



## Health Information Needs and Seeking Behaviour of Parents/Caregivers of Children with Autism Spectrum Disorder (ASD) in Nigeria

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### Abstract

**Purpose** – The study aims to assess health information needs, seeking behaviour and patterns of parents/caregivers of children with autism spectrum disorder (ASD) in Don Guanella Centre, Nnebukwu in Nigeria. The study mainly investigated information needs of the parents/caregivers, their preferable sources and seeking patterns, information grounds they are familiar with and their challenges they are faced with in meeting their health information needs.

**Design/methodology/approach** – A case study research design approach was adopted for the study. The study sampled 45 participants whose ages ranged from 25 – 65 years. Structured questionnaire was used for data collection at the Centre while a descriptive analysis of the data collected was done with the use of Statistical Package for Social Sciences (SPSS) version 15.

**Findings** – Findings of the study revealed that health information needs of parents/caregivers were mostly about health care matters like nutrition/diets ( $M = 4.07$ ,  $SD = 0.92$ ), causes of disease ( $M = 3.13$ ,  $SD = 1.28$ ) and health education ( $M = 4.02$ ,  $SD = 0.97$ ). The parents/caregivers have exposure to different information grounds (example, workplaces, activity groups, religious groups, social groups and professional groups). They depend on their exposure to information groups such as workplaces ( $M = 4.72$ ,  $SD = 0.49$ ), Social groups ( $M = 4.15$ ,  $SD = 0.91$ ), and religious groups ( $M = 4.56$ ,  $SD = 0.62$ ) for their information needs. Parents/caregivers expressed preference for some information sources in their search for health information. These sources include printed books and journals, newspapers/magazines, television and radio, healthcare professionals and information specialists, and the internet.

**Practical implication** – The implication of this study is that it will provide a paradigm shift on information seeking and use among parents and caregivers of children with autism spectrum disorder (ASD) in Nigeria and other developing countries of the world with similar conditions.

**Originality/value** – There is dearth of literature on this topic and therefore, this study provides important insight into the information needs and seeking patterns of parents/caregivers of children with ASD in developing countries.

**Keywords:** Health information, Information needs, Health information sources, Children with autism spectrum disorder (ASD), Don Guanella Centre – Nigeria.

### Introduction

There is no doubt that health information is of eminent importance in developing countries of Africa where societies are deluged with daunting health problems. Pilusa (2006) posits that most parents /caregivers in Africa lack adequate experience of taking care of children with autism and therefore need information and support to cope with the condition. There has been proliferation of health-related information disseminated through different media over the past



few decades. Resources in the internet have provided greater public access to health information in addition to offline resources.

Taking care of children with autism spectrum disorder (ASD) no doubt is a challenging task and it affects family life of the parents/caregivers as well as the children. Meeting the demands of the affected children involves much time, patience and sacrifice. Children with autism spectrum disorders usually exhibit difficulties in language communication and social interaction. They are usually stereotyped and show restricted patterns of behaviours (American Psychiatric Association, 2013). Hayes and Watson (2012) reveal that parents/caregivers of children with autism syndrome disorder experience significant stress and challenges in care giving.

In a generic sense, parents/caregivers are always cautious about health information related to children. They would want to pay adequate attention about the authority and credibility of information they receive, which oftentimes they have their own criteria for judgment. They assess information credibility and sources based on their experiences. According to Wilson and Walsh (1996), “an individual may be motivated to engage in health information-seeking pattern and behaviour in an attempt to fulfill his or her needs.” Therefore, there should be subjective expression for people to experience information need and to engage in information seeking behaviour.

### **Purpose of the Study**

The major aim of this study is to assess information needs and seeking behaviour of parents/caregivers of children with autism spectrum disorder (ASD). Specifically, the study is aimed to:

- (1) ascertain types of information grounds parents/caregivers of children with autism spectrum disorders (ASD) have.
- (2) assess the information needs of parents/caregivers of children with autism spectrum disorder (ASD).
- (3) determine the information seeking patterns of parents/caregivers of children with autism spectrum disorder (ASD).
- (4) identify factors that may prevent the parents/caregivers of children with autism spectrum disorder (ASD) from seeking information.

