past. An autoethnography study by Clasquin-Johnson and Clasquin-Johnson (2018) which was a reflection of their experience as parents of a child with ASD established the two authors are both scholars who are PhD holders yet when their son was diagnosed with ASD they reported agonizing over one of them resigning from their work to meet the demands of their child. However, a study by Kheir et al (2012) had dissimilar finding that in Qatar most of the caregivers and their spouses work in addition to taking care of their children. This was attributed to the support the caregivers are accorded by their government.

The caregivers adjusted from working class status to be the caregivers of children with ASD status. This transition came with its own challenges. For instance the caregiving role is not valued as much as a working status by the society, therefore, the caregiver may be perceived with less dignity. The caregivers reported that it was also after the diagnosis that most relationships took a turn for the worst. This study established that 23.8% of the caregivers went through the psychological anguish of separation from the father of their children. These findings are consistent with Hoopen et al (2020) findings that marital relationships is one of major problems the caregivers of children with ASD experienced. The separation came after their spouses realized that the child (ren) had ASD symptoms which included problematic behaviours. Separation from their spouses meant these caregivers were left without social status thus exposing them to double social stigma of acquiring a divorcee status and caregivers' of children with ASD. This is congruent with Sandberg et al (2015) finding that a marital union gives an individual adult status in social standing and protects them from loneliness. This study found that caregivers' separation from their spouses caused them a sense of shame, loss and grief. Shame because of now entering the status of divorced women and loss of dignity given by a marital status according to their culture. Going through these transitions, for instance the process of separation or abandonment by their spouses besides trying to navigate the world of ASD overwhelmed the caregivers. A caregiver experiencing loss of income, adopting the role of the caregiver and the new status of a divorcee, single motherhood, make the burden of caregiving of a child with ASD heavier. Negativity in an individuals' life impair their ability to peruse their personal development subsequently affect their psychological wellbeing.

Caregivers of children with ASD live with their families which are within the community and therefore the caregivers share the community beliefs about disorders. This study found that the family beliefs about ASD determined the type of intervention the caregivers sought when the children seem not respond to conventional interventions. For example if the family assumption was that ASD was caused by ancestral curses they offer sacrifices to appease the spirits. Where the family suspect influence of evil spirits, they seek tradition healing interventions. The findings of this study confirm what a study by Gona et al (2015) had revealed, it established that many families in Africa hold "pluralistic beliefs" about the treatment of ASD. Pluralistic practice is where an individual or a family seek both traditional (traditional healers, witch

doctors and spiritual healers) intervention alongside the conventional medical interventions. At some point this affect the caregivers' psychological wellbeing because they felt confused and they did not know which way to follow. The study established that where caregivers practiced both conventional and tradition intervention it reduces the caregivers sense of purpose thereby affecting their psychological wellbeing.

Notable, all the respondents in the study were Christians. Therefore, their belief in God enhanced their psychological wellbeing because it helped them to make meaning of their experiences. Faith in God acts as a source of hope and comfort to those who are suffering, strength to the weak. (Matthew 7:7, New International Version, 1984). Hope acts as a buffer against despair and hopelessness thereby enhancing the psychological wellbeing of the caregivers. Similarly a study by Hrydari, et al (2016) established that faith is an effective strategy of dealing with troubling chronic life issues. Belief that God was in control reduced worry and anxiety thereby enhanced the caregivers' psychological wellbeing In seeking answers to the question how the caregivers' beliefs affected the way they made decisions about their children with ASD the study established that scarcity of facilities and resources influenced the caregiver's decision compared to beliefs about ASD. This study established that caregivers of children with ASD did not have autonomy to make decisions in regard to their children with ASD. This was attributed to lack of information about ASD and the available resources and limited facilities. The study established that the struggle to access these scarce facilities and resources override the influence of individual, family and community beliefs about ASD. The caregivers reported that they made decisions based on what was available, accessible and affordable including schools, health facilities, therapies, diet and where to reside but not based on beliefs. This affected the caregivers' psychological wellbeing because it caused them to experience a sense of despondency purporting that most of the issues that concern their children with ASD were beyond them.

