

## **Health Information Seeking Behavior (HISB) Among Malaysian Parents of Children with Autism Spectrum Disorder (ASD): A Conceptual Framework**

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**Abstract.** Autism Spectrum Disorder (ASD) is a form of the developmental condition that has been shown to impact verbal and non-verbal communication and social interaction profoundly. Children with autism typically demonstrate verbal delays, repetitive behaviors, issues with concentration, a lack of desire, and deficiencies in social interaction. However, changes in socioeconomic and demographic sectors provide obstacles for parents with limited health information-seeking behavior (HISB) about their autistic children's health. This paper aims to discuss and propose the conceptual framework of health information-seeking behavior (HISB) among parents of children with autism spectrum disorder (ASD) in Malaysia. The significance of this study may assist the government, NGOs, and autism research center with information for a better understanding of HISB among parents of children with ASD.

**Keywords:** Autism Spectrum Disorders, Health Information Seeking Behaviour, socio-economic, demographic, information management, library management.

### **1 Introduction**

The term "autism spectrum disorder" (ASD) is a neurodevelopmental condition characterized by social communication difficulties and repetitive behavioral patterns. Children with autism will engage in behaviors characterized by repetition and imitation. The major issues addressed in this paper is to investigate how parents' starts

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their information-seeking and when the parents need new information to fulfil their information needs and existing knowledge which is affected by demographics, experience, beliefs, and salience. In addition, children with autism spectrum disorders (ASD) have communication and language issues, narrow interests, and imitation behaviors. (Chang et al., 2015; He et al., 2018). Difficulty in managing children with ASD causes parents to struggle with stress, finances, time, social activities, medical care, intervention, and inadequate support services (Ludlow et al., 2012). Consequently, socioeconomic, and demographic shifts obstruct parents' health information-seeking behavior (HISB). Autistic children in Malaysia have estimated that 52 million cases of autism spectrum disorders (ASD) have been reported globally. (Ilias et al., 2015; Ludlow et al., 2012). According to (Sukeri et al., 2017), 10-16 percent of all children in Malaysia have disabilities, and with a multiethnic population, the prevalence rate for autism spectrum disorder as stated by (Ramachandram, 2019). According to the data in Malaysia, over 47,000 Malaysians suffer from autism syndrome. It is estimated that 1 in 600 children in Malaysia is born with autism, and the symptoms can be diagnosed as early as 2 or 3 years. In Malaysia, the prevalence of autism is estimated to be 1 in 600 children (Zulkafli et al., 2018). In light of the growing incidence of autism spectrum disorders (ASD), parents who lack relevant expertise frequently seek support and advice from organizations, specialists, educators, nongovernmental organizations (NGOs), and communities to obtain information concerning the pertinent aspects of their children's health such as National Autism Society of Malaysia (NASOM) or National Autism Resource Centre (NARC), government and private hospital and other organization related to Autism.

Several studies have pointed out that socio-economic and demographic changes are creating challenges for parents of children on the autism spectrum (ASD) in health information-seeking behavior (HISB). Studies show with different socio-economic and socio-cultural status can limit the information seeking by parents and (Alsem et al., 2017) mentioned that parents of children with disabilities feel that not all of the information they require is clear and that there is still a lack of information. Cultural barriers and changes in socioeconomic and demographics were the common factors that might create challenges for the parents with disabilities regarding their health information-seeking behavior such as cultural barriers, low -income, social and financial support, and community services which are frequently unmet. In (Sukeri et al., 2017), the mothers of the village of Kelantan have complained of their unmet needs in terms of information, social support, community services and funding. Some mothers complained that their needs were not being met by medical professionals. Their observations highlighted numerous unmet needs of mother's children with disabled (CWD) in Kelantan. Socioeconomic and demographic changes potentially impact the parents of children with autism spectrum disorder (ASD). These two factors will affect parents with disabled children's marital quality, life control, and financial support and contribute to parental stress. Parents often point out the difficulties and problems they face. The quality of marriage is worse because of financial stress. (Chu et al., 2020; Ludlow et al., 2012).

