

Health Information Seeking Behavior and Socioeconomic Influences Among Parents of Children with Autism Spectrum Disorder (ASD): Implications for Support and Interventions

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Abstract. Autism Spectrum Disorder (ASD) is a worldwide public health concern that poses unique challenges for both people on the spectrum and their families. It is critical that the world recognizes the magnitude of the problem without discrimination based on socioeconomic reasons. The goal of this study is to look at the relationship between health information-seeking behavior (HISB) and socioeconomic factors in parents of autistic children, as well as the implications for support and therapies. This paper presents the conceptual framework of health information seeking behavior and socioeconomic influences among parents of children with autism spectrum disorder (ASD) on the impact of socioeconomic factors such as parent's age, income, qualification, and occupation as factors that may lead on their information-seeking tendencies. This study will be using a quantitative method. The findings have important consequences for both research and practice. It may help the government, non-governmental organizations, and autism research centers provide specific support services and interventions in the development of policies and programs that address knowledge and resource gaps, thereby increasing the well-being of ASD households.

Keywords: Autism Spectrum Disorder, health information seeking behavior, informational behavior, socioeconomic, information management

1 Introduction

Health Information seeking behaviors is the process on addressing health promotion and individual actively seek for and use of medical condition. In the context of parents who have autistic children, knowledge searching is critical in assisting them in navigating the complex landscape of autism. They are looking for information about various elements of autism, such as early intervention programs, educational services, therapeutic interventions, support groups, and coping skills (Hussain & Tait, 2015).

Parents who have children with autism confront distinct challenges and duties. Their responsibilities extend beyond day-to-day caregiving as they assume a pivotal role in searching for and securing suitable resources, therapies, and educational opportunities. The timely acquisition of pertinent information becomes paramount, enabling them to make well-informed choices concerning the most effective interventions and support for their children's growth and welfare (Disorder, 2018; Matin et al., 2021; Weiss et al., 2014).

Information seeking behavior involves the active pursuit and utilization of information to meet needs, resolve issues, or reach decisions. For parents raising autistic children, information seeking assumes a crucial role in guiding them through the intricate realm of autism. They actively search for information pertaining to diverse facets of autism, encompassing early intervention programs, educational services, therapeutic approaches, support networks, and strategies for coping (Tordjman et al., 2019). Although examining information seeking behaviors among parents of autistic children is an important research subject, but it is critical to recognize that this behavior does not exist in isolation; rather, it is inextricably connected with broader socioeconomic dynamics. Income level, educational background, healthcare accessibility, and geographical location all have a significant impact on how parents connect with, interpret, and use knowledge (Ibrahim et al., 2020; Matin et al., 2021). These factors can either help or hinder their ability to make educated choices and obtain appropriate services on behalf of their children.

Understanding the complicated interaction between information seeking behavior and socioeconomic circumstances among parents of autistic children is critical for several reasons, such as improving outcomes for autistic children, policy implications related to the autism awareness, healthcare access and equitable system. Other than that, enhancing parental well-being of parents by providing them with more effective tools and resources to navigate the challenges associated with autism spectrum disorder (Chang et al., 2015; Chu et al., 2020). It is because, from the previous observation shown when there are changes in cultural barriers and demographics creating challenges for parents of children on the autism spectrum disorder (ASD) such as low income, unmet community needs and financial support (Chu et al., 2020)

2 Literature Review

A review of the literature on prior studies that focused on health information-seeking behavior for health information requirements among parents of children with autism spectrum disorder (ASD) was undertaken. The goal of this literature review is to get a better knowledge of the current state of research in this field. Autistic parents actively seek information regarding the nature of ASD, early intervention tactics, therapeutic therapies, educational resources, support networks, and coping mechanisms. The desire to give the greatest possible care and support for their children's growth and well-being drives these information needs (Lambert & Loiselle, 2007a; Zimmerman & Shaw, 2020).

However, results from the previous research showed that there are some issues in socioeconomic percentage of health information seeking behavior among parents of autistic children. The activity of information seeking is getting slower because of the information are not related to them and some of the parents are struggling to obtain a relevant information because of having lower level of information seeking skills. The nature of the accountability and role of parents of children with autism spectrum disorder (ASD) have changed drastically time to time in different areas of information-seeking behavior. When parent start using technology as a digital platform for getting autism information health, the information overload is increased abundantly in providing a widening scope on autism health information.

