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The lived Experiences of Care givers of Children Living with Autism Spectrum Disorder

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Abstract

Background: Globally, it is estimated that approximately 1-3% of the general population has an intellectual impairment. Out of these, approximately 85% of persons having an intellectual disability, have a mild impairment, about 10% are estimated to have a moderate impairment, 4% with severe impairment and 2% having profound intellectual impairment. Studies have also shown that there is a higher prevalence of intellectual disability in males, and in low socio-economic families (Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2010).
Prevalence of intellectual disability: A meta-analysis of population-based studies. http://doi.org/10.1016/j.ridd.2010.12.018).

Purpose: This study seeks to investigate the experiences of the caregivers of children living with ASD.

Method: The opinions of ten caregivers who had children living with Autism Spectrum Disorder and were living in Accra were investigated. Among these caregivers were nine females and a male, nine caregivers were parents to the children and an Aunty to the children.

Results and Discussion: What participants failed to understand was the fact that ASD knows no boundaries irrespective of your creed or colour, poverty or wealth. One thing that caregivers dwelled on was an availability of social support from families which provides emotional relief to the caregivers of children living with ASD. However, people living in the same community do pass negative comments about children living with ASD.

Conclusion: Caring with children with ASD poses a challenging experience including caregivers quality of life but better managed if caregivers have some training.

Introduction

Autism spectrum disorder (ASD) is a serious neuro-developmental condition that causes impairment in a child's ability to talk and relate well with others including restricted repetitive behaviours and activities [1]. Other authors also define Autism spectrum disorders (ASD) as a range of multiplex heterogeneous neuro-developmental disorders with varied levels of severity that can cause considerable social, communication and behavioural challenges [2,3]. Heterogeneous developmental disorder means that individuals living with ASD show evidence of both characterized symptoms and a number of related symptoms [2]. The shortfalls in social interaction, social communication, and cyclical patterns of behaviours, activities or interests are the usual indicators in many children living with Autism [2]. Adding to these basic symptoms, are anxiety, depression, sleeping and eating disorders, attention issues, temper tantrums, and hostility or self-mutilation [3].

Globally, it is estimated that approximately 1-3% of the general population has an intellectual impairment [4,5]. Out of these, approximately 85% of persons having an intellectual disability, have a mild impairment, about 10% are estimated to have a moderate impairment, 4% with severe impairment and 2% having profound intellectual impairment [4]. Studies have also shown that there is a higher prevalence of intellectual disability in males, and in low socio-economic families [4]. While there is no cure for Autism spectrum disorder (ASD), intensive, early intervention and training in the areas of social skills and nutrition can make a significant difference in the lives of many children suffering from this childhood disability [6].

Talking about provision of care, parents or guardians also known as caregivers, are the most vital individuals in any child's life. The child's way of advancing towards promotion of autonomy or sovereignty has a direct consequence on the present and future quality of life of their Caregivers [1]. Additionally, during life's transitions of a child diagnosed with this condition, caregivers are considered the most important part of this child's life. Caregivers do play a central role in these children's psychological, social, and academic development" where does your inverted commas begin? [7]. Studies have established that children with chronic disabilities' welfare and developmental outcomes can substantially be determined by their caregivers' mental health [8,9]. All the fore mentioned situations make it very necessary for caregivers to render timely interventions to these children.

Accra cosmopolitan area in Accra is a place where all the hustle concerning life can be mostly located, hence, the densely populated nature of Accra. Due to the populous nature of this area and the fast movement of both human and economic activities in this area it has become very burdensome for relatives of children living with ASD to stay at home in the bit of rendering care at expense of commercial business that would put food on their table. In addition, majority of people living in this area are mostly small business owners and as a result other issues are regarded as serious disincentive. Meanwhile, taking care of a child living with ASD demands the caregiver's time, patience, and tolerance and for that matter, anything short of these virtues, frustration is most likely to occur.

The fundamental objective of this study is to investigate the experiences of the caregivers of children living with ASD in Accra and to explore effective ways that these caregivers use to cope with the demands of caring for children living with autism and to inquire into the experiences of caregiving for children living with ASD from the caregivers in Accra.

