Libres *volume 35, issue 1, pages 104-128 (2025).* https://doi.org/10.32655/LIBRES.2025.1.5

Information Behaviour of Ghanaian Parents of Children with Autism Spectrum Disorder

Doris Nimako
Sam Jonah Library
University of Cape Coast, Ghana
doris.nimakoh@ucc.edu.gh

Monica Mensah Danquah
Department of Information Studies,
University of Ghana, Ghana
momensah@ug.edu.gh

Philip Kwaku Kankam
Department of Information Studies
University of Ghana, Ghana
pkkankam@ug.edu.gh

ABSTRACT

Background. In Ghana, parents of children with autism spectrum disorder (ASD) face significant information challenges, which greatly impact their ability to provide appropriate care and support for their children. Many parents struggle with limited access to reliable and culturally relevant information about ASD, including intervention strategies and available support services. These challenges prompted this study, as understanding the information needs of parents with ASD children is crucial in improving the access to credible information for enhancing the overall support system available to them.
Objectives. This study aims to identify the information needs of parents of children with ASD in Ghana; examine the sources parents used to access ASD related information; assess information usage and satisfaction among parents; seek out the challenges in accessing ASD related information; and recommend strategies to improve information access for parents.
Methods. The qualitative case study approach was employed, involving 41 parents of ASD children from two schools. Telephone and face-to-face interviews served as the data collection instrument. Data collected were analysed using the thematic approach.
Results. Key findings are that the parents exhibiting diverse information needs sought for information in various forms and from different sources. They expressed dissatisfaction with the quality and quantity of information obtained and encountered numerous challenges in accessing supportive resources to help take care of their children with ASD.
Contributions. This study recommends targeted strategies to enhance information behaviour among parents of children with ASD. Key recommendations include awareness of specific information needs, evaluating information sources,

Published by WKW School of Communication & Information & NTU Libraries,
Nanyang Technological University

balancing information needs, navigating information overload and initiating government-led ASD information.

INTRODUCTION

> *"As soon as my son and I entered the taxi, she began to withdraw her child from where I was sitting to avoid contact with my autistic child. This experience made me feel very sad, and I cried throughout the journey with my son. But I did not blame her so much but blamed the entire society for failing to provide enough education and information on children with autism especially in Ghana. If the society as a whole had, my church members would have known that autism is not infectious, and that, these kids are just born special.*"

Extracted from a preliminary conversation with a parent of a child with ASD, March 2023

This study aims to examine the information behavior patterns of Ghanaian parents of children with ASD, focusing on their specific information needs, the sources they rely on, the challenges they face in accessing adequate and reliable information and potential strategies for improvement. By understanding how these parents seek and use information, the research seeks to inform the development of targeted interventions to better support them in managing the complexities of raising children with ASD. The study is particularly important as it highlights systemic issue within the Ghanaian context, including limited resources, social stigma, and varying levels of awareness about ASD which may not be fully addressed in researches from other regions. Additionally, it addresses a significant gap by amplifying the experiences of parents, whose perspectives are often neglected in broader conversations on autism care and support. This research also provides valuable insights into the struggles faced by these families and offers actionable recommendations to improve information access and support systems, making it a useful resource for policymakers, educators, healthcare professionals and researchers dedicated to enhancing ASD care in Ghana and similar contexts.

AUTISM SPECTRUM DISORDER

ASD, first identified by Leo Kanner in 1943, is a complex neuro-developmental disorder characterized by deficits in social communication, challenging social interactions, restricted interests, and repetitive behaviours (Harris, 2018). ASD is a range of complicated brain development diseases which altogether, are referred to as autism spectrum disorder. It is characterized by its spectrum nature, indicating a broad range of symptoms, severity levels, and varying degrees of impairment (Pino et al., 2024; Andreou, Lymperopoulou & Aslanoglou, 2024). Initially, Kanner observed 11 children who preferred solitude, exhibiting severe social and language impairments, alongside repetitive behaviours (Archibald, Dwyer & Bury, 2024).

According to Autism Speaks (2018) individuals who receive substantial support are more likely to experience symptoms that are similar to those of other developmental disorders, such as language delay and non-verbal social disorder. Most children with this disorder are challenged with responsiveness to peers and their initiation sense is affected (Acheampong, 2024). Common ASD signs and symptoms include inconsistent eye contact, social withdrawal, delayed speech and language development, unrelated responses to questions, sensitivity to routine changes, repetitive language or phrases, and difficulty maintaining conversations (Hirota & King, 2023). Despite advancements, ASD diagnosis remains highly challenging due to its diverse and varied clinical presentations (Hyman et al., 2020). Nevertheless, studies reveal a significant gender disparity in ASD diagnosis, with boys being more frequently diagnosed than girls (Bougeard, Picarel-Blanchot, Schmid, Campbell & Buitelaar, 2024; Saure, Castrén, Mikkola & Salmi, 2023).

Although research has shown higher prevalence rates of ASD, these findings have been well-regulated. However, it is unknown how common it is in many low and middle income nations, including Ghana (Acheampong, 2024). Yet, globally, ASD is estimated to affect approximately one in 100 children and 1% of the population, according to the World Health Organization (2020). In Ghana, prevalence rates are estimated at 1.4% among children under 18 and one in 52 children (Ghana Autism Awareness, Care and Training Center, 2018).

Over the years, literature (e.g. Nicholas et al., 2008; Bougeard, Picarel-Blanchot, Schmid, Campbell & Buitelaar, 2021; Prevalence of autism spectrum disorder and co-morbidities in children and adolescents: A systematic literature review. Frontiers in psychiatry, 12, 744709.2021; Falck-Ytter, Kleberg, Portugal & Thorup, 2023) largely refers to children with ASD as ‘autistic’, or ‘children with autism’ or ‘autistic children’. Consistent with literature, this study adopts the terms "autistic children", "children with autism" and "autism spectrum disorder (ASD)” interchangeably.

LITERATURE REVIEW

According to Baffoe (2013), individuals with ASD in Ghana often face misconceptions and stereotypes, leading to prejudice, discrimination, and ultimately, denial of their rights and access to resources. Consequently, the relevance of people, especially those with any type of disability, in accessing and using information to help in their education and successful participation in any form of development has been emphasized especially in today's information and knowledge society (Han, Zhong & Hansen, 2024a). In fact, due to the emotional, psychological, and physical stress associated, ASD has become a global concern (Mcfayden et al., 2024), and the need for professional information to support autistic children and their families is a global priority (Suvarna, Farrell, Adams, Emerson & Paynter, 2024). Like all other parents, there is a need for continuous search of information by parents with autistic children to assist their children live a fulfilling life. This implies that an important role played by every parent with autistic child is to be an advocate for their child. The role could become a lifelong journey that would require different skills and information depending on the child’s needs.

According to Georgiou and Spanoudis (2021), parental involvement typically encompasses various activities such as participating in school events, helping with homework, attending parent-teacher conferences, and being actively engaged in a child's learning process. Research demonstrates that parents of children with ASD use a diversity of coping methods to alleviate the psychological pain associated with raising a kid with ASD (Mcfayden et al., 2024; Mansour, 2021). In other words, given that ASD requires parents to make ongoing efforts to manage its implications when a child is diagnosed of autism, the parents will have to seek for continuous knowledge from multiple sources until the need is satisfied or a goal is achieved (Bashir, Tariq, Khan, Ali & Azman, 2023). So, when parents have difficulties in finding and accessing information for their autistic children, it will result in their inability to meet their children’s needs (Lord et al., 2022), and hence the need to access their information behaviour is critical.

The concept of information behaviour originated in the 1960s even though it was applied in the late 1990s (Khan & Shafique, 2011). According to Bates (2010), throughout the past 50–60 years, three different terms had been used interchangeably to refer to research on information behaviour—usage studies; information seeking, or information need and uses; and information behaviour. These days, it appears that the phrase, information behaviour is the most popular and pervasive. The term information seeking behaviour is defined as an individual's way and manner of gathering and sourcing for information for personal use, knowledge updating and development (Zimmerman & Shaw, 2020). Therefore, information behaviour involves exchanging information with people either verbally or in writing form, using any information resource, and passively consuming information like watching TV commercials or receiving unsolicited email. Information literacy has been significantly impacted by the centrality of information behaviour and its development among people, including parents with ASD children (Orlu, 2016).

Scholars employ various models, often diagrammatic, to describe information behaviours. The *Wilson's Model of Information Behaviour* (1999, 2000, 2010) is particularly influential, with applications in studies by Sabelli (2023), Soong, Au, Kyaw and Theng (2020), and Nsibirwa and Kankam (2018) among others.

This study adopts Wilson's Model to understand the information behaviour of parents with autistic children. According to Wilson (2000), information seeking behaviour arises from perceived needs, influenced by personality, roles, and surroundings. Users demand information through formal (libraries, information centres) and informal sources. Successful information retrieval satisfies the perceived need, while failure prompts repeated searching. Wilson's (2010) model highlights the social aspect of information behaviour, when individuals share recovered information with others, demonstrating reciprocation as a vital component of human interaction (Wilson, 2010). Parents with autistic children evaluate information through value judgments, deciding whether to utilize or share it with others (Case & Given, 2016). Wilson's (2000) model aligns with this research's objectives, focusing on information users (parents with autistic children), their needs, sources, and actions when information is unavailable. The model provides a comprehensive understanding of the complex information behaviour exhibited by parents navigating the challenges of autism. Key components of Wilson's Model relevant to this study include: (1) information needs: perceived gaps in knowledge or understanding driving information seeking; (2) information sources: formal and informal channels utilized to satisfy information needs; (3) information utilization: application of retrieved information to meet needs; and (4) reciprocation: sharing information with others. By applying the Wilson's Model, this study explains the information behaviour of parents with ASD children, informing strategies to support their information needs.