The study sought to establish how beliefs affected the caregivers' view of self. The caregivers and the children with ASD do not live in isolation but live in a family nested in a community within the society therefore the cultural beliefs affects the way caregivers think about themselves. A belief can be personal or collective view of how a group or individuals make meaning of a common or a rare occurrence, for example a disorder. A caregiver's subjective belief about the causes of ASD and the role they presumed to have played in their child having autism determines how the caregiver will think about themselves. The study established that the caregivers' beliefs about ASD affected their psychological wellbeing because it negatively influenced how the caregivers' viewed themselves. The caregiver's subjective belief about disabilities was informed by their family perception about the causes of disabilities based on the cultural dominant narrative about disability. Some of the cultural beliefs about ASD constitutes finger pointing where the caregivers are seen as culpable of causing harm to their children yet they are the one that are bearing the burden of care. These findings agree with Bakare and Munir, (2018) findings which revealed that caregivers are blamed for involving themselves with the malevolent spirits and witchcraft and subsequently causing ASD to their children. This predisposed the caregivers to bear the negative reactions of the society directed towards them and their children with ASD. This affect the caregivers' psychological wellbeing because it alienates them from their other people who are the source of their social support.

This study established that after the initial shock of learning that their children have ASD was over the majority of the caregivers were able to stabilize despite the fact that they were still learning how to find their way in the new world of ASD. This is true according to cognitive behavioural theory that posits that a person's emotions are not caused by a situation, or a problem, but by the way one perceives, that situation or the problem (Corey, 2014). In this regard the caregivers were able to reframe their mind and bravely accept the reality that their children had ASD, the fact that it is a permanent condition and that their children are different from other children. In this regard Ryff and Singer as cited by Medvedev and Landhuis (2018) asserts that the ability of an individual to accept numerous aspects of self-including the positive and the negative is a step in the direction of enhancing their positive self- acceptance. Thereby, enhancing their psychological wellbeing. Similar findings are established by Karst and Hecke (2012) study that the caregivers ability to make meaning out of their experience help to reduce negative emotions including fear, uncertainties and worries. This increase the caregivers' capacity to adapt to their situation thereby enhance their psychological wellbeing.

Conclusion

The conclusion that can be drawn from the findings of this qualitative study are that indeed caregiving of children with ASD affect the caregivers' psychological wellbeing Most of the psychological challenges the caregivers of children with ASD contend with are hinged on lack of awareness and knowledge about ASD from the individual, community, and the service providers' level. The findings of this study confirmed that interventions for ASD are more costly than any other childhood disorders. This is in form of finances, time, energy and emotions. Caregiving of child (ren) with ASD affect the caregivers' ability for personal development because all their energy and resource are channelled to meet the caregiving demands. Depending on the child's level of functioning the caregivers assist their children in activities of daily living including feeding, dressing, grooming and personal hygiene. Therefore the caregivers of children with ASD require support from their family members, friends' neighbours, service providers and the society at large to meet their psychological wellbeing.

Recommendations

The stake holders in the field of ASD especially the ministry of health need to spear a collaborative efforts to create ASD awareness.in the Kenya. This is because part of the problem of delayed diagnoses appear to be caused by lack of awareness and knowledge about ASD. Based on the findings of this study there is need for creating and increasing awareness and empowerment of health care professionals with adequate knowledge pertaining to the management of ASD. The primary health care workers are in the first line of healthcare and they interact with children from early age. There is also a need for the caregiver of child (ren) with ASD to have access to authenticated information about ASD. The caregivers need to know: a) the tell-tale early signs to look for in their children's b,) where to go for professional help c,) what kind of intervention is beneficial for the child. This will help the caregivers to seek early interventions for their children with ASD.