Parental Health Information Seeking in the Context of Autism Spectrum Disorder (ASD)

Children who are affected with ASD will triggers the parents are looking for the solutions and research without boundaries. Parents of autistic children encounter a plethora of tasks that extend beyond traditional parenting roles. They are not just primary carers, but also champions and decision- makers for their children's well-being. Information searching becomes a key tool for parents navigating the intricacies of autism, addressing topics such as early intervention, educational services, behavioral therapy, and managing associated challenges. Parents want to learn more about accessible support services such as support groups, respite care, and financial aid program. They also want to know how to navigate the healthcare system, obtain financing for interventions, and gain access to accessible educational options because health information seeking as a lifeline inn an uncharted sea (Lambert & Loiselle, 2007b).

However, A survey of children late diagnosed with ASD in Malaysia may be impacted due to parents in Malaysia having limited knowledge or information about children with Autism (ASD) (Chu et al., 2020). There are quite number of studies that have been focused on information health seeking behavior parents on disabled children in Malaysia (Alsem et al., 2017) but not focusing on autism spectrum disorders and it's supported by (Hamzah et al., 2015). He mentioned about 762 articles has been reviewed systematically and from the only 32 articles were qualified in the search for health

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from Malaysian perspectives in Malaysia, and the rest of 22 articles was out of the theme. From the previous research, the researcher mentioned from the 762 papers was successfully obtained showed that there are no studies relating health information seeking in Malaysia are focusing on autism spectrum disorders (Hamzah et al., 2015). It will be a higher percentage for children with autism (ASD) in the Klang valley areas and it will be a benchmark for other states in Malaysia if this study will be focus on.

Socioeconomic Factors

Parents of autistic children's information-seeking behaviors are significantly influenced by socioeconomic characteristics, which include income, education, occupation, access to healthcare, and geography (He et al., 2018b; Sukeri et al., 2017). Results showed that most respondents lived in rural areas with low levels of educational attainment and socio-economic status. Most respondents only maintained follow-up appointments with hospitals and continued to advance their children. at community-based rehabilitation centers (CBRC) in Kota Bharu (Sukeri et al., 2017). Often in many cases, several authors mentioned on caring for a child with a disability contributes to higher levels of stress. (Ludlow et al., 2012) highlighted on parents will face concurrent challenges, such as the financial burden and time of medical treatment, parenting and family changes (Disorder, 2018). Most of the parents with lower income levels are complained about the financial burden that they have to fulfilling the basic needs such as high cost of food, transportation, medication and they also rely on freely accessible services, government-funded initiatives, or neighborhood assistance. Their access to specific procedures or therapies may be restricted by financial limitations (Biruk Befkadu et al., 2022).

Furthermore, the educational level of their parents may affect their children's capacity for comprehension and information analysis. Parents who are less educated than average may be better at conducting research, assessing the reliability of information sources, and promoting their children (Yan et al., 2023). Diagnosis and treatment could be delayed for parents who have limited access to healthcare. They might rely more on internet resources and informative networks. Parents with a stable socioeconomic status can affect access to healthcare services compare to parents with limited access to healthcare (Chu et al., 2020; Yan et al., 2023). The way that people search out information can also be influenced by their cultural background and level of linguistic competence. Different-background parents could run into linguistic hurdles or seek information from sources that are culturally relevant. These elements may cause changes in the kinds of information obtained and the applications to which it is put to use (Mona, 2012; Papoudi et al., 2021; Shamsudin et al., 2021).

Underpinning Theories and Models Related with Autism Spectrum Disorder (ASD)

Previous studies have been referred to several models that related to the health information seeking behavior, parents of autistic children, and related with socioeconomic influences. Wilson's model of Information Behavior (1996) explains the

information seeking behavior that highlighted the crucial of information need and behavior among the users. Users need to identify the accurate information to solve their problem or making a right decision. Other information seeking models directly focus on the health information seeking such as The Health Information Acquisition Model of Friemuth, Stein and Kean Lenz's Information Seeking, Model Longo's Et Al Expanded Model of Health Information Seeking Behavior and Andersen Behavioral Model. This model commonly exploring on how motivation and skills that parents of autistic children have when seeking information and making decision about interventions and support services. The other element is socio economic factors and it based from Longo's Et Al Expanded Model of Health Information Seeking Behavior investigate through parent's age, education level, income and occupation can create their health information seeking behavior (HISB) in finding the health information. Therefore, this paper aims to discuss on how socioeconomics factors may influence health information-seeking behavior among parent with ASD.

3 Discussions

HISB among parent with ASD has been widely discussed as there is an increasing number of ASD in the world. This paper discusses the socioeconomic elements towards HISB among parent with ASD.

Parent Age

A person's search, discovery, and use of information about diseases, health threats, and other health-related topics are all considered health information seeking behavior. There are various theories about how patients look for health information, In Longo's model, he investigates including the sorts of information sought, the characteristics of the information seeker, such as personal understanding, and many others. However, one of the notions associated to the information seeking behavior is the influence of personal characteristics like gender, age, income, and education level (Zare-Farashbandi & Lalazaryan, 2014). His model counts both active and passive information seeking behavior and the model considered to be a linear model.