Generally, parents with ASD children have been noted to have difficulty in terms of accessibility to the resources and information they require to provide comfortable lives for their children (Alothman, Ebrahim & Gadelrab, 2024; Papoudi, Jørgensen, Guldberg & Meadan, 2021). Nonetheless, quite a number of studies have examined the information behaviour of parents of children with autism, particularly among scholars in the library and information fields (e.g. Bozkurt, Uysal & Düzkaya, 2019; Chavez & Sabelli, 2020; Zaytun, 2017). For instance, Bozkurt, Uysal and Düzkaya (2019) from Turkey examined the inconvenience of caregivers of ASD children by scrutinizing the coping mechanisms when facing stress that comes with caregiver burden. Their study employed 131 parents with children who were found in seven different educational settings in Istanbul, using the Ways of Coping Questionnaire and the Caregiver Strain Index as end measures throughout the data collection.

Likewise, the information behaviours of parents of autistic children were studied by Chavez and Sabelli (2020), and it was revealed that there are challenges in finding trustworthy information sources. To make up for the absence of trustworthy information, parents with autistic children generally exchanged information with their closest friends and family members and on social media, particularly with peers going through similar experiences. In Syria, Zaytun's (2017) study of 5,182 parents with ASD children to determine their information needs as well as the differences in those needs depending on the child's sex, age, and severity of autism disorder, it revealed that the level of needs of parents of autistic children was high and there were significant differences statistically in the way they assessed their children's needs based on sex variables. The study in the end recommended an increase in specialized center for the care of children with autism. Lastly, in 2016 Martinovic and Stricevic conducted interviews with 13 parents whose children have ASD and discovered that parents do not typically have enough knowledge on ASD and its potential effects on the child's behaviour. This according to Martinovic and Stricevic (2016)'s study can lead to delayed and poorer identification of the disorder's symptoms, therapy and rehabilitation.

Improving support for families affected by ASD in Ghana necessitates understanding their information seeking behaviours. This is particularly critical given the country's limited speech and language therapy services, high financial burden, and the stigma and emotional distress experienced by parents of autistic children. Surprisingly, little research has explored the experiences of Ghanaian parents seeking information to support their children with ASD. The complexities surrounding ASD have devastating consequences for children's overall welfare, hence demanding urgent attention. Parents bear the responsibility of finding, evaluating, and utilizing vital information despite facing significant challenges. However, they lack access to sufficient resources, hindering effective decision-making. To optimize their child's quality of life and navigate the disorder, parents require accurate, pertinent, and timely information.

The field of information science has developed numerous models to comprehend how individuals interact with their information environment. However, despite the vast global literature on ASD (Autism Speaks, 2018; Depape & Lindsay, 2014; Lwoga & Mosha, 2013), research in Ghana remains scarce (Gyesi, 2020; Mangortey, 2019; Lamptey, 2017). Notably, studies focusing on ASD related information behaviour are even more limited (Kankam & Baffour, 2023). Ghanaian research has primarily explored information behaviour among diverse population groups, overlooking the specific needs of parents with autistic children. Given the significant presence of autistic children in Ghana, it is crucial to address this knowledge gap. This study therefore investigates the information behaviour of Ghanaian parents with ASD children, with the aim of proposing strategies for improvement.

RESEARCH QUESTIONS

This study pursues to answer the following questions:

1. What are the information needs of parents of children with ASD in Ghana?
2. What are the information sources used by parents of children with ASD in Ghana?
3. What are the information access barriers to parents of children with ASD in Ghana?
4. How satisfied are parents of children with ASD in Ghana with the information they receive regarding their child's condition and care?
5. What strategies can be employed to enhance information access for parents of children with ASD in Ghana?

METHODOLOGY

Study Approach

This study employed a qualitative research approach, wherein a multiple case design was considered as an appropriate research design to purposively collect data from parents who had enrolled their children in autism care centres in Ghana. At the time of this study in 2023, Ghana had 35 special schools catering to children with disabilities, including autism. However, only two institutions out of the 35 exclusively focused on autism care: Autism Awareness Care and Training Center (AACT) and Autism Compassion Africa (ACA). These institutions served as the study's case sites. The study population consisted of parents with children enrolled in the AACT and ACA. The total population comprised 41 parents from both schools, who were all invited to participate in the study to achieve a high response rate.

Data Collection Instruments

Both face-to-face and telephone interviews served as the data collection instruments. Data was collected within a period of one month and six days spanning from 4 August to 10 September 2023. A semi-structured interview guide (see Appendix B) was used for collecting data from the respondents. Parents were interviewed in person at school premises, when they came to drop off and or pick up their wards, at homes or offices. Others participated via scheduled telephone interviews. The interviews were primarily conducted in English (n=27), with a smaller subset conducted in Twi (n=8), a local Ghanaian dialect, and subsequently translated into English. All responses were recorded. Individual interviews with the 35 participating parents ranged from 22 to 40 minutes, averaging 25 minutes. To ensure accurate data collection, face-to-face interviews were recorded using a tape recorder, while telephone interviews were recorded using the mobile device used for the call. Using thematic analysis, the study identified key themes and sub-themes that emerged from the parents' narratives as well as patterns that provided insight into the experience of parents.

Ethical Considerations

Prior to data collection, the researchers obtained permission from the management of both AACT and ACA for the case study. Parents of the Children with ASD were fully informed about the study's objectives, purpose, and intended use of their responses. Participation was voluntary, and parents could withdraw at any time. Participants, by completing the consent form (see Appendix A), were assured of anonymity and confidentiality of their responses and personal information. The ethical clearance letter (from an ethics committee (see Appendix C) further strengthened the assurance that the study was approved.

Data Analysis

This study employed thematic analysis to identify patterns and themes within the collected data (Braun & Clarke, 2006). The data analysis process involved five stages, namely, the data description stage, coding stage, theme identification stage theme, refinement stage, and theme verification. At the data description stage, the data obtained were carefully read and re-read to ensure familiarity with the content. Thereafter, at the coding stage, initial codes were generated through an inductive approach, allowing themes to emerge from the data. Subsequently, at the theme identification stage, the codes generated were then categorized into potential themes and further analysed to identify patterns and relationships. The themes were refined and defined through an iterative process, ensuring a comprehensive understanding of the data at the refinement stage. Finally, at the verification stage, the identified themes were verified through a review of the original data, ensuring accuracy and validity. The thematic analysis revealed four primary themes, that highlighted needs, sources, usefulness and challenges faced by parents of children with ASD in Ghana.

RESULTS

Of the 41 targeted respondents, 35 parents participated in this study gave a response rate of 85%. Among the 6 parents who couldn't participate, one had travelled abroad with the child, 3 cited busy schedules despite prior appointments, and two had withdrawn their children from the school. As presented in Table 1, for anonymity and confidentiality, the respondents are represented by self-generated pseudonyms. The respondents comprised 26 females and 9 males who were parents of the ASD children.

Information Needs of Parents With Autistic Children

This study's first objective aimed to investigate the diverse information needs of parents with ASD children. The findings generally highlight the importance of addressing parents' information gaps to effectively support their ASD children. The study found that parents of ASD children require various types of information to support their children's development. The study's results indicate that parents prioritize health, nutrition, and autism-specific information to provide optimal care for their children. All parents interviewed reported diverse information needs, with the most popular being; health-related issues, nutrition and dietary recommendations and information on ASD. Additionally, parents require information on communication tools to understand their children’s needs, educational resources and financing opportunities. One of the respondents for instance, said:

> *“I always look out for information on financial aids for my child, but I am yet to find one. I know that such assistant is available in some European countries. The financial burden is just too much. Medical expenses incurred in the care of my child coupled with, transportation costs, and the cost involved in her going to school, as well as food and nutrition is very expensive. I pray the government and other agencies will come to our aid.” (*Akosua, August 5, 2023; 11am)

Some other responses from the parents on their information needs are:

> *“My son has communication challenges. Some information needs I look out for is on communication tools, speech assistance software, sign language and its meanings. I always want to keep up to date with communication tools to assist my autistic child in expressing himself. Again, I look out for what will help understand him better and know the type of therapy he needs.” (*Desmond, August 8, 2023; 2:34pm)
> *“I look out for information on medical services especially on my child’s seizures. His seizures compel me to search for information from everywhere possible on his health. So, for me health information on my child’s condition is my topmost priority.”* (Ohemaa, September 10, 2023; 9:30 am)