Reference

Adib, N., A., Ibrahim, M. I., Rahman, Z., A., Bakar, R.S., Yahaya, N., A., Hussin, S., M., & Mansor, W., N., A., W. (2019). Perceived Stress among Caregivers of Children with Autism Spectrum Disorder: A State-Wide Study. *International Journal of Environmental Research and Public Health*, 16, 1468; doi: 10.3390/ijerph16081468

- Alderson, J. (2011). *Challenging the myths of autism*. Auckland, New Zealand: Harper Collins Publishers Ltd.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing
- Anwar M.S., Tahir M, Nusrat K & Khan M.,R.(2018) Knowledge, Awareness, and Perceptions Regarding Autism Among Parents in Karachi, *Pakistan. Cureus* 10(9): e3299. DOI 10.7759/cureus.3299
- Autism Speaks. (2018).
- Bahry, N., S., Mat, A., Kori, N., L., Ali, A., M., Munir, Z., & Salleh, M., Z., M. (2019). Challenges faced by Malaysian parents in caregiving of a child with disabilities, *Global J. Bus. Soc. Sci. Review* 7 (2): 118 – 124 doi.org/10.35609
- Bakare, M., O., & Munir, K., M. (2015). Autism spectrum disorders (ASD) in Africa: a perspective. *African Journal of Psychiatry*; 14:208-210.
- Black, D., W., & Andreasen, N., C. (2014). *Introductory textbook of psychiatry. 6th Ed.* Washington, DC: American Psychiatric Publishing, Inc.
- Bennett, M., Webster, A., A., Goodall, E., & Rowland, S. (2018). *Life on the Autism Spectrum: Translating myths and misconceptions into positive futures*. Singapore: Springer.
- Berns, R., M. (2015). *Child, Family, School, Community: Socialization and Support. 10th eds:* Cengage Learning.
- Bryman, A. (2012). *Social Research Methods*. Oxford University Press Inc.,
- Clasquin-Johnson, M., G., & Clasquin-Johnson, M., (2018) “‘How deep are your pockets?’ Autoethnographic reflections on the cost of raising a child with autism’, *African Journal of Disability* 7(0), a356. <https://doi.org/10.4102/ajod.v7i0.3>.
- Chu, S., Y., Syamim, S., N., Mohd, A.B., McConnell, G.E., Tan, J., S., & Singh, S., .K, D., (2018). Challenges faced by parents of children with autism spectrum disorder in Malaysia, *Speech, Language and Hearing*, DOI: 10.1080/2050571X.2018.1548678
- Cicognani, E. (2014) Social Well-Being. In: Michalos A.C. (eds) *Encyclopedia of Quality of Life and Well-Being Research*. Springer, Dordrecht. https://doi.org/10.1007/978-94-007-0753-5_2797
- Crane, L., Chester, J., Goddard, L., Henry, L.A., & Hill, E.L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research and Practice*, 20(2), 153-162. DOI:
- Cooper, R. (n.d). *what is psychological wellbeing*. <https://www.robertsoncooper.com/blog/what>
- Creswell, J., W., & Creswell J. (2016). *Research design*. Singapore: SAGE Publications Corey, G. (2014). *Theory and Practice of Counseling and Psychotherapy: Ninth Edition*. Belmont: Brooks/Cole Cengage learning
- DSM - *Diagnostic and Statistical Manual of Mental Disorders* 5th Ed. (2013). American Psychiatric Association: Washington, DC
- Dujaili, A., H., & Al-Mossawy, D., A. (2017). Psychosocial burden among caregivers of children with autism spectrum disorder in Najaf province. *Curr Pediatric Res* 2017; 21 (2): 272-282.
- Dziegielewski, S., F. (2015). *DSM-5TM inaction*. John Wiley & Sons, Inc
- Eapen, V., Guan, J., (2016). Parental quality of life in Autism Spectrum Disorder: Current status and future directions. *Acta Psychopathology*. 2016, 2:1.
- Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders*, 44, 3185–3203