Methods

Design

The study used a descriptive-exploratory qualitative approach for this study to investigate the experiences of the caregivers of children living with ASD in Accra and to explore effective ways that these caregivers cope with the demands of caring for children living with autism.

Sample and sampling

The sampling method used in this study was the purposive sampling technique. Ten participants in the support group of caregivers of children living with ASD were selected who were pupils of community day care centre in Kokomlemle, Accra. Those who excluded were caregivers who were or did not have constant contacts with their wards and whose wards were above the age of 18 years.

Data collection

A semi-structured interview guide was used to conduct face-to-face in-depth interviews with the participants. This instrument was used in order to capture emotions, feelings, and opinions regarding this research about experiences with caring with children living with autism [10,11,12]. The instrument was pre-tested for accuracy and consistency using participants from Accra Psychiatric Hospital. Based on the outcome of the pre-test, the semi structured questionnaires were validated by revising a few items. Each interview was audio recorded and fields notes written. The questionnaires captured both the demographics of the participants and the experiences living with a child with autism. An interview lasted 45- 60 minutes. This allowed the researcher to gather "thick and rich" interviews as required for a qualitative research study [13,14,15].

Transcription

Some of the interviews were conducted in English and others conducted in a local language ("Twi"). Both interviews were transcribed verbatim. The "Twi" interviews were translated into English, and both types of typed transcript corrected by an expert without altering the import and understanding the participants' ideas. Scripts were read back to participant to ensure the true interpretation of participants' accounts These were all done in order to present the caregivers opportunity to confirm their stories.

Data Analysis

Following the transcription and the cleaning of data in Microsoft word, it was transferred to Microsoft excel and subjected to four levels of coding [16]. These are open or initial coding: this involves reading through the transcript thoroughly and labeling sections of the transcript that were very significant to some facts that the data represented. Memos were also jotted out of these concepts.

The next was focus coding and category development where questions as to "what is the data saying' with reference from level one coding (open/initial coding) were answered. Additionally, data from the first level of coding that articulated similar ideas were merged at this stage.

Then, axial and thematic coding: discussions into details the implications emerging from the second level of coding was done by relating codes into a larger category of common meaning. This was achieved by linking codes to context, to consequences, and to causes with the aim of becoming the category of the axis around which a number of codes revolve [16].

Finally, Development of theoretical concept: generation of theoretical concepts constructed based on the implications that were discussed under the axial and thematic coding.

Rigour

The methodological rigour was made possible by applying the trustworthiness criteria of Lincoln and Guba [17]. Credibility was ensured through the use of several sources of information such transcripts, field notes and memoirs. Transferability was also reached by keeping an audit trial and documenting every step of the process such as (the number of participants involved in the study, any restriction to the type of people who contributed to the data, the number of participants involved in the field work, the kind of data collection method that was used, the number and length of the data collected per session, the time period over which the data was collected For dependability a detailed explanation and reflexivity of the research process had been offered for reader's review where the study design may be used as a prototype for the production of a similar study [18]. Finally, confirmability was guaranteed by stating the participants view and bracketing the researchers view.

Ethics

Ethical approval was obtained from the Ethics Review Board at the Noguchi Memorial Institute for Medical Research (NMIMR), University of Ghana, Legon. The participants of the study were given a verbal and written explanation of the objectives and purpose of the study. Upon agreement to participate, they were asked to either sign or thumbprint a consent form. The participants were informed that they had the freedom to opt out of the study anytime they wished despite signing the consent form. It was ensured that information given by any of the caregivers in the study was held confidential and not publicly displayed in a manner that would lead to their identification. To ensure participants' right to anonymity and confidentiality, pseudonyms were used in the study. The typed transcripts and the signed consent forms were kept under lock and key in a cabinet. The transcripts were kept in the database and password protected for at least 5 years before destroying it.