### **Research Questions**

The study was guided by the following research questions:

- (1) What types of information grounds do parents/caregivers of children with autism spectrum disorder (ASD) have?
- (2) What are the information needs of the parents/caregivers of children with autism spectrum disorder (ASD)?
- (3) What are the information seeking patterns of the parents/caregivers of children with autism spectrum disorder (ASD)?
- (4) What are the factors that may prevent parents/caregivers of children with autism spectrum disorder (ASD) from seeking information?

### **Area of Study**

The study was conducted using Don Guanella Centre, Nnebukwu, Nigeria as the case study. The centre belongs to the Congregation of the Servants of Charity (Opera di Don Guanella) and was founded in 1992. The centre is situated in a rural community of Nnebukwu in Oguta Local Government Area of Imo State, Nigeria. The centre has as its objectives the care, education and rehabilitation of disabled persons with special needs that have challenges like



autism, down syndrome, cerebral palsy and epilepsy, in that manner promoting their human dignity and integral development. For the past twenty-seven years of its existence, hundreds of physically challenged persons have been rehabilitated in the centre of which some have gone back to their various families and in turn re-integrated in the society. Presently, the centre in its capacity runs both boarding and day-care rehabilitative assistance with activities such as: special school, the physiotherapy, the speech therapy, and agricultural activities. These sterling qualities of the centre made it a right choice for the study of this nature.

### **Literature Review**

This section reviews related research in information grounds, theoretical framework, parents/caregivers information needs, and information seeking of ASD-related information. On information grounds, Counts and Fisher (2008) maintain that research has shown that information grounds such as workplaces, activity groups, and religious groups are very important information sources for everyday information seeking. Information grounds serve physical and virtual places where people get together in temporal social settings. Information grounds can serve different roles for different groups (An, Na, and Zhang, 2019). Counts and Fisher (2010) reveal that information grounds can also be online in forms of online social networks. Twitter creates a place for information technology professionals' informal and social communication, through which they keep connected socially and share information (Talip, Narayan, Edwards and Watson, 2017).

This study adopts the Wilson 1996 information behaviour model for the purposes of explaining information needs and seeking patterns of parents/caregivers of children with ASD. The Wilson 1996 model suggests that an information user seeks information in order to satisfy a perceived need. The model provides three theoretical aspects to explain why people seek information: stress/coping theory, risk/reward theory, and social learning theory. The stress/coping theory propounds possibilities for explaining why some needs do not invoke information-seeking behaviour. The risk/reward theory explains that some sources of information may be used more than others by a given individual. Finally, the social learning theory embodies the concept of self-efficacy, the idea of the conviction that one can successfully execute the behaviour required to produce the desired outcomes. This model identifies that users seek information from formal or informal information sources or services, which may result in success or failure in finding relevant information. If successful, the user may make use of the information. On the contrary, the user may be fully or partially satisfied, or may fail to fulfill the perceived need, and repeat the search process. The model also recognizes the intervening variable, which may support or prevent information use by the user (Wilson and Walsh, 1996).

Generally, parents/caregivers of children with autism spectrum disorder (ASD) need reliable and relevant information which will help them facilitate the process of adapting and coping with their situation. Previous studies show that information needs of parents/caregivers of children with ASD tend to differ according to individuals location, and are associated with their cognitive and affective needs (Mnubi-Mchombu and Ocholla, 2011). Despite the extensive range of available information, parents rely more on personal communication with professionals as their main source of information. This is evident in a study of parents of disabled children with physical and learning difficulties who indicated professionals as their main source of information (Corcoran, Haigh, Seabrook, and Schug, 2010).