Information Sources Used by Parents With ASD Children

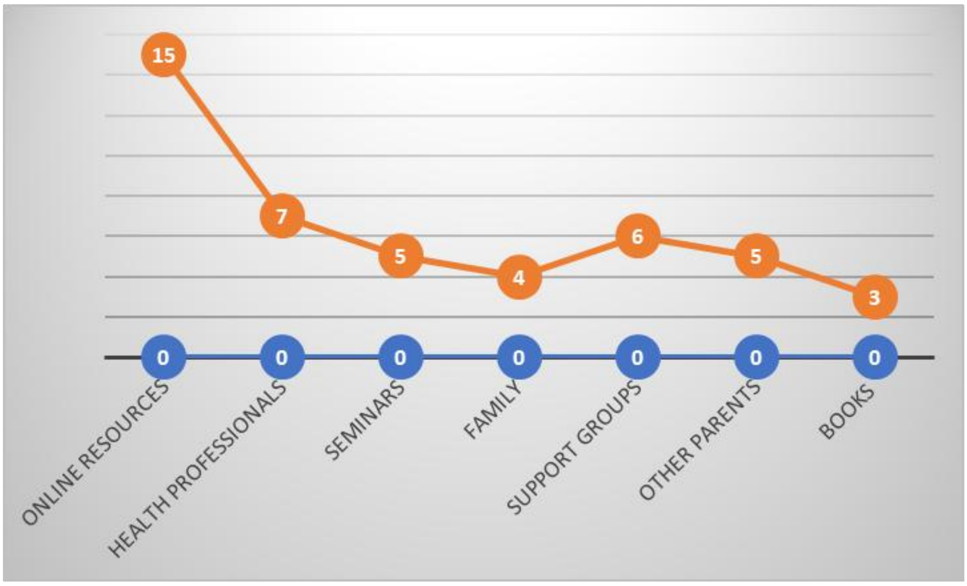
To effectively manage the challenges of raising autistic children, understanding the sources of information used by parents is crucial. The findings highlight the importance of accessible and reliable information sources for parents of autistic children. The study found that parents

Table 1. Respondents characteristics (n=35)

Respondent	Gender	Age	Interview		
			Mode	Date	Time
Mavis	Female	36	Face-to-Face	Aug 31, 2023	11:00am
Jason	Male	45	Face-to-Face	Aug 17, 2023	3:20pm
Esther	Female	41	Telephone	Aug 26, 2023	6:00pm
Ivy	Female	32	Face-to-Face	Aug 29, 2023	10:00am
Eva	Female	43	Face-to-Face	Aug 4, 2023	10:00am
Bernice	Female	31	Face-to-Face	Sept 5, 2023	3:30pm
Desmond	Male	37	Face-to-Face	Aug8, 2023	2:34pm
Emmel	Male	42	Face-to-Face	Aug 7, 2023	11:45pm
Chris	Male	32	Face-to-Face	Aug 5, 2023	3:00pm
Akua	Female	36	Face-to-Face	Aug 9, 2023	3:30pm
Alfred	Male	45	Face-to-Face	Aug 14, 2023	3:40pm
Magaret	Female	46	Face-to-Face	Sept 9, 2023	10:45pm
Harriet	Female	48	Telephone	Aug 12, 2023	7:00pm
Abraham	Male	34	Telephone	Aug 20, 2023	6:15pm
Kesewaa	Female	38	Face-to-Face	Sept 7, 2023	11:30pm
Esi	Female	28	Telephone	Aug 21, 2023	12:00pm
Oteng	Male	39	Face-to-Face	Aug 30, 2023	3:15pm
Monica	Female	44	Face-to-Face	Sept 7, 2023	3:30pm
Doris	Female	47	Telephone	Aug 18, 2023	10:00am
Mary	Female	35	Face-to-Face	Aug 10, 2023	11:00am
Aba	Female	37	Face-to-Face	Aug 22, 2023	3:00pm
Rita	Female	41	Telephone	Aug 23, 2023	9:00pm
Ohemaa	Female	40	Telephone	Sept 10, 2023	9:30am
Beatrice	Female	32	Face-to-face	Sept 1, 2023	4:00pm
Agnes	Female	28	Telephone	Aug 19, 2023	8:00pm
Gifty	Female	36	Face-to-Face	Aug 11, 2023	3:10pm
Cynthia	Female	29	Telephone	Aug 27, 2023	7:00pm
Frank	Male	27	Telephone	Sept 3, 2023	6:00pm
Owusu	Male	42	Telephone	Aug 28, 2023	4:30pm
Esther	Female	38	Face-to-Face	Aug 30, 2023	11:00am
Abigail	Female	35	Telephone	Aug 15, 2023	7:00pm
Dorcas	Female	37	Telephone	Sept 6, 2023	9:00am
Akosua	Female	29	Telephone	Aug 5, 2023	11:00am
Abena	Female	30	Telephone	Aug 5, 2023	6:00pm
Ama	Female	35	Face-to-Face	Sept 4, 2023	3:15pm

Source: Field data (2023)

gather information from diverse sources to obtain knowledge, direction, and support. All respondents identified various information sources, including online resources, health professionals, support groups, family, books, seminars, and fellow parents (see Figure 1). Notably, the most preferred information sources consulted by parents were online resources, health professionals and support groups. Conversely, books on special needs were the least consulted source of information, cited by only three of the parents. These are reflected in some of the responses from the parents:



Source: Field data (2023)

Figure 1. Information sources consulted by parents of children with ASD

"*My preferred places to find information includes online sources, social media groups, healthcare professional and autism specific organisations."* (Alfred, August 14, 2023, 3:40pm)
"Any time I need information or clarification on something urgent for my boy, I quickly go to google to search. I can tell you that I also get what I want, and it works for me." (Dorcas, September 6, 2023; 9:00am)

"Well for me I consult a number of places for information, but my first stop is to call my child's doctor and find out what I need to do before anything. Sometimes when I call and he doesn't pick up because maybe he is busy and what I need is also very urgent, then my next stop is my mum because she knows a lot about what to do for my girl in times of difficulty." (Magaret, August 9, 2023; 10:45am)

"I mostly rely on my family members for information. Whatever information I get from them works for my child." (Jason, August 17, 2023; 3:20pm)

"You know because of my child's situation I consult anything and everything I think can give me information on anything I need as far his health and wellbeing is concerned. Hmmm! You know I sometimes went for conferences, seminars, and workshops I came across which were offering care to children with autism like my girl." (Harriet, August 12, 2023; 7:30pm)

"I prefer information from online resources, books and publications, therapists and specialists, and health institutions." (Agnes, August 19, 2023; 8:00pm)

"Anytime I need any information I speak to her doctors, but I also sometimes ask other parents who are also in my situation for advice." (Doris, August 18, 2023; 10:00am).

I mostly consult his school, the internet as well as some training organized online. I also join groups which are made up of other parents who have children with ASD to learn and seek for solutions for my child." (Aba, August 22, 2023; 3:00pm)

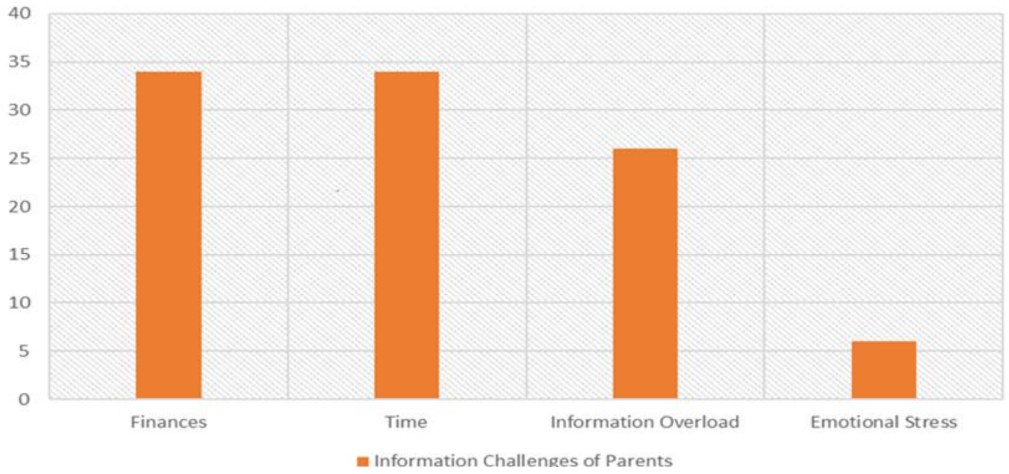
Information Satisfaction Among Parents with ASD Children

Regarding their satisfaction with the obtained information, majority of parents (35) reported being unhappy with the information they obtained, emphasizing the need for improved resources and guidance. Only five parents were satisfied with the information they received, while 30 expressed dissatisfaction and frustration highlighting a significant gap in meeting their informational needs. The parents cited inadequacies in guiding and supporting their children with ASD, difficulties in interpreting the varied information provided, and the struggle to distinguish reliable and applicable advice due to information overload and contradictory guidance. Most parents (n=30) found it challenging to interpret information from their preferred sources, leading to difficulties in making informed decisions. Some comments from some of the parents who were generally not satisfied with information obtained are:

> *"Well, I am a bit satisfied. As I said what works for one child may not work for another, so although information resources can be helpful, they should not replace the guidance and expertise of qualified healthcare professionals, therapists, educators, and specialists who can provide personalized assessments and recommendations. Sources especially those online can be misleading and might not work for my child, and at this point I do not need wrong information for my child as anything wrong might cause a lot of problems for her and myself."* (Owusu, August 28, 2023; 4:30pm*)*
>
> *"Yes, I am fairly satisfied with the information retrieved. My satisfaction is however backed by what I retrieve online, and it is not always to the point or directed to what I need exactly."* (Ama, September 4, 2023; 3:15pm)
>
> *"I am not always satisfied with the type of information I receive when I search through the available sources at all. First, there is so much available such that anytime I search, I get confused as to what to even belief or trust to apply on my child. So, for me satisfaction with information from books and the internet is a no. I will rather rely on my parents who are well experienced or my doctors."* (Esi, August 21, 2023; 12:00pm)

That notwithstanding, one of the parents who expressed some level of satisfaction with the information retrieved from their preferred sources, for instance, replied:

> "*Information retrieved are mostly very useful. In fact, 9/10 information I retrieve from my preferred sources are always very useful. Every child with autism has certain similar reactions. So, mostly parents will share how they were able to control theirs, and when I try it works for me too.*" (Frank, September 3, 2023; 6:00pm)
>
> *"I don't believe in information from any other person than my doctors for my child. Yes, I sometimes go online to generally look for information on autism, but because I listened and followed all instructions given by doctors. Now my child is doing very well and I am always very grateful to the health workers for their time and patience, so I trust them than any other source."* (Akua, August 9, 2023; 3:30pm)
>
> *"Autism is a complex and diverse spectrum, and there are varying perspectives and opinions within the autism community and among experts. Providing a balanced and comprehensive overview of the topic can be challenging, as different sources may present different viewpoints. I do not have access to real-time information or the ability to browse*



Source: Field date (2023)

Figure 2. Information challenges of parents of children with ASD

> *the internet for the latest developments, news, or research related to autism. Therefore, I may not be aware of recent breakthroughs or changes in the field."* (Emmel, August 7, 2023; 11:45pm)

Challenges in the Search for Information by Parents with ASD Children

The fourth study objective aims to identify challenges faced by parents of children with ASD in accessing credible information. All 35 respondents reported encountering various challenges while searching for information on their child's well-being. Parents cited multiple challenges, including information overload, time constraints, financial issues, and emotional stress (see Figure 2). Financial difficulties and time constraints emerged as the primary obstacles to information access, affecting parents' ability to support their children with ASD. As one parent noted:

> *"My major challenge is financial constraints. It is very expensive caring for my child and again the means to get access to internet is also not cheap here in our country. To be honest, it is a struggle".* (Bernice, September 5, 2023; 3:30pm)

One of the parents also said:

"We often have busy schedules with therapy sessions, school activities, and caregiving responsibilities, leaving limited time for research. Also, the sheer volume of information available online can be overwhelming, making it challenging to identify reliable and relevant sources. In addition, understanding complex medical or educational terminology can be difficult for us without a background in the field. Again, managing the emotional aspects of having a child with ASD can make it challenging to focus on research effectively." (Abraham, August 20, 2023; 6:15pm)

In another breath, quite a number of the parents also mentioned information overload as an information behaviour challenge. According to one of the parents, for instance:

> *"Sorting through conflicting or inaccurate information on the internet can be confusing and frustrating. Also, finding information that directly addresses your child's unique needs and challenges can be difficult, as ASD is a spectrum disorder with varying characteristics. Again, we encounter obstacles in locating and accessing specialized*

> *therapies, interventions, or support services in their area, and lastly, the cost of therapies and interventions can be a significant challenge for many families."* (Ivy, August 29, 2023; 10:00pm)

DISCUSSION

This study highlights Ghanaian parents' extensive information needs regarding ASD, motivated by desires to understand and support their children's development.

To start with, the study findings emphasise the comprehensive information needs of Ghanaian parents with children with ASD, spanning communication tools, health, education, finances, and nutrition. The quest for diverse information needs stems from the parents' desires to have a fair knowledge of their child's requirements and needs. As Dini (2022) put forward, empowering parents with accurate information enables them to cultivate supportive environments, fostering autonomy and optimal development (Dini, 2022). Indeed, inadequate access to quality information poses significant risks to the well-being and quality of life for children, parents, and families (Çolak & Kahriman, 2023). As anticipated, the parents' concerns regarding their child's care align with existing research (Rooney et al., 2023). The findings of this study, align with Beesoon's (2015) discovery that parents' information needs diverge in purpose, highlighting autistic children's diverse support requirements. Further, consistent with the findings of Papoudi, Jørgensen, Guldberg and Meadan (2021), parents seek information on social, family, monetary, childcare, professional, and community assistance.

Furthermore, the study's findings on information sources consulted by parents of children with ASD in Ghana emphasise the importance of recognising and leveraging diverse sources and support networks to empower these parents. The study findings collaborate with Severs, Noel, Talley and Getch (2020), Mansour (2021), Holly (2023), Alper (2023), Daskalakes, and Cahill (2024), who stressed parents' utilization of multiple formal (books, articles) and informal (friends, family) information channels to help support their children with ASD. For instance, parents of children with ASD have been noted to be consulting various sources, including online resources, health professionals, family, support groups, books, and seminars, with each family's unique needs dictating their preferred sources (Severs, Noel, Talley & Getch, 2020). The study also confirms the significance of support from fellow parents through parent support groups and mentor-mentee relationships (Lee, Terol, Yoon & Meadan, 2024; Meadan, Stoner & Angell, 2010). As Dolan, Žegarac and Arsić (2020) suggested, lacking primary family support would substantially hinder individuals with special needs from overcoming social obstacles.

Additionally on information usage and satisfaction, this study highlights the challenges parents of autistic children face in accessing valuable information that can affect their decision-making and ability to support their children effectively. Majority of the parents who served as respondents expressed dissatisfaction with the accessed information, deeming it inadequate for their child's needs. Conversely, high satisfaction levels would indicate that parents perceive the information as relevant, practical and beneficial in addressing their child's unique challenges. The usefulness and satisfaction derived from information by parents of ASD children are crucial, and are influenced by factors such as accuracy, relevancy, timeliness and accessibility (McCrimmon & Gray, 2021). Parents of children with ASD often confront significant obstacles in accessing credible and comprehensive information due to the complexity of the condition, conflicting data, and limited specialized services (Han, Zhong & Hansen, 2024b). The sheer volume of available information can exacerbate the search process, making it difficult for parents of children with ASD to discern accurate and reliable sources (McFayden, Bristol, Putnam & Harrop, 2024). With conflicting or outdated information pervasive across various platforms, including books and online resources, distinguishing between trustworthy and untrustworthy sources poses a considerable challenge, particularly for those lacking specialized expertise as disclosed by the respondents in this study.

This study also reveals significant challenges faced by parents of children with ASD, including information overload, emotional stress, time constraints, and financial difficulties. Notably, financial constraints, particularly those resulting from screening and treatment costs, posed unexpected hurdles despite Ghana's National Health Insurance Scheme. Since ASD treatment is excluded from the scheme, parents must bear all expenses, including screening, checkups, and treatment. Beyond these direct costs, raising a child with ASD incurs additional financial burdens, such as transportation, childcare, career adjustments, and increased household expenses. Consequently, parents often struggle to disclose their financial problems, which can have long-term, detrimental effects on the family. This finding aligns with previous researches (Anderson, Roux, Rast, Garfield & Shea, 2024; Lynch et al., 2023; Seeridaram & Rashid, 2023), highlighting financial constraints as a major challenge for parents of autistic children. Additionally, parents of children with ASD often face challenges navigating the complex online information landscape, where conflicting and inaccurate sources abound (Carter et al., 2023). The vast array of available sources makes it difficult for parents to distinguish reliable information, exacerbating their information-seeking struggles. Furthermore, as revealed in this study, parents of ASD children encounter additional time management pressures due to their child's intensified care, supervision, and support needs. This includes devoting time to collaborate with educators, attend meetings, and support their child's learning at home. These demands can overwhelm parents (Grant, Rodger & Hoffmann, 2015; Filipova, Galevska Jovčvska, Torte-Chiche & Jankova, 2024), who highlight the emotional toll of information overload on parents of autistic children. Notably, possessing ample information does not guarantee satisfaction; rather, it underscores the importance of accessible, reliable, and tailored information to meet parents' unique needs.

CONTRIBUTIONS

Strategies to Improve Information Behaviour of Parents With ASD Children in Ghana

To enhance the information behavior of parents with ASD children in Ghana, this study proposes the following strategies intended to serve as key recommendations for a tailored approach:

- Awareness of Information Needs

Effective information-seeking begins with parents' awareness of their specific needs, enabling targeted searches for health, communication, financial, dietary, and educational information. Three key triggers are proposed to drive parents' information seeking, namely, "push forces" (critical events or circumstances, such as health emergencies or communication challenges), "frequency" (regularly seeking information to address ongoing demands), and "medium" (accessible communication channels). Recognizing these triggers empowers parents to proactively seek relevant information, addressing their dynamic needs and improving their information behaviour patterns. By understanding what drives their information seeking, parents can navigate resources more efficiently, ultimately supporting their child's unique requirements.

- Evaluating information sources

To optimize information seeking, parents of children with ASD should consider the influence of various information sources on their decision-making and behaviour. This influence is shaped by three key factors: cost, accessibility, and applicability. Parents must carefully weigh the cost implications of each source, selecting options that align with their needs and resources. Accessibility, or ease of access, is also crucial, as parents must prioritize sources that are readily available and user-friendly. Ultimately, parents must choose sources that are comfortable and suitable for them, ensuring informed decision-making that benefits their child's unique needs.

- Balancing information needs

To enhance information-seeking, parents of children with ASD should consider the applicability of their chosen sources. We recommend a tiered approach, utilizing primary sources (medical experts, online resources, teachers, and family members) as the initial point of contact. When primary sources are insufficient, secondary sources (support groups, conferences, seminars, and training) can provide cutting-edge research, treatments, and educational insights. Although secondary sources offer valuable opportunities for networking with other parents, accessibility limitations may hinder participation. Therefore, parents should prioritize practical, readily available, and reliable sources, balancing information needs with personal circumstances.