A study by (Chu et al., 2020) conducted in Malaysia in 2014 on the facilities given in urban and rural areas for children with an autism spectrum disorder and the study

was conducted in urban and rural areas. Refer to the results, more public and private centers offer services in urban areas as opposed to rural areas, which benefits the parents who bring their children to urban areas for evaluation and diagnosis. When compared to rural areas, where youngsters frequently receive outdated knowledge regarding current events, urban areas generally do a better job of providing timely updates (Chu et al., 2020). The researcher indicated that a family-centered model is the best practice standard for the delivery of services to children with autism spectrum disorders (ASD). This is because of parents with limited knowledge of health information seeking their child's problems contributed to the problem. Additionally, the researcher mentioned that the family-centered model is the best practice standard. According to Ibrahim et al. researches from 2020, It has been found that there is a link between socioeconomic and demographic aspects of adaptive behavior among diagnosed children with an autism spectrum disorder. The study evaluated the socioeconomic position of families using the Socioeconomic Status Scale. This was done to address better the social factors that influence health.

## 2 Literature Review

Research on autism in Malaysia has spanned a variety of fields, including education, engineering, information technology, medicine, psychology, and other areas, and has been beneficial to both the nation's parents and children who have autism spectrum disorder (ASD) (Chu et al., 2020; Ting, 2010). However, a local survey was conducted in 2005, and the results showed that one in every 625 Malaysian children has autism spectrum disorder (unpublished data by the Ministry of Health) (Kaur et al., 2015). This information was compiled and included in the technical report of the research on autism spectrum disorder that was carried out in Malaysia. The number of reported cases in Malaysia of parents seeking medical treatment for their children has risen. This suggests that many parents are becoming aware of the significance of obtaining medical information for their children with an autism spectrum disorder. On the other hand, Kaur et al. (2015) state that there is not currently a compilation of local research on. Additionally, the researcher proposed the establishment of a support structure as well as services for both the children and the parents. The breadth of the studies reported in this Technical Report of Autism Spectrum Disorder Research in Malaysia, which includes cross-sectional, case studies, case-control studies, and qualitative studies, is one of the report's strengths (Kaur et al., 2015). There are a few selected information seeking behaviour models that relevant to the qualitative research methods. By investigating, exploring and analysing their patterns of information seeking behaviour can provide them a useful strategies and approach for effective transfer of information to the parents by using models and theories that related to the information seeking behaviour of patients. Wilson's nested Model of Conceptual Areas is to discover on how the information need may link with one to another. This nested model explained on all the three elements are depending on each other and by increasing by an concern, it will move to a deeper levels with better quality wise details on human. Once the user identified the information and way of searching information,

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they will share with others or using by themselves. But according to (Bhattacharjee & Sinha, 2017) some theories are not enough just to understand the specific problems but by developed a model, it will lead to the improvement and better understanding with a clear content and concept to see the process. Wilson's 1981 model is to outline the different domains covered by his proposed 'information seeking behaviour' as an alternative to 'information need'. However, according to (Al-Suqri & Al-Aufi, 2015) one of the contributions made by Wilson's models mentioned that information behaviour warrant is for the need to study their evolution in information behaviour research. Wilson expanded his model to analyse the behaviour of human information within the context of information-seeking behaviour and also mentions that information users seek information to satisfy a perceived need.

### *2.1 Health Information Seeking Behavior (HISB)*

Most ASD parents deal with many difficulties and combat abundant information about autism in their daily life. Challenges are living with disabilities. Children often struggle with their daily routine, behaviors, health support and searching for information (Ludlow et al., 2012). Limited information or barrier access will add parental stress due to limited experienced, poor support system or service provider (Hussain & Tait, 2015). The nature of the responsibility and role of parents with children with autism spectrum disorder (ASD) have changed drastically from time to time in different areas of information-seeking behavior. When parents start using technology as a digital platform for getting autism information health, the information overload is increased abundantly in providing a widening scope of autism health information. However, parents still explore and seek out information on their children's health even though the info is overabundance. The activity of information seeking is getting slower because the information is not related to them and some of the parents are struggling to obtain relevant information because of having a lower level of information-seeking skills. Health information-seeking behavior is important for parents with children diagnosed with autism spectrum disorder (ASD). One way to educate parents in getting the right information on autism is through health information-seeking behavior (HISB). By understanding the unique needs of their children's health information, parents will begin to find a way to make their information-seeking work in assorted styles and contexts. Doctors and child psychologists have always been the most people in their contact. The technological advancement in checking, acquiring, selecting, and implementing are known as information-seeking behaviors. It's how people use and utilize the information.