Report of the study done by Gibson, Kaplan, and Vardell (2017) on ASD-related information seeking shows that health information behaviour of parents of children with ASD run through the whole process of raising children. The report further shows that parents of younger children with ASD pay more attention to physical growth and education information, and they tend to



communicate more with doctors and teachers, and their information sources decrease as their children grow up. Parents' health information behaviours can be swayed by their socioeconomic status, education background and condition of children. This is confirmed by Walker (2009) in a study he conducted where he discovered that parents with lower socioeconomic status depend more on information gatekeepers to obtain information while parents with higher socioeconomic status source information themselves to support decision-making. Johnson, Frenn, Feetham & Simpson, (2011) have observed that chronic exposure to stress as a result of care-giving for a child with disability significantly affects parents and caregivers in several domains of their lives such as poor health and mental health statuses. General stress coping is a transitional process whereby coping methods vary across time and contexts to match the changing demands of stressful events (Folkman and Lazarus, 1985). Chun, Moos & Cronkite (2006) advise that caution should be taken when applying general coping constructs across distinct cultural groups such as that between Western and Asian parents of children with ASD because of their different cultural and social backgrounds.

### **Methodology**

A case study research design was adopted for this study, which was conducted at Don Guanella Centre, Nnebukwu in Nigeria. The sample size of 45 respondents was randomly determined from among the population of about 156 parents/caregivers aged between 25-65 years, who have children with autism spectrum disorder (ASD) in the centre. The instrument used for data collection was a questionnaire. The researcher personally administered the structured questionnaire to the 45 respondents at Don Guanella Centre. Approval to conduct the study was first sought and approval granted from the Owerri Catholic Archdiocese, Nigeria. Thereafter, data was collected at the centre in November and December of 2019. Data collected was analyzed with the Statistical Package for Social Sciences (SPSS), version 15. A descriptive analysis of the sample was performed.

### **Results and Discussion**

The researcher distributed a total of 45 copies of the questionnaire to the participants in this study. All the 45 copies of the questionnaire were retrieved and found useful for this study, indicating a 100 percent return rate of the instrument.

### **Demographic Information of Participants**

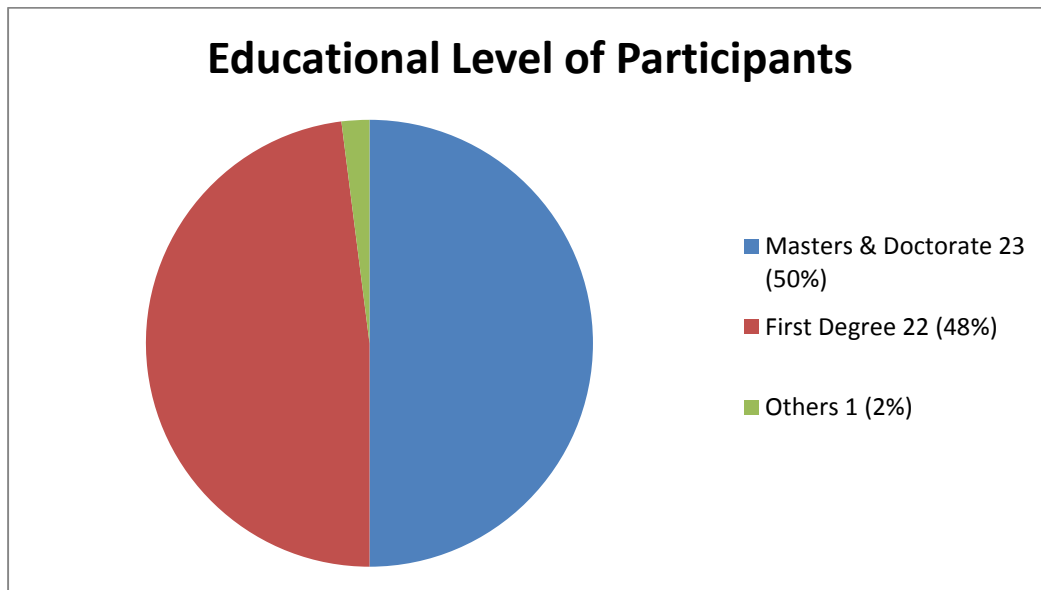
The age of the participants ranged from 25 years to 65 years. It is worthy of note that the education level of the participants are considered, with more than half of them (50%) possessing either a Master or Doctoral degree. 48% of them have a first degree level leaving only 2% of them who could be considered as having one form of formal education or the other. About the gender of the participants, 25 (56%) of them are female while 20 (44%) are male. All the participants are gainfully employed, with about 12% of them owning their private enterprises.