- Navigating information overload

Parents of children with ASD often face information overload, leading to emotional stress, and financial strain. To overcome this, parents of children with ASD in Ghana, can implement targeted strategies. First, they could set specific information seeking goals, focusing on relevant and reliable sources, such as the Autism Society, Autism Speaks, or peer-reviewed journals. They could also utilize online filters, aggregators, and bookmarking tools to streamline search results. These parents could also schedule dedicated information seeking sessions, allocating 30 minutes daily or two hours weekly, to maintain consistency. Leveraging mobile apps, such as Autism iHelp, Autism Tracker, or Toca Life, could also help for convenient access to reliable information. Further, delegation of some tasks to family members or support networks, could encourage collaborative information gathering. Connection with support groups, online forums, or social media communities to share experiences and receive emotional support could also be very helpful. Parents of children with ASD could also explore free or low-cost resources, such as public libraries, online webinars, or local workshops on autism and the spectrum at large. They could also consider consulting with information specialists, librarians, or ASD experts for personalized guidance on their information needs. It is envisaged that by implementing these strategies, parents of children with ASD can effectively navigate information overload, ensuring informed decision-making and improved well-being for their child.

- Government-led ASD information initiatives

The government and agencies in Ghana can play a pivotal role in facilitating access to information for parents of children with ASD. Firstly, establishing a national ASD database and resource center can provide a centralized hub for information dissemination. The Ghana Health Service and Ministry of Health can collaborate with organizations like the AACT and the Ghana Autism Society to develop and disseminate informational materials, such as guidelines, brochures, and websites. Regular workshops, seminars, and conferences can also be organized to educate parents and caregivers.

Further, to enhance information accessibility, government agencies can leverage technology, such as mobile apps and online platforms. For instance, developing an ASD-specific app, like the “Ghana ASD Guide” can provide parents with localized resources, support groups, and expert advice. The Ministry of Education can integrate ASD information into school curricula, promoting inclusion and awareness. Partnerships with international organizations, such as the World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF), can facilitate knowledge sharing and best practices. Furthermore, allocating funds for ASD research and initiatives can inform policy decisions and improve service delivery. By implementing these measures, the government and agencies can empower parents of ASD children in Ghana with timely, accurate, and relevant information, ultimately enhancing their children's well-being and quality of life.

Study Implications

The findings of this study have significant practical implications for improving the information behaviour pattern for parents of children with ASD in Ghana.

For the parents, the study’s identification of information needs provides useful information for the development of targeted resources, addressing specific knowledge gaps and concerns. This will enable the parents to access relevant information, make informed decisions, and optimise their information seeking strategies Moreover, recognizing the challenges faced by the parents will facilitate support systems, addressing emotional and psychological stress.

Further, the study findings on training programs that are tailored towards enhancing the understanding of ASD information needs could lead to better support and care for children with ASD. Tailored resources and support services can be developed to address specific parental concerns, and healthcare providers can guide parents in navigating reliable information sources.

Besides, the study's recommendations could help the policy makers and government to ensure the allocation of resources for ASD information initiatives. Government agencies can develop targeted programs to address information disparities and inequalities, and collaborate with international organizations to facilitate knowledge sharing and best practices.

Information service providers would also benefit from the study's findings, which guide the development of ASD-specific information resources that address local needs. Information providers can optimize dissemination strategies, increase accessibility and usability, and evaluate existing resources to inform improvements.

Finally, this study's findings could guide future research agendas and direction for exploring ASD information needs in diverse contexts. The methodologies developed can be replicated, facilitating comparative studies, and interdisciplinary collaborations can be fostered through the integration of insights from healthcare, education, and information science.

Limitations of Study

A key limitation of this study is its reliance on a qualitative case study with a small sample which may not fully represent the diverse experiences of all Ghanaian parents of children with ASD, limiting the generalizability of the findings. Future research could hence focus on expanding the sample size and geographic scope, incorporating diverse stakeholder perspectives, and exploring longitudinal and digital approaches to better understand the information behaviour of parents of children with ASD in Ghana.

CONCLUSION

The sheer volume of information available online and offline can be overwhelming, particularly for parents of children with ASD seeking accurate and reliable guidance. The lack of awareness and information about autism extends beyond parents to the broader public, underscoring the need for targeted awareness campaigns and accessible resources. Parents often embark on a frantic search for knowledge after diagnosis, relying on personal experiences and anecdotal evidence due to insufficient information. However, given ASD's complexities, trusted information should come from multidisciplinary sources. Therefore, medical, educational, and relevant institutions must provide verified, trustworthy, and relevant information, making it freely accessible and shareable. By addressing these information gaps, we can empower parents, caregivers, and the public, ultimately enhancing the care and support for individuals with ASD.

REFERENCES

Acheampong, J. O. (2024). Caring for autism in Ghana: Exploring the psychological impact and coping strategies of caregivers. *Cogent Education*, *11*(1), 2374686.

Alothman, A. A., Ebrahim, M. T., & Gadelrab, H. F. (2024). Challenges, practices, and impact of COVID-19 among mothers of children with autism spectrum disorder in cities and remote areas in Saudi Arabia. *Research in Developmental Disabilities, 148*, 104718.

Alper, M. (2023). *Kids across the spectrums: Growing up autistic in the digital age*. MIT Press.

Anderson, K. A., Roux, A. M., Rast, J. E., Garfield, T., & Shea, L. (2024). Low-income households of children with autism and the economic safety net. *Academic Pediatrics, 24*(2), 258-266.

Andreou, G., Lymperopoulou, V., & Aslanoglou, V. (2024). Developmental Language Disorder (DLD) and Autism Spectrum Disorder (ASD): Similarities in pragmatic language abilities. A systematic review. *International Journal of Developmental Disabilities, 70*(5), 777-791.

Archibald, D., Dwyer, P., & Bury, S. M. (2024). Current debates on autism language preferences: An overview. *The Palgrave Encyclopedia of Disability,* 1-13.

Autism Awareness, Care, Training – AACT. (2018). Autism Awareness, Care, Training - AACT (Ghana). *Autism Awareness Centre Inc.* Retrieved October 22, 2024, from https://autismawarenesscentre.com/resources/autism-awareness-care-training-aact-ghana/

Autism Speaks. (2018). *Autism Speaks demands an urgent, new response to the autism epidemic as CDC updates prevalence estimates*. New York NY. Retrieved February 12, 2023, from http://www.autismspeaks.org/about-us/press-releases/cdc-autism-prevalence-1-88-autism-

Baffoe, M. (2013). Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Education and Social Research*, *3*, 187–198.

Bashir, A., Tariq, A., Khan, A., Ali, I., & Azman, A. (2023). The challenges and coping strategies of single mothers caring for children with special needs: Experiences from Kashmir, India. *Asian Social Work and Policy Review, 17*(1), 15-26.

Beesoon, G. (2015). The information seeking Behaviours of Parents of Children with Autism Spectrum Disorders. Available at: https://era.library.ualberta.ca/items/991f442c-74aa-47c8-b082-eb60ecd29b68

Bates, M. J. (2010). Information behavior. *Encyclopedia of library and information sciences*, (5 ed.), 2074-2085. Retrieved February 12, 2023, from https://infocom.hyperlib.sjsu.edu/wp-content/uploads/2019/07/information_behavior_bates.pdf

Bougeard, C., Picarel-Blanchot, F., Schmid, R., Campbell, R., & Buitelaar, J. (2021). Prevalence of autism spectrum disorder and co-morbidities in children and adolescents: A systematic literature review. *Frontiers in psychiatry*, *12*, 744709.

Bougeard, C., Picarel-Blanchot, F., Schmid, R., Campbell, R., & Buitelaar, J. (2024). Prevalence of autism spectrum disorder and co-morbidities in children and adolescents: A systematic literature review. *FOCUS*, *22*(2), 212-228.

Bozkurt, G., Uysal, G., & Düzkaya, D. S. (2019). Examination of care burden and stress coping styles of parents of children with autism spectrum disorder. *Journal of Pediatric Nursing*, *47*, 142–147.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3(2), 77-101.*

Carter, E. W., Lanchak, E. R., Guest, L., McMillan, E. D., Taylor, J. L., Fleming, L. P., & Dao, A. (2023). Family perspectives on the complexities of pursuing integrated employment for adults with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *128*(3), 219-236.

Chavez, R. & Sabelli, M. (2020). Information behaviour of parents of children with autism spectrum disorder (ASD): A case study. Information Research, 25(4). Retrieved April 18, 2023, from http://informationr.net/ir/25-4/isic2020/isic2014.html

Çolak, B., & Kahriman, I. (2023). Evaluation of family burden and quality of life of parents with children with disability. *The American Journal of Family Therapy*, *51*(2), 113-133.Daskalakes, D. T., & Cahill, M. (2024). “We’re all pretty welcoming”: Inclusion of children with disabilities in library storytime programs. *Journal of Early Intervention*, *46*(3), 407-427.

Depape, A., & Lindsay, S. (2014). Parents’ experiences of caring for a child with Autism Spectrum Disorder. *Qualitative Health Research,25*(4), 569-583.

Dini, J. P. A. U. (2022). Management of parenting activities in forming character of early childhood. *Jurnal Obsesi: Jurnal Pendidikan Anak Usia Dini*, *6*(4), 3169-3179.

Dolan, P., Žegarac, N., & Arsić, J. (2020). Family support as a right of the child. *Social Work and Social Sciences Review*, *21*(2), 8-26.

Falck-Ytter, T., Kleberg, J. L., Portugal, A. M., & Thorup, E. (2023). Social attention: Developmental foundations and relevance for Autism Spectrum Disorder. *Biological Psychiatry*, *94*(1), 8-17.

Filipova, S., Galevska Jovčvska, V., Torte-Chiche, D., & Jankova, R. (2024). Challenges faced by families of children with Autism Spectrum Disorder. *Education Journal of Educational Research*, *6*(11-12), 10-20.