Results

The study explored the experiences of family caregivers caring for children living with Autism Spectrum Disorders in Accra. Ten caregivers were interviewed by the principal investigator. The age range of the caregivers was from 20 to 60 years. None of the caregivers were within the ages of 20 to 30 years; two of the caregivers were within the ages of 31 to 40 years representing 20% of the total caregivers, five of the caregivers were within the ages of 41 to 50 years representing 50% of the total caregivers, three of the caregivers were within the ages of 51 to 60 years representing 30% of the total population. Concerning the genders of the caregivers, one (10%) of them was a male whiles the nine (90%) of them were females. With respect to caregiver's relationship to the child living with ASD, eight (80%) of the caregivers were mothers to the children living with ASD, one of the caregivers was a father to the child living with ASD and one of the caregivers was an Aunty to child living with ASD. Considering the duration of care three (30%) of the caregivers have been caring for the child living with ASD for the past 5 to 10 years and seven (70%) of the caregivers have been caring for the child living with ASD for the past 11 to 15 years. Looking at the marital status of the caregivers, one (10%) care givers was single whiles the remaining nine (90%) remained married. The religious background of the caregivers also indicated that nine (90%) of them were Christians, one (10%) being a Muslim and none was a traditionalist.

Responses of lived experiences of an Autistic caregiver have been grouped into three main themes, namely: The relationship between caregivers and children living with ASD, the quality of time of care spent with the living with the children living with ASD and the experiences of caring for children living with ASD.

Table 1: Socio-demographic characteristics of the participants [n=10].

Identification code	Relationship to child	sex	education	Marital status	Employment status	religion	Duration of care (years)
IR#1	niece	Female	Tertiary	Married	Government employee	Christian	13
IR#2	First Son	Female	Tertiary	Married	Self employed	Christian	15
IR#3	Second Daughter	Female	Primary	Married	Self employed	Christian	11
IR#4	First Son	Female	primary	Single	Government employee	Christian	14
IR#5	Last Son	Female	secondary	Married	Government employee	Christian	15
IR#6	Second Son	Female	Secondary	Married	Self employed	Muslim	6
IR#7	First Son	Female	Secondary	Married	unemployed	Christian	16
IR#8	Last Son	Female	Tertiary	Married	Government employee	Christian	18
IR#9	Only Daughter	Female	Tertiary	Married	Privately employed	Christian	7
IR#10	First Son	Father	Tertiary	Married	Self employed	Christian	5

The relationship between caregivers and children living with ASD

The study found that carers for these children are their immediate relatives and not the required professional caregivers. This implies that children living with ASD who lives in Accra may not be receiving a much professional care as done elsewhere in the well-equipped nations. As the immediate family members, caregivers demonstrated more affection towards their recipients as shown in their descriptions of the relatives such as stated below:
"She is my niece, my sister's daughter..." (IR#1)
"My sister does the caring sometimes, but during the day my mother does it..." (IR#8)

The quality of time of care spent with the children living with ASD

The study indicated that children living with ASD can hardly gain their independence and for that matter caregivers do not even believe that children living with this condition would ever live on their own in future. Caregivers expressed their experiences in a discouraging tone.

"For almost fifteen (15) years... From birth till date" (IR#5).
Since birth, He was born in 2002 and diagnosed with this condition in the year 2005..." (IR#4).
Some caregivers even indicated that the thought of this task (providing care for children living with ASD) throughout their lifetime puts a psychological strain on the caregivers which leads to exhaustion and burnout among them.

"...it is very stressful both emotionally and psychologically ...accepting or coming to terms with the fact that you have to care for a child with this condition is one challenge. Then, getting the kind of support you need at home; I mean here in Ghana is another issue altogether ...combining caring for the child with your work involves money ...you end up spending approximately about double of what you spend on a normal child ...Even, letting people know that you have a child who is autistic is a big challenge. Family members and work colleagues sometimes question what is wrong with my child. ...both you and your child are tagged and that also adds to your frustration." (IR#4).

"I was frustrated by the way my child uses to behave. I could hardly understand him. He could "Pupu" (ease himself or go to toilet) on himself and smear it all over. That was very disgusting and made me very angry. I am out of a relationship with the father because there has always been disagreement between the two of us and this is what I would be living with." (IR#7).

"...My worry was growing up; he won't be like the other children. He can't go to a normal school and learn and earn his own living. so that is my challenge..." (IR#8).