**Table 1:** Age and Gender Distribution of the Respondents

<b>Years</b>	<b>Male</b>	<b>Percentage</b>	<b>Female</b>	<b>Percentage</b>
25 – 35	8	40	12	48
36 – 45	6	30	8	32
46 – 55	4	20	4	16
56 – 65	2	10	1	4
Total	20	100	25	100

N = 45

Table 1 shows the age and gender distribution of the respondents in this study. The Table reveals that majority of the respondents fall within the age bracket of 25 years and 35 years (Male = 8(40%) and Female = 12(48%). Also, reasonable proportion of the respondents are within the ages of 36 years and 45 years (Male = 6(30%) and Female = 8(32%).



**Figure 1: Educational Level of Participants**

Figure 1 shows the educational level of the participants. The figure indicates those with postgraduate degrees (Master and Doctoral degrees) are 23 (50%). First degree certificate holders are 22 (48%), while 1 (2%) represents others with one form of formal education or other

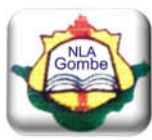
**Table 2: Information Grounds Parents/Caregivers of Children with ASD**

Information Grounds	Mean (M)	Standard Deviation (SD)
Workplaces	4.72	.49
Activity Groups	4.62	.58
Religious Groups	4.56	.62
Social Groups	4.15	.91
Professional Groups	3.82	1.03
Community Centres	2.29	1.26

Note. Scale used: 4 = Very important; 1 = Not important.

The participants were asked to indicate, on a 4 point Likert scale (4 = Very important to 1 = Not important) physical places or environment temporarily created by the behaviour of people for information sharing and exchange. Workplaces and activity groups were found to be highly important (M = 4.72, SD = .49) and M = 4.62, SD = .58 respectively). Furthermore, there were some other grounds found to be important such as religious groups (M = 4.56, SD = .62), social groups (M = 4.15, SD = .91), and professional groups (M = 3.82, SD = 1.03).





**Table 3:** Information Needs of Parents/Caregivers of Children with ASD

Health Information Needs	Mean (M)	Standard Deviation (SD)
Nutrition/Diet	4.07	0.92
Health Education	4.02	0.97
Physical Fitness	3.78	1.08
Causes of Disease	3.13	1.28
Disease Prevention	3.07	1.32
Treatment	2.98	1.41

Note. Scale used: 4 = Strongly agree; 1 = Strongly disagree.

Table 3 shows that majority of respondents indicated their need for health information border in the need for nutrition and diets (M = 4.07, SD = .092), health education (M = 4.02, SD = 0.97), physical fitness (M = 3.78, SD = 1.08), causes of disease (M = 3.13, SD = 1.28), and disease prevention (M = 3.07, SD = 1.32).

**Table 4:** Information Seeking Patterns of Parents/Caregivers of Children with ASD

Sources of Information	Mean (M)	Standard Deviation (SD)
Printed Books	4.57	0.60
Printed Journals	4.82	0.40
Television	4.55	0.61
Verbal Discussions	4.68	0.57
Newspapers/Magazines	4.64	0.49
Health Care Professionals	4.15	1.23
Information Specialists/Librarians	4.05	1.19
Internet	3.85	1.14
Radio	3.82	1.03
Leaflets	3.95	1.27

Note. Scale used: 4 = Strongly agree; 1 = Strongly disagree.

As shown in Table 4, all the participants in the study had sought information relating to ASD. The participants expressed overall preference for most of the information sources presented in the instrument for data collection. From the table, the participants indicated their preference in sourcing information through the following sources: printed books (M = 4.57, SD = 0.60), printed journals (M = 4.82, SD = 0.40), television (M = 4.55, SD = 0.61), and verbal discussions (M = 4.68, SD = 0.57). Also the participants indicated information specialists/librarians (M = 4.05, SD = 1.19), and the healthcare professionals (M = 4.15, SD = 1.23). The participants equally source health information through the internet/digital repositories (M = 3.85, SD = 1.14), television (M = 4.55, SD = 0.60), newspapers/magazines (M = 4.64, SD = 0.49) and radio programmes (M = 3.82, SD = 1.03).