Georgiou, N., & Spanoudis, G. (2021). Developmental language disorder and autism: Commonalities and differences on language. *Brain Sciences*, *11*(5), 589.

Grant, N., Rodger, S., & Hoffmann, T. (2015). Evaluation of autism-related health information on the Web. *Journal of Applied Research in Intellectual Disabilities*, *28*, 276–282.

https://onlinelibrary.wiley.com/doi/pdf/10.1111/jar.12127?casa_token=TDqehzydCPUAAAAA:O1BnjPf_47E3P3MPuqagIXcQ9SvGwNNQa5JTrE3C_L9cn51d7TjxGTVWnCF1mP

Gyesi, K. (2020). Information seeking behaviour of graduate students of the University of Professional Studies, Accra (UPSA). *Library Philosophy and Practice*, *4155*, 1-24.

Han, Z., Zhong, H., & Hansen, P. (2024a). The complex information needs of chinese parents of children with autism spectrum disorder. *Online Information Review*, *48*(3), 601-618.

Han, Z., Zhong, H., & Hansen, P. (2024b). Worried, anxious and uplifted: Emotions of chinese parents of children with autism spectrum disorder when expressing information needs. *Aslib Journal of Information Management*. Vol. ahead-of-print No. ahead-of-print. https://doi.org/10.1108/AJIM-09-2023-0336

Harris, J. (2018). Leo Kanner and autism: A 75-year perspective. *International review of psychiatry*, *30*(1), 3-17.

Hirota, T., & King, B. H. (2023). Autism Spectrum Disorder: A review. *Jama*, *329*(2), 157-168.

Holly, C. R. (2023). Inclusive communities? Collaborative communication practices between stakeholders supporting secondary students on the autism spectrum (Doctoral thesis, Edith Cowan University). Edith Cowan University. https://doi.org/10.25958/yfd3-q538 Available at chromeextension://efaidnbmnnnibpcajpcglclefindmkaj/https://ro.ecu.edu.au/cgi/viewcontent.cgi?article=3728&context=theses

Hyman, S. L., Levy, S. E., Myers, S. M., Kuo, D. Z., Apkon, S., Davidson, L. F., ... & Bridgemohan, C. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, *145*(1).

Kankam, P. K., & Baffour, F. D. (2023). Information behaviour of prison inmates in Ghana. *Information Development.* Advanced online publication. Published ahead of print (accepted/in press) https://doi.org/10.1177/02666669231178661

Khan, S. A., & Shafique, F. (2011). Information needs and information-seeking behavior: A survey of college faculty at Bahawalpur. *Library philosophy and practice*, 1.

Lamptey, D. L. (2017). *Access to healthcare for children with intellectual and developmental disabilities (IDD) in Accra, Ghana: Challenges and strategies for improvement* (Doctoral dissertation, Queen’s University). https://qspace.library.queensu.ca/server/api/core/bitstreams/fa729b54-cd03-4309-9f07-18a0beaf25b7/content

Lee, J. D., Terol, A. K., Yoon, C. D., & Meadan, H. (2024). Parent-to-parent support among parents of children with autism: A review of the literature. *Autism*, *28*(2), 263-275.

Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., & McCauley, J. B. (2022). The Lancet Commission on the future of care and clinical research in autism. *The Lancet*, *399*(10321), 271-334.

Lwoga, E. & Mosha, N. (2013). Information seeking behaviour of parents and caregivers of children with mental illness in Tanzania. *Library Review*, *62*(8/9), 567-584.

Lynch, Frances L., Joanna E. Bulkley, Alexandra Varga, Phillip Crawford, Lisa A. Croen, Yihe G. Daida, Eric Fombonne, Brigit Hatch, Maria Massolo, and John F. Dickerson. (2023). "The impact of autism spectrum disorder on parent employment: Results from the r-Kids study.". *Autism Research 16*(3), 642-652.

Mangortey, D. (2019). *Parents’ perception on the quality of care for children with intellectual disability by healthcare professionals in the Adenta Municipality, Ghana*. (Doctoral dissertation, Ensign Global College). https://repository.ensign.edu.gh/handle/123456789/109

Mansour, E. (2021). *The information-seeking behaviour of Egyptian parents of children with Autism Spectrum Disorder (ASD): A descriptive study*. Emerald Publishing Limited. 1189-1207.

McCrimmon, A. W., & Gray, S. M. (2021). A systematic review of factors relating to parental satisfaction with the diagnostic process for Autism Spectrum Disorder. *Review Journal of Autism and Developmental Disorders*, *8*(3), 334-349.

McFayden, T. C., Bristol, S., Putnam, O., & Harrop, C. (2024). ChatGPT: Artificial intelligence a potential tool for parents seeking information about autism. *Cyberpsychology, Behavior, and Social Networking*, *27*(2), 135–148.

Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *22*, 83-100.

Nicholas, J. S., Charles, J. M., Carpenter, L. A., King, L. B., Jenner, W., & Spratt, E. G. (2008). Prevalence and characteristics of children with autism-spectrum disorders. *Annals of epidemiology*, *18*(2), 130-136.

Nsibirwa, Z., & Kankam, P. (2018). Barriers to high school learners' online information behaviour in Ghana. *Mousaion: South African Journal of Information Studies*, *36*(3), 1-22.

Orlu, A. D. (2016). Information seeking behaviour of masters students: Affective and behavioural dimensions. *Library Philosophy and Practice* (e-journal), 25-79.

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2021). Perceptions, experiences, and needs of parents of culturally and linguistically diverse children with autism: A scoping review. *Review Journal of Autism and Developmental Disorders*, *8(2)*, 195-212.

Pino, M. C., Donne, I. L., Vagnetti, R., Tiberti, S., Valenti, M., & Mazza, M. (2024). Using the Griffiths Mental Development Scales to evaluate a developmental profile of children with autism spectrum disorder and their symptomatologic severity. *Child Psychiatry & Human Development*, *55*(1), 117-126.

Rooney, J., Hodge, R., Smith, J., Vanstone, K., Laugharne, R., & Shankar, R. (2023). Survey of parents of children with intellectual disabilities and/or autism who experience chronic constipation. *Journal of Applied Research in Intellectual Disabilities*, *36*(4), 830-846.

Sabelli, M. (2023). Thomas Daniel Wilson: Building a pathway in information science moving towards creating and accessing inclusive information and knowledge growth. *Informatio*, *28*(1), 12-41.

Saure, E., Castrén, M., Mikkola, K., & Salmi, J. (2023). Intellectual disabilities moderate sex/gender differences in autism spectrum disorder: A systematic review and meta-analysis. *Journal of Intellectual Disability Research*, *67*(1), 1-34.

Seeridaram, A., & Rashid, S. M. M. (2023). The impact of pressure upon parents in raising children diagnosed with autism spectrum disorders. International *Journal of Academic Research in Business and Social Sciences, 13*(1), 940-953.

Severs, R. N., Noel, C. R., Talley, R. C., & Getch, Y. Q. (2020). A collaborative perspectives approach for effective care coordination in autism spectrum disorder. *Advances in Neurodevelopmental Disorders*, *4*, 176-189.

Soong, A., Au, S. T., Kyaw, B. M., Theng, Y. L., & Tudor Car, L. (2020). Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. *BMC geriatrics*, *20*, 1-17.

Suvarna, V., Farrell, L., Adams, D., Emerson, L. M., & Paynter, J. (2024). Parenting practices and externalizing behaviors in autistic children: A systematic literature review. *Clinical Child and Family Psychology Review*, *27*(1), 235–256.

Wilson, T. D. (1999). Models in information behaviour research. *Journal of documentation*, *55*(3), 249-270.

World Health Organization (2020). Retrieved October, 22, 2024 from, https://www.who.int/news-room/facts-in-pictures/detail/disabilities

Wilson, T. D. (2000). Human information behavior. *Informing Science*, *3*, 49.