In addition caregivers were faced with the less hope for the future as they thought of who to care for these children of theirs in their absence, because these children require special attention.

Whenever I leave home and happened to be somewhere far from home, I do get worried because no one can give her the sort of treatment and patience I have for her. I have no one to help me take care of her, and for that matter, I have to do everything ... should someone will take care of her, it won't be like the way I would have taken care of her. So I prefer either me or her sister taking care of her (IR#3).

The experiences of caring for children living with ASD

The data revealed that caring for children living with ASD is difficult and requires caregivers to always remain alert because of the impulsive and disruptive behaviours. This implies that caregivers need to be observant to care for children living with ASD. Thus, when one is pre-occupied with other activities that take their attention off the child, they expose the child to danger due to the nature of their condition which requires their caregivers to be extra vigilant.

"...he goes about his daily routines; running, screaming, and failing to run from sources of danger. He just misbehaves. He can just cross the road without looking. He doesn`t fear anything. That is what I am saying. He doesn`t fear any danger or anything..." (IR #2).

"Sometimes, you come back from town to find out that the properties at home that you use to decorate your home with, are in a mess ...you arrive home and they are all destroyed. You just cannot have them. Recently he broke our television... Sometimes, he will just climb the table and slap the television with his hand. There was a time he brought the whole TV down just like that. So just imagine this... I can just receive a call from home while in town and be told that my son has destroyed something." (IR# 10).

On the contrary, when a caregiver becomes used to them and knows their normal routines, it becomes easy to handle them. This is because they are quick to adapt to activities when done in a routine form.

"...You have to be observant to be able to deal with her effectively...since they are people of few words, you have to be reasonably observant ...most of the time she would not say anything They just gesture in a certain way; then if you know them very well, then you may know this is what she means or this is what they want." (IR#1)

Additionally, it emerged from the data that caregivers of children diagnosed with ASD hardly have time for anything apart from the care of their children living with ASD

"I was restricted and couldn't go anywhere... For instance, I can now leave home without being much worried. Unlike three years ago, I could not do that. But now I can step out for an hour and keep calling and checking on the phone by asking: How is he? You know, don't leave the front gate open. Did he finish his food" (IR#3).

Furthermore, participants indicated that they (the caregivers) experience psychological distress because of their child's condition. This results in emotional turmoil among their families and may also predispose them (the caregivers) to other physical illnesses. In effect, it might not only lead to poor care towards them (the children living with ASD) when their caregivers become fed up but may also burden their caregivers in terms of trying to seek answers to their problems which they (the caregivers) consider as a predicament.

"Initially, I didn't believe the diagnosis of autism. I told them it was not autism and that it's not true... Accepting the diagnosis was so hard for me... I just had to bear with it, although it was painful. Prior to this disclosure, I could wake up and cry the whole day because I did not know why this child was behaving the way he did... I was always thinking and worried... I had been crying most often, and through that, I got diagnosed as B/P (Blood pressure). I starved myself, I was always thinking and worried and because of that I sometimes ate late at night which also resulted in me being diagnosed with diabetes... I don`t know how to say this but it was tough for me to realize that this girl too is an autistic child. I saw it and I knew that. "NO!" this is a child living with autism. I said to myself, "Oh! Should my only girl also be an autistic child? God! What have I done?" It was not easy for me at all. I didn`t even know the word to use in describing what I was feeling because I am still in it. Every day, it stares at me in my face. I see her. "This beautiful girl" I now know I do not know what surprises are. I was shocked and devastated. I do not know! I do not know! I do not know! Sometimes I ask myself, "Why me?" (IR#2).

Caregivers also worry about what society will say about their ASD children

"...Today you think this problem is solved; tomorrow there is another completely different problem. Especially in our society where the awareness has not really gone down well with the people, it is very, very difficult trying to even associate with the society and how the children would be accepted in the society... When the child comes there is that joy and high expectations for that child only to see that your child cannot really do things like any other child and he is a bit deficient. It breaks you down; you kind of lose some level of hope for this child. Finding yourself in this dilemma makes you feel disappointed... It keeps you always wondering the source of such a problem... You are haunted on daily basis with questions as to how this condition occurred" (IR#10).