### *2.2 Demographic And Socioeconomic Status Changes Create Challenges to The Parents of Children With Autism Spectrum Disorder (ASD)*

Parenting a child with autism while living in Malaysia is also part of the difficulties in seeking information. They are also concerned with the quality of life of the children. Likewise, the untold numbers of parents with autistic children who lack informational behaviors are not being reached. It is reported that culturally and linguisti-

cally diverse families have difficulty accessing the information and resources they need (Papoudi et al., 2021). Instead, from the past qualitative research on unmet needs among mothers of disabled children in Kelantan, Malaysia. The results showed that most respondents lived in rural areas with low levels of education and socioeconomic status. Most respondents-maintained follow-up appointments with hospitals and continued their children's progress in community rehabilitation centers (CBRC) in Kota Bharu (Sukeri et al., 2017). In fact, In the research perspective, parents are focused on meeting places organized by local organizations and therapists. They searched for any information provided by the local organization through email, conferences, online seminars and by searching information through libraries or digital libraries. It helps the parents to search for information on which they focus. However, several parents are still complaining about getting little health information about their autistic children. Perhaps the library or other community anchor points should improve learning spaces and information hubs from the health department for the community that doesn't know what it offers (Gibson et al., 2017a). However, in this scenario, the researcher also used a quantitative method to measure the correlations between the socioeconomic and demographic factors associated with adaptive behavior in children diagnosed with ASD in Egypt. The Socio-Economic Situation Scale was used to evaluate the family socio-economic situation (Ibrahim et al., 2020).

### 2.3 *Libraries Vs Medical Authorities*

Children with autism exist in every age group, ethnic and socio-economic in communities. However, some of the parents with disabled children have some negatives perception towards library. Libraries often over-looked the needs of special needs children. One of the objectives from public libraries is to meet people needs and libraries have a responsibility in supporting and educate people with disabilities and their guardians. According to Resources et al., (2002) public libraries have a responsibilities to served communities with library collections, educate people with disabilities and their advocates. American Library Association stated the library can play a transformative role by pledging to provide equal access to collections, services, and facilities for all library users. Two key acts relate to libraries with respect to access and services for persons with disabilities. Furthermore, service ethos and library orientation required an inclusive and accessible environment for people with disabilities and included children Shea & Derry (2019). To battle the day-to-day stresses of modern society, Husaini H., Noordin, S.A and Shuhidan S.M (2015) argue that incorporating the concept of a therapeutic landscape into a library has become necessary to match the views and expectations of library users. It all started with an attempt to comprehend the requirements of library patrons regarding the therapeutic environment that the public library provides. The study studied how the twelve (12) aspects of therapeutic library elements are connected. According to Husaini H., Noordin, S.A and Shuhidan S.M (2015, 2016), social and spiritual environments enhance library users' therapeutic enjoyment in terms of stress reduction and contribute to a healthy lifestyle. Today's libraries face a challenging environment, where users preferred to have a resourceful material which include daily activities such as health information.

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The responsibilities and goals of libraries are to act as a community center to encourage the growth of both the community and society. A library is uniquely positioned within a community because it has access to the required resources, services, and facilities to provide free access to books and conduct various community programs. Therefore, libraries must work with medical authorities to get the updated collections related to the health.

#### *2.4 Technology*

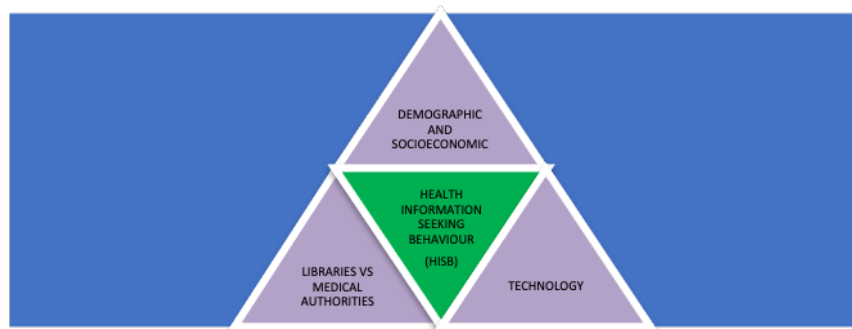
According to (Jung, 2014) free access, active research and obtaining accurate information related to health interest through advancements in technology, it is not easy for low-income people groups to freely acquire their children information health by using internet or even through smartphones. Despite technological achievements and social development in the country are broaden used but there are some parents still left behind when it comes to using technological tools such as the Internet or local information outlets because they have limited knowledge on health information seeking behavior. It has substantially affected all the world activities including changing daily activities for the parents of children with autism. Even though it's occasionally happened, but when some parents are not information literate enough with information sources on the digital platform, lacking on information-seeking strategy. It will have overwhelmed them. Most of the illiterate information-seeking parents only getting information provided by a physician or a doctor from the hospital. Likewise (Al-Daihani & Al-Ateeqi, 2015) stated that parent with autistic children's information-seeking behavior is helped by information professionals, doctors, and social workers. Even there is number of studies shown on parents' information-seeking behaviors on health information via borrowing books from the libraries, newspaper reading, and enquiring from other parents of children with autism (Beesoon, n.d.). However, research has been carried out into the unresolved barriers faced by mothers of children with disabilities in Kelantan.