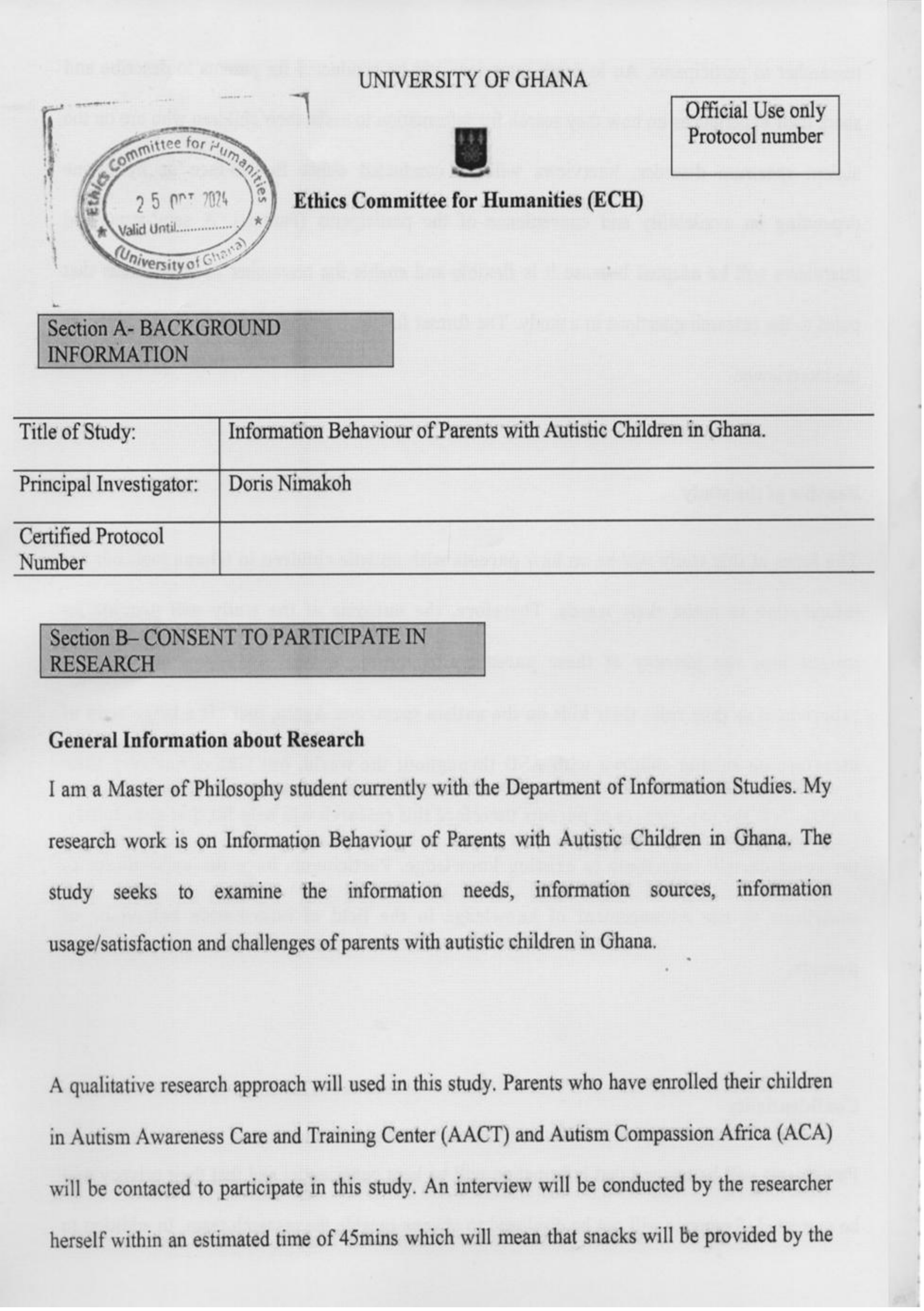
Wilson, T. D. (2010). Fifty years of information behavior research. *Bulletin of the American Society for Information Science and Technology*, *36*(3), 27-34.

Zaytun, A. (2017). The needs of parents of autistic children and their relationship to some variables. A field study in the city of Lattakia (In Arabic). *Tishreen University Journal for Research and Scientific Studies - Arts and Humanities Series*, *39*(3), 547-566.

Zimmerman, M. S., & Shaw Jr, G. (2020). Health information seeking behaviour: A concept analysis. *Health Information & Libraries Journal*, *37*(3), 173-191.

APPENDIX A

Participant Consent Form



UNIVERSITY OF GHANA

Official Use only
Protocol number

25 OCT 2024
Valid Until……………

Ethics Committee for Humanities (ECH)

Section A- BACKGROUND INFORMATION

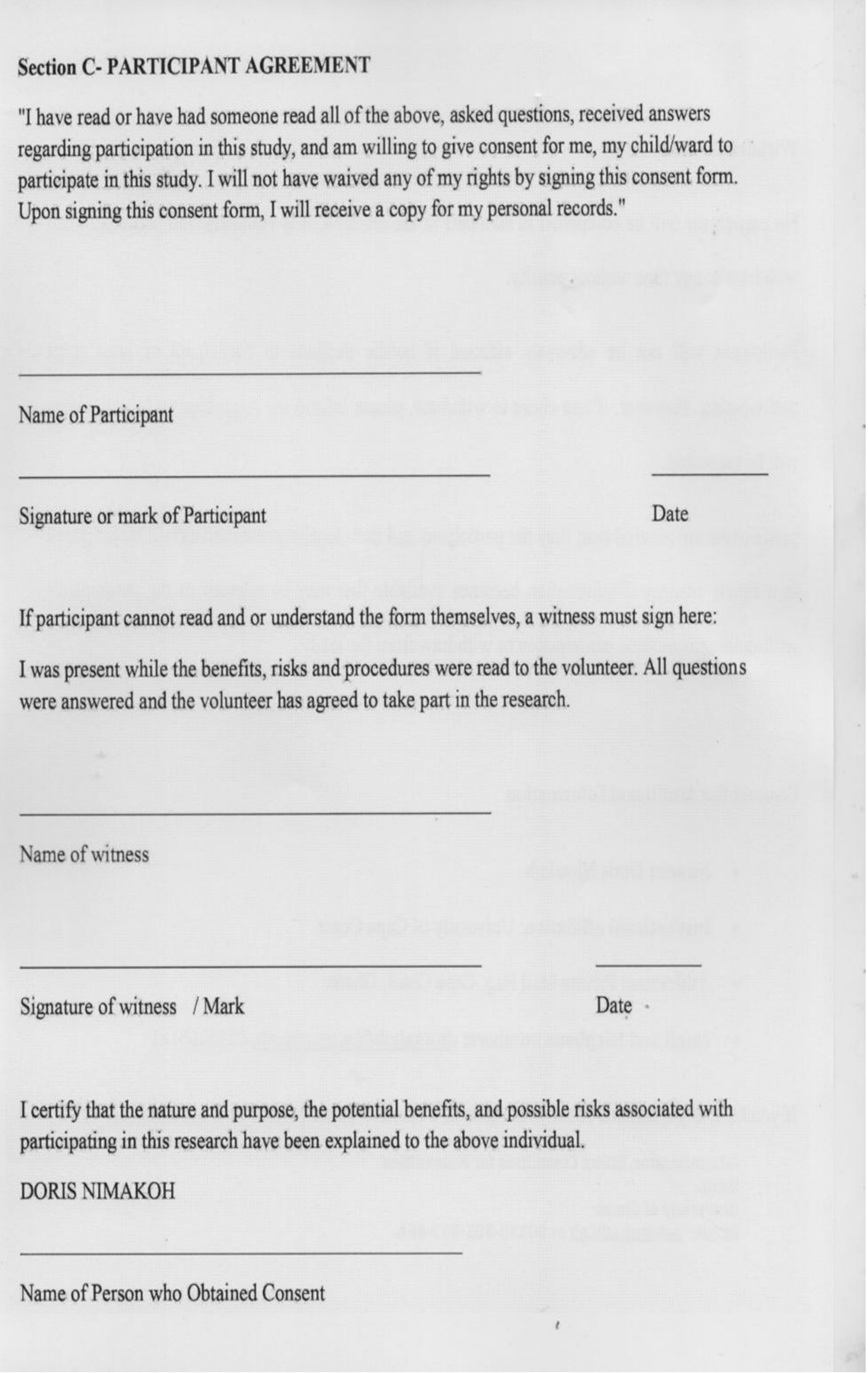
Title of Study:	Information Behaviour of Parents with Autistic Children in Ghana.
Principal Investigator:	Doris Nimakoh
Certified Protocol Number	

Section B– CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

I am a Master of Philosophy student currently with the Department of Information Studies. My research work is on Information Behaviour of Parents with Autistic Children in Ghana. The study seeks to examine the information needs, information sources, information usage/satisfaction and challenges of parents with autistic children in Ghana.

A qualitative research approach will used in this study. Parents who have enrolled their children in Autism Awareness Care and Training Center (AACT) and Autism Compassion Africa (ACA) will be contacted to participate in this study. An interview will be conducted by the researcher herself within an estimated time of 45mins which will mean that snacks will be provided by the



Section C- PARTICIPANT AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Participant

Signature or mark of Participant Date

If participant cannot read and or understand the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name of witness