- Farmer, J., & Reuper, A. (2013). Understanding Autism and understanding my child with Autism: An evaluation of a group parent education program in rural Australia s Australian. *Journal of Rural Health* (2013) 21, 20–27. Doi: 10.1111/ajr.12004
- Feinstein, A. (2010). *A History of Autism: Conversations with the Pioneers*. Oxford, UK. John Wiley & Sons Ltd
- Fuentes, J., Bakare, M., Munir, K., Aguayo, P., Gaddour, N., Ö., & Mercadante, M. (2012). Autism spectrum disorders .In Rey J.M., (e d), IACAPAP, e-Textbook of Child and Adolescent Mental Health. Geneva: International association for child and adolescent psychiatry and allied professions
- García-Alandet, J. (2015). Does meaning in life predict psychological well-Being? An analysis using the Spanish version soft the Purpose-In-Life Test and the Ryff's Scales *The European Journal of Counselling Psychology*, Vol. 3(2), 89–98, doi:10.5964.
- Gentles, S., J., Nicholas, D., B., Jack, S., M., McKibbin, A., & Szatmari, P. (2020). Coming to understand the child has autism: A process illustrating parents' evolving readiness for engaging in care. *Autism*, Vol. 24(2) 470–483
- Gouin, J., Estrela, C., Desmarais, K., & Barker, E., T. (2016).The impact of formal and informal support on health in the context of caregiving. *Stres Family Relations* 65: 191–206 DOI:10.1111/fare.12183.
- Gona, J., K., Newton, C., R., Rimba, K., Mapenzi, R., Kihara, M., Van deVijer, F., J., R., & Abubakar, A. (2015). Parents and professionals; perception on causes and treatment options for ASD in a multicultural context of Kenyan Coast *Plos One* 2015; 10:8.
- Hrydari, A., Shahidi, L.H., & Mohammadpour, A. (2016). Spiritual journey in mothers' lived experiences of caring for children with Autism Spectrum Disorders. *Global Journal of Health Science*; Vol. 7, No. 6; 2015.
- Hoopen, L.,W., Nijs P.,F.,A., Duvkot,J., Greaves-Lord ,K., Hillegers,M.,H.,J., Brouwer,W,B.,F., Roijen, L,H.(2020).Children with an Autism Spectrum Disorder and their caregivers: Capturing health-related and care-related quality of life. *Journal of Autism and Developmental Disorders* (2020) 50:263–277 doi.org/10.1007/s10803-019-04249-w
- Kamaralzamana, S. Toranb, H., Mohamedc, S., Abdullaht, N. (2018). The Economic Burden of Families with Autism Spectrum Disorders (ASD) Children in Malaysia. *Journal of ICSAR* Volume 2 Number 1 January 2018
- Kamau, L., Z. (2017). Autism Spectrum Disorders (ASD) in Kenya: Barriers encountered in diagnosis, treatment, and management *Journal of Research in Pharmaceutical Science* Volume 3~ Issue 7 (2017) pp: 01-11 I: 2347-2995
- Karst, J.S. & Van Hecke, A.V. (2012) Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation *a journal of Clinical Child*
- Kheir, N., Ghoneim, O., Sandridge, A., L, Al-Ismael, M., Hayder, S., & Al-Rawi, F. (2012).Quality of life of caregivers of children with autism in Qatar. *Autism* 0(0) 1 –6
- Kishore, J., Gupta, A., Jiloha, R., C., & Bantman, P. (2011). Myths, beliefs and perceptions about mental disorders and health-seeking behavior in Delhi, India. *Indian Journal Psychiatry*. 53(4): 324-329DOI: 10.4103/0019-5545.91906
- Matson, J., L., & William L., W. (2013).Differential diagnosis and comorbidity: distinguishing autism from other mental health issues. *Neuropsychiatry* 3(2), 233–243.177/1049732308320112
- Medvedev, O. N., & Landhuis, C. E. (2018). Exploring constructs of well-being, happiness and quality of life. *PeerJ*, 6, e4903