Finally, the study indicated that lack of awareness about Autism among the general populace including the family may leads to family volatility and discriminatory attitude towards the children living with ASD as well as their Caregivers. This implies that conflicts are likely to occur and when they do, caregivers need to resolve them quickly for the benefit of the child because the aftermath may affect the innocent child to be cared for. To add to this, these children are discriminated against, looked down upon and subjected to physical and verbal abuse. These negative attitudes may not be solely restricted to these children but may spill over to their caregivers. Other times, their caregivers may be culprits themselves due to the lack of understanding about the condition. Consequently, some caregivers may want to distant themselves from their children or hide them as a way of trying to avoid such negative attitude towards them (Caregivers). More so, others who may play their roles as caregivers stand the risk of experiencing emotional turmoil because of these negative attitudes from the general populace combined with the task involved in taking care of these children.

"...sometimes, my Dad makes comments here and there and it makes me angry... I do not expect those comments to be coming from him because I am really going through a lot already. I do not want anybody to remind me of what I'm already going through. So these are some of the things/issues with my cousin, aunties, uncles and I have stopped visiting them because they don't understand..." (IR#2).

"...in our society where the awareness has not really gone down well with the people, it is very, very difficult trying to even associate with the society coupled with how the children would be accepted in the society. The society we live in is too backwards it hasn't really accepted these children living with Autism that much. So for people who do not know generally, anytime about Autism, when it is mentioned to them they call them "gyimi gyimi" (literally meaning the foolish ones). And some others refer to them as river babies or babies gotten from traditional rituals. There are a lot of people who hide these children or even kill them because they think such children have nothing to offer the world. People think you the caregivers are cursed. They would not tell you to your face but you would know. Ghanaians have a nice way of putting their messages across. They will not tell you but they will start avoiding you...they would not call you, will not even pick your calls. They would even stop asking about you totally in a very nice subtle way. (IR#10)

Discussion

The data gathered indicates that children living in Accra who live with ASD are taken care of by their immediate family relations and not professional caregivers. The above finding supports a study conducted by the national alliance for caregivers which indicated that a large majority of caregivers offer care to a relative (86%). One out of seven cares for their own child (14%), with three out of ten having given care to their loved one for five years or more (31%). Concerning this subject matter [19,20,21].

Data gathered from the interviews of the study revealed that children living with ASD are dependent on their caregiver throughout their lifetime. The study conducted by [22] among rural and urban counties of the Kenyan coast revealed that, among other worries, parents are faced with concerns such as caring burdens as a result of demands in relation to caring for children living with ASD, which mirrors the findings from this study [22].

Comparably, a study conducted to find the value of caregiver time, costs of support and care for individuals living with autism spectrum disorder indicated that a lot of individuals living with ASD will need some level of support over their entire lives [23]. Likewise, ASD impact on the family particularly appears to be severe and there is a high level of dependency on the caregivers [24,25,26].

Additionally, caregivers may be faced with unanswered questions regarding their children's survival in their absence because these children require special attention for which these caregivers feel they would be the best people to render these service because of their length of time of stay with these children (children living with ASD) [25,27].

The data show that giving care to children living with ASD is cumbersome and requires caregivers to always remain vigilant. Thus, when one is pre-occupied with other activities that take his attention off the child, they expose the child to various forms of dangers due to the nature of their condition which requires their caregivers to be extra alert. This supports the findings where mothers' glumness were associated with child's functional independence and severity of ASD [28,29]. Also, a study conducted in Jamaica by Mann (2013) reported that caregivers' lives were too busy, especially because they were dealing with their child's challenging behaviors on a daily basis [30]. It is expected that cultures in Africa which are more family oriented will have profound tolerance for such children.

Caregivers can hardly have time for other activities due to the demanding nature of care needed by children living with ASD as indicated by the study. Similarly, considering the time that is exhausted during care for the child living with ASD disallows one from doing anything for oneself. This not surprising consider the fact many of the participants were not trained and therefore lack appropriate care techniques for such a population.