Signature of witness / Mark Date

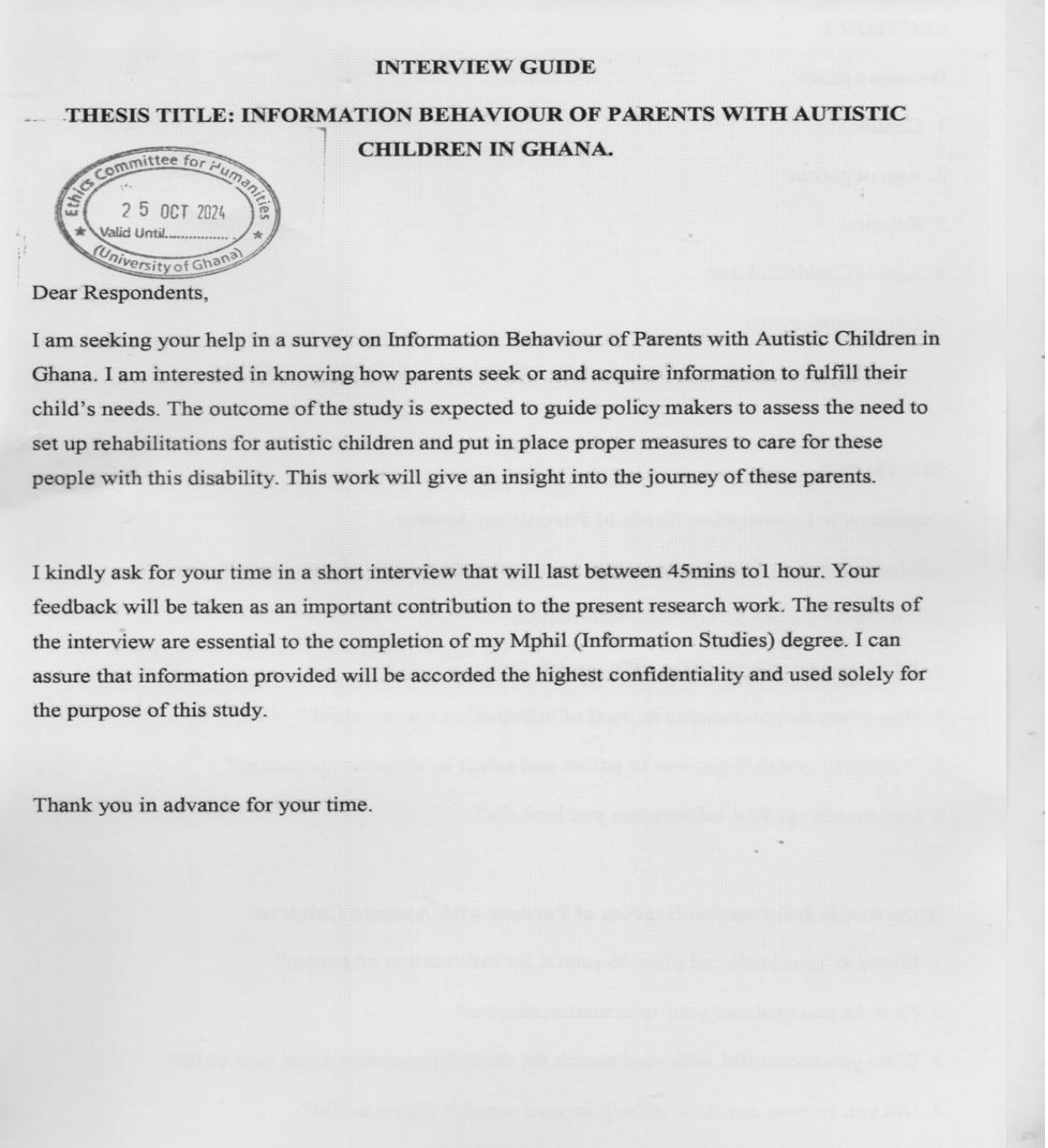
I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

DORIS NIMAKOH

Name of Person who Obtained Consent

APPENDIX B

Interview Guide



INTERVIEW GUIDE

THESIS TITLE: INFORMATION BEHAVIOUR OF PARENTS WITH AUTISTIC CHILDREN IN GHANA.

Ethics Committee for Humanities
25 OCT 2024
Valid Until..............
(University of Ghana)

Dear Respondents,

I am seeking your help in a survey on Information Behaviour of Parents with Autistic Children in Ghana. I am interested in knowing how parents seek or and acquire information to fulfill their child's needs. The outcome of the study is expected to guide policy makers to assess the need to set up rehabilitations for autistic children and put in place proper measures to care for these people with this disability. This work will give an insight into the journey of these parents.

I kindly ask for your time in a short interview that will last between 45mins to1 hour. Your feedback will be taken as an important contribution to the present research work. The results of the interview are essential to the completion of my Mphil (Information Studies) degree. I can assure that information provided will be accorded the highest confidentiality and used solely for the purpose of this study.

Thank you in advance for your time.

THESIS TITLE: INFORMATION BEHAVIOUR OF PARENTS WITH AUTISTIC CHILDREN IN GHANA

SECTION 1

Demographics

1. Age
2. Gender
3. Age of parent
4. Relation
5. Educational status
   a. Primary b. Secondary c. post-secondary d. Tertiary e. Others…………

SECTION 2

Objective 1- Information Needs of Parents on Autism

1.What are some of your information needs?
2. For what purpose do you seek information?
3. What type of information do you search for?
4. How often do you become in need of information?
5. What is the method you use to gather and select information on autism?
6. Do you always find information you look for?

Objective 2- Information Sources of Parents with Autistic Children

1. Where is your preferred place to search for information on autism?
2. How do you evaluate your information sources?
3. Were you successful with your search for the information to assist your child?
4. Did you receive any form of help in your search? Was it useful?
5. Are you able to conduct effective search?
6. Do you possess the necessary skill to conduct a search?

Objective 3- Information Satisfaction Among Parents With ASD Children

1. How useful was the information resource you obtained?
2. Where you satisfied with the information retrieved?
3. How would you rate your level of satisfaction?

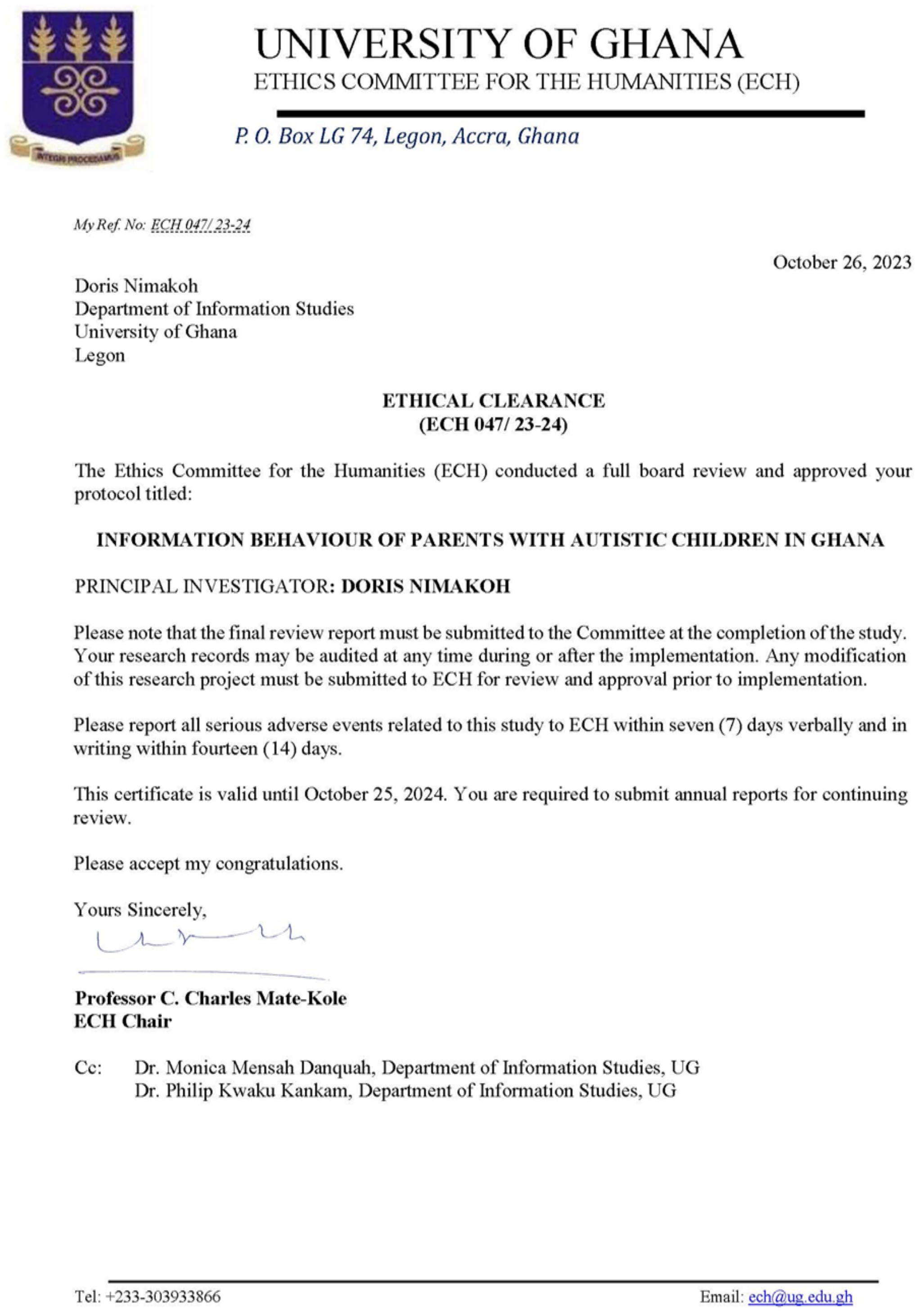
Objective 4- Challenges Experienced by Parents With ASD Children Searching for Information

1. What are some of your day-to-day challenges in conducting a search for information?
2. Did you encounter any challenges in your search for information to support your child? If yes, please tell me about it?
3. How did you cope with these challenges?
4. Is there anything else you would like to tell me?

Thank you

APPENDIX C

Ethical Clearance Letter



UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)
P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No: ECH 047/ 23-24

October 26, 2023

Doris Nimakoh
Department of Information Studies
University of Ghana
Legon

ETHICAL CLEARANCE
(ECH 047/ 23-24)

The Ethics Committee for the Humanities (ECH) conducted a full board review and approved your protocol titled:

INFORMATION BEHAVIOUR OF PARENTS WITH AUTISTIC CHILDREN IN GHANA

PRINCIPAL INVESTIGATOR**: DORIS NIMAKOH**

Please note that the final review report must be submitted to the Committee at the completion of the study. Your research records may be audited at any time during or after the implementation. Any modification of this research project must be submitted to ECH for review and approval prior to implementation.

Please report all serious adverse events related to this study to ECH within seven (7) days verbally and in writing within fourteen (14) days.

This certificate is valid until October 25, 2024. You are required to submit annual reports for continuing review.

Please accept my congratulations.

Yours Sincerely,

Professor C. Charles Mate-Kole
ECH Chair

Cc: Dr. Monica Mensah Danquah, Department of Information Studies, UG
Dr. Philip Kwaku Kankam, Department of Information Studies, UG

Tel: +233-303933866 Email: ech@ug.edu.gh