Qualification

The education level of parents of autism spectrum disorder (ASD) children is a crucial socioeconomic factor that significantly influences their health information seeking behavior and access to resources. Education is linked to access to find and diverse information sources. Several research demonstrated, low family socio-economic status is one of the factors that affect the way of health information seeking from parents with low education level and household (Yan et al., 2023) compared to parents with high level of education qualification who will actively involve in children's health information seeking for the development of children with ASD (Sharabi & Marom-Golan, 2018). The relationship between socio-economic status or education status rate are higher of children whose parents have higher levels of education (Kelly

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et al., 2019). However, in Sweden, rates were higher in families with lower socioeconomic level, while a prior well-designed study in South Thames discovered that the prevalence of autism was higher in kids whose parents had completed secondary school (Rai et al., 2012).

Income

The healthcare-seeking behavior within households is influenced by individual's characteristic, the nature of their ailments, and their ability to access medical care. One of the major issues is financial barriers Previous research identified cultural tradition, place of residence, proximity to functional healthcare facilities, and financial obstacles as the primary factors inhibiting the utilization of healthcare services within health facilities. Result shown, on household in urban or rural area did not seek health care information because of they were lack of money, long distance and symptoms were not severe (Begashaw & Tesfaye, 2016). Whereas in China, (He et al., 2018a) they conclude that children from low-income families and those with less education were more likely to develop autism as children.

Occupation

Career adaptability of parents of children with autism spectrum disorder (ASD), a complex neurodevelopmental condition, is a multifaceted phenomenon that requires them to navigate an intricate interplay of caregiving responsibilities, understanding the unique needs of their children, accessing diverse resources and support networks, advocating for tailored educational and therapeutic interventions, all while managing their own career aspirations and maintaining work-life balance.

In summary, as presented in figure 1, there are four (4) factors of socioeconomics that may influenced the HISB among parent with ASD namely: parent age, qualification, income, and occupation.

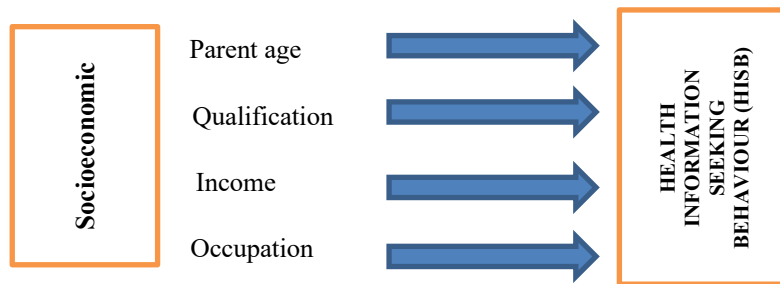


Figure 1: Proposed Conceptual Framework on Health Information Seeking Behavior and Socioeconomic Influences Among Parents of Children with Autism Spectrum disorder (ASD): Implications for Support and Interventions.

Altiere et al. (2022) mentioned in his previous research, due to the needs of children, parents tried to organize their working and lives according to the needs and behaviors of children. There are four significant themes that have arisen, indicating trauma or changes in work-like behavior following ASD, career adaptability, the effects of the covid-19 epidemic, and post-interview knowledge of a specific sample. Due to those issues, parents are having difficulties in maintaining the balance between working life and family functioning. According to (Montes & Halterman, 2008), when compared to parents of usual development children, parents of children with ASD were more likely to change jobs, quit jobs, or not take jobs.

4 Data and Methodology

A survey on health information seeking behavior among parents and socioeconomic influences among parents with autism was developed to validate the suggested framework and meet the goal of this research. The survey aims to look at the potential determinants and relationships between socioeconomic attributes, such as parent age, qualification, education, and occupation, that may influence parents' health information seeking behavior. Children with autism spectrum disorder (ASD). This research is one of the contributions that has investigated deeper aspects of HISB among parents of children with ASD attributes by linking socioeconomic attributes that positively used and related to the implications for support and interventions. The future research might focus on confirmation of the above relationships in other setting and enhance another seeking process guidance for parents in health information seeking behavior.

5 Conclusions

In order to determine whether the information retrieved successfully or failed, it comes from demands upon formal and informal information. If the user feels satisfied with the result, the individual will make use the information either in fully used or partially. With a different socio-economic level and structural status with a limited access also will be part of the deterrents HISB challenges. The significance of this study is to address the gap's issues in the existing health information seeking behavior and socioeconomic influences among parents with ASD children. Indirectly it can lead to improve the socioeconomic influences for the betterment. It stands for not just the search for solutions but also for a better future for their children as well as for hope and empowerment.

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