Furthermore, with respect to the psychological distress, emotional turbulence and the physical illnesses that the care of these children leave the carers with makes the caring experience very much involving and very soon, the caregivers get fed up and frustrated. Confirming the above data, Karst and Vaughan (2012), Kheir et al. (2012) and Tung et al. (2014) proposed that children living with ASD may pose a clear psychological unease to their caregivers and mentioned factors like lack of functional independence, maladaptive behaviours and severity of ASD linked to an inferior quality of life [31,32,33].

Additionally, health issues are recently becoming familiar in the literature and time spent in taking care of a child living with Autism can also add up to caregiver burden [34,35]. Also, vancourver style indicated that caregivers experience feelings of sadness and inner pain or bitterness due to the disturbing behaviour of the children [36]. However, vancourver style considered this in light of mental illness which has some similarities with the outcome of this study.

Concerning the awareness level of the general populace the study discovered that lack of awareness about autism among the general populace lead to discriminatory attitude towards the children living with ASD as well as their caregivers. In effect, such children were discriminated against, such as distancing, gazing, starring looked down upon and subjected to physical and verbal abuse. This agreed with the lack of understanding of Autism in Kenya and in Africa in general. This caused restriction of access to appropriate services that may advance the quality of life and prognosis in children living with ASD [22]. Despite general unfavorably attitudes towards the disorder, a few institutions have dedicated their energy into improving the situation. One of them is the Autism Awareness Care and Training Centre in Accra, Ghana that seeks to help caregivers of children living with ASD to improve their understanding of the disability and equip them with the knowledge to help them. The focus of AACT is to furnish children living with ASD with the ability to function more effectively in the society. In Ghana, like any other country worldwide, lack of knowledge and information about ASD ends up with families feeling ostracized from their communities and even their extended families. In Ghana, it is common for families to be named witches whose children possess spirits. This causes a feeling of shame, pain and trauma due to lack of awareness of the condition of the general populace [37].

Conclusion

The lived experiences of caregiving for children, living with ASD from the caregiver's viewpoints in Accra established that children living in Accra and who are living with ASD are taken care of by their immediate relations and not professional caregivers. The study also indicated that children living with ASD are dependent on their caregivers throughout their lives and the stress of caring for children living with ASD puts a strain on the caregivers. It is obvious that caring for children living with ASD is challenging because they require special care and it also requires the devotion of time. Also, caring for children living with ASD results in psychological distress among their caregivers which may predispose them to other health related condition [38-52].

Conflict of Interest

Conflict of Interest and Authorship Conformation Form The authors of this article hereby declare that:

1. All authors have participated in (a) conception and design, or analysis and interpretation of the data; (b) drafting the article or revising it critically for important intellectual content; and (c) approval of the final version.
2. This manuscript has not been submitted to, nor is under review at, another journal or other publishing venue.
3. The authors have no affiliation with any organization with a direct or indirect financial interest in the subject matter discussed in the manuscript

References

1. Psaila E (2016) Parenting a Child with Intellectual Disability–Factors That May Contribute in Making Parenthood a Positive Experience Elvira Psaila, 1.
2. Amjad A, Bakhtiar SM, Azevedo V (2014) Autism Spectrum Disorders (ASD): From Diagnosis to Management. Journal of Molecular and Genetic Medicine 09: 10-12.
3. Kumar B, Prakash, Sewal RK, Medhi B, Modi M (2012) Drug therapy in autism: a present and future perspective. Pharmacol Rep 64:

1291-1304.

4. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S (2010) Prevalence of intellectual disability: A meta-analysis of population-based studies.
5. Harris JC, Greenspan S (2016) Definition and Nature of Intellectual Disability.
6. James S, Montgomery P, Williams K (2011) Omega-3 fatty acids supplementation for autism spectrum disorders (ASD). In S. James (Ed.), Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd.
7. Dardas LA, Ahmad MM (2014) Research in Developmental Disabilities Quality of life among parents of children with autistic disorder: A sample from the Arab world. Research in Developmental Disabilities 35: 278-287.
8. Groeneveld GM, Vermeer HJ, van Ijzendoorn MH, Litting M (2012) Stress, cortisol, and wellbeing of caregivers and children in home-based childcare: A case for differential susceptibility. Stress, Cortisol and Well-Being of Caregivers and Children in Home-Based Child Care: A Case for Differential Susceptibility 38: 251-260.
9. Neece CL, Green SA, Baker BL (2012) Parenting Stress and Child Behavior Problems: A Transactional Relationship Across Time.
10. Langos S (2014) M Sc in Marketing Management INDEPENDENT STUD Y "Athens as an international tourism destination: An empirical investigation to the city' s imagery and the role of local DMO' s.", (September).
11. Stuckey HL (2013) Three types of interviews: Qualitative research methods in social health Methodological Issues in Social Health and Diabetes Research. Journal of Social Health and Diabetes 1.
12. van Teijlingen E (2014) Semi-structured interviews.
13. Aldiabat KM, Le Navenec C (2018) Data Saturation: The Mysterious Step In Grounded Theory Method. The Qualitative Report 23: 245-261.
14. Creswell JW (2013) Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Research design Qualitative quantitative and mixed methods approaches.
15. Fusch PI, Ness LR (2015) Are We There Yet? Data Saturation in Qualitative Research. The Qualitative Report How to Article 20: 1408-1416.
16. Cohen L, Manion L, Morrison K, Keith R B (2011). Research methods in education. Routledge.
17. Lincoln Y, Guba E (1985) Strategies for ensuring trustworthiness in qualitative research projects.
18. Shenton AK (2004) Strategies for ensuring trustworthiness in qualitative research projects. Education for Information 22: 63-75.
19. Fianco A, Sartori RDG, Negri L, Lorini S, Valle G, Delle A (2015) Research in Developmental Disabilities Review article The relationship between burden and well-being among caregivers of Italian people diagnosed with severe neuromotor and cognitive disorders. Research in Developmental Disabilities 39: 43-54.
20. Hounsell C, Jed Johnson W, Seals Carol Levine E, Stein R, Vuckovic N, et al. (2014) Caregiving in the U.S. – AARP 2015 Report.
21. Riebschleger J, Scheid JW, Luz C, Mickus M, Liszewski GC, Eaton M (2008) How are the Experiences and Needs of Families of Individuals with Mental Illness Reflected in Medical Education Guidelines? Academic Psychiatry 322.
22. Gona JK, Newton CR, Rimba KK, Mapenzi R, Kihara M, et al. (2016) Challenges and coping strategies of parents of children with autism on the Kenyan coast 1-12.
23. Dudley C, Emery JCH (2014) www.policyschool.ca THE VALUE OF CAREGIVER TIME: COSTS OF SUPPORT AND CARE FOR INDIVIDUALS LIVING WITH AUTISM SPECTRUM DISORDER.
24. Benson PR (2010) Coping, distress, and well-being in mothers of children with autism. Research in Autism Spectrum Disorders 4: 217-228.
25. Cox CR, Eaton S, Ekas NV, Van Enkevort EA (2015) Death concerns and psychological wellbeing in mothers of children with autism spectrum disorder. Research in Developmental Disabilities 229-238.
26. Mcgrew JH, Keyes ML (2014) Research in Autism Spectrum Disorders Caregiver stress during the first year after diagnosis of an Autism Spectrum Disorder. Research in Autism Spectrum Disorders 8: 1373-1385.
27. Hoefman R, Nalin P, Van Exel J, Kuhlthau K, Kovacs E, et al. (2014) Caring for a Child with Autism Spectrum Disorder and Parents' Quality of Life: Application of the Carer.
28. Hartley SL, Barker ET, Seltzer MM, Floyd F, Greenberg J, et al. (2010) The relative risk and timing of divorce in families of children with an autism spectrum disorder. Journal of Family Psychology 24: 449-457.
29. Orsmond GI, Seltzer MM, Greenberg JS, Krauss MW (2006) Mother? Child Relationship Quality Among Adolescents and Adults with Autism. American Journal on Mental Retardation 111: 121.
30. Mann AR (2013) The Experiences of Mothers of Children with Autism in Jamaica: An Exploratory Study of Their Journey.
31. Karst JS, Vaughan A (2012) Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation 247-277.
32. Kheir NM, Ghoneim OM, Sandridge AL, Hayder SA, Al-ismail MS, et al. (2012) Concerns and considerations among caregivers of a child with autism in Qatar 1-8.
33. Tung L, Huang C, Tseng M, Yen H, Tsa Y, et al. (2014) Research in Autism Spectrum Disorders Correlates of health-related quality of life and the perception of its importance in caregivers of children with autism. Research in Autism Spectrum Disorders 8: 1235-1242.
34. Durkin MS, Maenner MJ, Meaney FJ, Levy SE, Diguiseppi C, et al. (2010) Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study 7: 11551.
35. Foley Nicpon M, Doobay AF, Assouline SG (2010) Parent, teacher, and self perceptions of psychosocial functioning in intellectually gifted children and adolescents with autism spectrum disorder. Journal of Autism and Developmental Disorders 40: 1028-1038.
36. Ambikile JS, Outwater A (2012) Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam – Tanzania 1-12.
37. Kopetz P, Endowed EDL (2012) Autism Worldwide: Prevalence, Perceptions, Acceptance, Action Patricia B. Kopetz and E. Desmond Lee Endowed Department of Education of Children with Disabilities, Center for the Research and Study of Disability, Education and Culture (CRSDEC), U. Journal of Social Sciences 8: 196-201.
38. Alwi N, Harun D, Jh L (2015) Archives of Psychiatric Nursing Multidisciplinary Parent Education for Caregivers of Children with Autism Spectrum Disorders (ASD): Implications for Clinical Practice. Archives of Psychiatric Nursing 29: 5.
39. Autism in Ghana (n.d.) Retrieved September 19, 2016, from http://aactgh.org/.
40. Igwe MN, Bakare MO, Agomoh AO, Onyeama GM, Okonkwo KO (2010) Factors influencing knowledge about childhood autism among final year undergraduate Medical, Nursing and Psychology students of University of Nigeria, Enugu State, Nigeria 13: 36-44.
41. Knock J, Kline E, Schiffman J, Maynard A, Reeves G (2011) Brief Report Burdens and difficulties experienced by caregivers of children and adolescents with schizophrenia-spectrum disorders: a qualitative study 349-354.
42. Marchionini G, Teague J (1987) Elementary Students' Use of Electronic Information Services. Journal of Research on Computing in Education 20: 139-155.
43. Martos TR (2013) A Qualitative Examination of Factors Influencing Parents' Decision Making Process When Choosing or Rejecting Recommended Services for Their Child Following a Diagnosis of Autism