### **3 Conceptual framework development**

Previous studies has been referred to several models that related to the HISB. As for these studies, few models and theories will used to develop the conceptual framework. There are Wilson's Model of 1981, Wilson's Model of Information Behaviour (1996), Dervin's Model, Ellis's Model of Behaviour, The Health Information Acquisition Model of Freimuth, Stein and Kean Lenz's Information Seeking and Model Longo's Et Al Expanded Model of Health Information Seeking Behaviour. As presented in figure 3.0, the proposed model presented 3 elements of information seeking behavior that related to autism information findings. There are demographic and socio-economic, libraries versus medical authorities and technology. As for the first element, demographic. And socio-economic based from Longo's Et Al Expanded Model Of Health Information Seeking Behavior will investigate through parent's age, education level, income and occupation can create their information seeking behavior

in finding the health information. The second element is libraries versus medical authorities. With health provider works closely with libraries will be the best venture as a healthcare provider. Through this, both parties will function as sources of information and a channel to promote and deliver health information collection, resources, and health-care management in providing equal access to collections, services, and facilities for all library users. Technology is the third element of the proposed model for health information research behaviors. In order to determine whether the information retrieved successfully or failed, it comes from demands upon formal and informal information. If the user feel satisfied with the result, the individual will make use the information either in fully used or partially. On top of that, with the technology will be useful to the parents because it will help them expose to the communication, information exchange, social networking among parents. Indirectly can contribute for the health communication campaign through technology. As (Bhattacharjee & Sinha, 2017; Kumar Kundu, 2017) the aforementioned information-seeking behaviour may involve other persons through the exchange of information and, if useful to others, may involve other persons.

*Figure 3.0: Proposed Model Health Information Seeking Behavior for Parents with Autism Spectrum Disorder (ASD) Children*



#### **4 Conclusion and recommendations**

Health Information Seeking Behavior (HISB) is defined as various types of information-seeking patterns that involve finding, selecting, and using related information to the diseases and health before and after the patient's diagnosis. Research into health information-seeking behavior in parents of children with autism spectrum disorder is very important. Hence, the parents require knowledge, searching skills and support to get the right information through HISB. By understanding the unique needs of their children's health information, parents will begin to find a way to make their information-seeking work in assorted styles. This study is expected to contribute to comprehensive research on information-seeking behavior for the health information needs among parents with autism spectrum disorder (ASD) children in Malaysia and makes theoretical and practical contributions to the literature, as well as suggestions for fu-

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ture research and contribution on the body of knowledge. Other than that, the systematic and comprehensive method will help the researcher to help parents with their information-seeking patterns on getting the information health needs of their autism spectrum disorder (ASD) children and developing an understanding of autism spectrum disorders (ASD) children specific needs on information health. This study is expected to contribute to comprehensive research on information-seeking behavior for the health information needs among parents with autism spectrum disorder (ASD) children in Malaysia and makes theoretical and practical contributions to the literature, as well as suggestions for future research and contribution on the body of knowledge. Other than that, the systematic and comprehensive method will help the researcher to help parents with their information-seeking patterns on getting the information health needs of their autism spectrum disorder (ASD) children and developing an understanding of autism spectrum disorders (ASD) children specific needs on information health. Based on the National Child Policy and the Convention on the Rights of the child and the Children Act, 2001, the researcher will contribute through research to improve the quality of information seeking patterns and support such as providing special programs for parents and help to improve health information center service friendly environment. It is hoped that this research will make suggestions and recommendations from those respondents to make improvements towards the health information-seeking behaviour (HISB) among parents with autism spectrum disorder (ASD) children in Malaysia and indirectly will support the agenda of Malaysia Education Blueprint, 2015-2025 and Sustainable Development Goals by UNESCO (SDGs 4) quality education and no one left behind in education. However, this paper will be further investigated in the next phase with a field interview with parents.

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### **Paper Contribution to Related Field of Study**

This paper will contribute to the body of knowledge and practice that will support the ASD parent in making decisions and reduce uncertainty in managing their ASD children. It is also will use as a baseline for the government and policymakers to improve the current guidelines to support health information for ASD.

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