- Miot, S., Akbaraly, T., Michelon, C., Couderc, S., Crepiat, S., Loubersac, J., & Baghdadli, A. (2019). Comorbidity burden in adults with Autism Spectrum Disorders and Intellectual Disabilities—A report from the EFAAR (Frailty Assessment in Ageing Adults With Autism Spectrum and Intellectual Disabilities) study. *Front. Psychiatry* 10:617. doi: 10.3389/fpsy.2019.00617
- Mitter, N., Ali, A., & Scior, K. (2018). Stigma experienced by family members of people with intellectual and developmental disabilities: multidimensional construct. *BJPsych Open* 4, 332–338. doi: 10.1192/bjo.2018.39.
- Morrison, J. (2014). *DSM-5 Made Easy: The Clinician's Guide to Diagnosis*. The Guilford Press. World Health Organization. (2013). Autism Spectrum Disorders & other developmental disorders. From raising awareness to building capacity,
- Muhoho, N. (2017). Autism Spectrum Disorder (ASD) in Kenya: a neglected none communicable disease. *East and Central Africa Medical Journal* 2017; 3(1): 1-2
- Neubauer, B., E., Witkop, C., T., & Varpio, L., (2019). How phenomenology can help us learn from the experiences of others. *Perspect Med Educ* .8:90–97://doi.org/10.1007/s40037-019-0509-2.
- Oades, L. G., & Mossman, L (2017). *The Science of Wellbeing and Positive Psychology Wellbeing*. London: Published by Cambridge University Press.
- Obaigwa, E., O., & Cloete, L., G. (2019). Challenges to accessing crucial services in the management of children having Autism Spectrum Disorders: Caregivers' perspective in Kenya. *Open J Pediatr Child Health* 4(1): 031-039. DOI: <https://dx.doi.org/10.17352/ojpch.000018>.
- Olin, S., S., Hoagwood, E., K. Rodriguez, J., Ramos, B., Burton, G., Penn, M., & Crowe, M. (2011). The Application of Behavior Change Theory to Family-Based Services: Improving Parent Empowerment in Children's Mental Health. *J Child Fam Stud*. 2010; 19(4): 462–470. doi:10.1007/s10826-009-9317-3.
- Papadopoulos C., Lodder, A., Constantinou, Randhawa, G., (2019) Systematic Review of the relationship Between Autism Stigma and Informal Caregiver Mental Health. *Journal of Autism and Developmental Disorders*. 49:1665–1685 <https://doi.org/10.1007/s10803-018-3835-z> h.
- Pilapil, M., Coletti, D., J., B., Rabey, C., & DeLaet, D. (2017). Caring for the caregiver: supporting families of youth with special health care need. In *Current Problems in Pediatric and Adolescent Health Care: https://www.researchgate.net/publication/319128366https://www.researchgate.net/publication/319128366*
- Rosa, E., M., & Tudge, J. (2013). Urie Bronfenbrenner's theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review* 5: 243–258.
- Seligman, M., & Darling, R., B. (2017). *Ordinary families, special children: A systems approach to childhood disability (3rd ed.)* Guilford Press.
- Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Morris, A. (2016). Evaluation of the Cygnet parenting support programme for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*. pp. 166-178.
- Uwaezuoke, S., N. (2016). Autism Spectrum Disorder in Children: The disparities between the developed and developing countries. *Autism Open Access* 5: 1000152. doi:10.4172/2165-7890.1000152.
- Viljoen, M., Mahdi, S., Griessel, D., Bölte, S & de Vries P., J. (2019). Parent/caregiver perspectives of functioning in autism spectrum disorders: A comparative study in Sweden and South Africa Article in Autism · DOI: 10.1177/1362361319829868

- Woodgate, R., L., & Ateah, C. (2014). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research Volume* 18 Number 1075-1083 10.1
- World Health Organization. (2013). Autism Spectrum Disorders & other developmental disorders. From raising awareness to building capacity, WHO, Geneva, Switzerland,
- World Health Organization (2017). Regional Office for South-East Asia. Regional strategy on autism spectrum disorders. World Health Organization. *Regional Office for South-East Asia*. <http://www.who.int/iris/handle/10665/259505>. License: CC BY-NC-SA 3.0 IGO
- Zaki, R., & Moawad, G., N., A. (2016). Influence of autism awareness on the psychological well-being of mothers caring for their children with autism. *Journal of Nursing Education and Practice* 2016, Vol. 6, No. 9