Spectrum Disorder.
44. Neuman WL (2014) Social Research Methods: Qualitative and Quantitative Approaches.
45. Onwuegbuzie AJ, Leech NL, Collins KMT (2010) The Qualitative Report Innovative Data Collection Strategies in Qualitative Research Innovative Data Collection Strategies in Qualitative Research. The Qualitative Report 15: 696-726.
46. Parish SL, Seltzer MM, Greenberg JS, Floyd F (2004) Economic implications of caregiving at midlife: comparing parents with and without children who have developmental disabilities. Mental Retardation 42: 413-426.
47. Peek ME, Nunez-Smith M, Drum M, Lewis TT (2011) Adapting the everyday discrimination scale to medical settings: Reliability and validity testing in a sample of African American patients. Ethnicity and Disease.
48. Ruble LA, Mcgrew JH (2007) Community services outcomes for families and children with autism spectrum disorders.
49. Russell S, McCloskey CR (2016) Parent Perceptions of Care Received by Children with an Autism Spectrum Disorder. Journal of Pediatric Nursing 31: 21-31.
50. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, et al. (2017) Saturation in qualitative research: exploring its conceptualization and operationalization.
51. Sawyer MG, Bittman M, La AM, Angela G, Harchak TF, Martin J (2010) Time Demands of Caring for Children with Autism: What are the Implications for Maternal Mental Health ? 620-628.
52. Thomas PD, Badoe EV, Akua N, Owusu V (2009) Family Perspectives of Autism Spectrum Disorder in Urban Ghana 1-7.

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