**Table 5:** Factors that May Prevent Parents/Caregivers of Children with ASD from Seeking Information

Factors	Mean (M)	Standard Deviation (SD)
Health information illiteracy	3.82	0.33
Low level of education	2.33	1.28
Lack of funds	4.62	0.58
Ignorance	2.13	1.59
Lack of time	3.42	0.91
Wrong beliefs	2.00	1.34
Lack of family support	2.29	1.26
Low level of ICT literacy	2.91	0.92

Note. Scale used: 4 = Highly dominant; 1 = Not dominant.

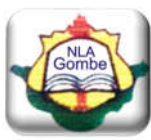


Table 5 shows the responses of the participants which sought to identify the dominant factors that tend to prevent parents/caregivers of children with ASD from seeking health information they need. The table shows that combination of factors pose as barriers to effective information seeking pattern for the parents/caregivers of children with ASD. These factors include health information illiteracy ( $M = 3.82$ ,  $SD = 0.33$ ), low level of ICT literacy ( $M = 2.91$ ,  $SD = 0.92$ ) and lack of time ( $M = 3.42$ ,  $SD = 0.91$ ). It could be deduced from the table that the most dominant factor preventing parents/caregivers of children with ASD is lack of fund ( $M = 4.62$ ,  $SD = 0.58$ ). This lack of fund generally affects all aspects of their information seeking pattern.

### **Discussion and Conclusion**

People with different professions, educational backgrounds, and social roles have different types of information grounds. “For college students, information grounds would include campus, restraints and community. “Information grounds for stay-at-home mothers include children’s activities, shops, community centres and parks/playgrounds (Fisher and Landry, 2007). In this study, it was revealed that parents/caregivers of children with ASD at Don Guanella Centre, Nnebukwu leverage on various information grounds to share and exchange information relating to autism spectrum disorder (ASD). Information grounds serve different roles for them towards achieving the same objective of satisfying their information needs. Furthermore, the study revealed that health information needs of the parents/caregivers mainly aligned with physiological and cognitive needs like nutrition/diets, physical fitness, and causes of disease and health education. Their preferences for these health information needs is in tandem with cognitive needs as identified in Wilson’s 1996 model on why people seek for information.

In the study, parents/caregivers expressed more inclination to the use of printed materials like books, journals, newspapers and magazines to source their information. This corroborates previous studies (Jackson and Baird, 2007; Zach et al., 2012) that printed books were also seen as important sources of health information among parents of children with health conditions. Additionally, other sources were used by the parents/caregivers such as television, radio and internet. In line with the global trends, it does appear that future delivery of health information to parents/caregivers of children with ASD would be best achieved through digital platforms in combination with robust and relevant television and radio programmes.

Finally, the study findings revealed that issues relating to financial problems ranked highest amongst the factors that tend to prevent parents/caregivers from seeking information. This is followed by health information illiteracy and lack of time. The parents/caregivers dedicate much of their time caring and attending to the needs of the autism children that there is barely time enough for them to read and seek for information. Low level of ICT literacy was also highlighted by the parents/caregivers as among the inhibiting factors against seeking health information. Comparable findings were revealed in other studies (Roche and Skinner, 2009; Zach et al., 2012) who revealed that inadequate information searching skills pose as barriers for parents to seek internet-based information about their children’s health.

### **Recommendations**

As a way to enhance access to relevant health information for parents/caregivers of children with autism spectrum disorder (ASD), this study recommends the following:

- Use of traditional Mass Communication media platforms (example, radio, television and newspapers) to disseminate relevant and appropriate health information programmes for the public. The programmes and news should carry wide range of topics to educate the general public about different health issues regarding autism spectrum disorder.



- Involvement of public libraries in organizing information literacy programmes for the general public to assist parents/caregivers of children with autism spectrum disorder and other illnesses to enhance their capacity to seek for health information.
- Institutions of higher learning, hospitals, Non-governmental Organizations (NGOs) and public libraries across Nigeria should build online repositories of authoritative resources on health information and ensure access to the resources for parents/caregivers of children with ASD and other types of illnesses.
- Government, religious bodies and NGOs should provide sustainable financial or materials supports to parents/caregivers, institutions and bodies involved in taking care of children with ASD.

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