KNOWLEDGE OF AUTISM SPECTRUM DISORDER AMONG

PARENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

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by

NAZIHAH BINTI MOHMAD DIAH

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the requirements for the degree of
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CERTIFICATE

This is to certify that the dissertation entitled KNOWLEDGE OF AUTISM SPECTRUM DISORDER AMONG PARENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA is the bona fide record of research work done by Ms NAZIHAH BINTI MOHMAD DIAH during the period from October 2023 to June 2024 under my supervision. I have read this dissertation and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation to be submitted in partial fulfillment for the degree of Bachelor of Nursing (Honours).

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated and duly acknowledged. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at Universiti Sains Malaysia or other institutions. I grant Universiti Sains Malaysia the right to use the dissertation for teaching, research and promotional purposes.

Signature

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Lists of Symbols and Abbreviations

ASD -Autism Spectrum Disorder

USM -Universiti Sains Malaysia

M-CHAT - Modified Checklist for Autism in Toddlers

TAHAP PENGETAHUAN GANGGUAN AUTISME SPEKTRUM DALAM KALANGAN IBUBAPA DI HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRAK

Gangguan autisme spektrum (ASD) semakin meningkat di seluruh dunia. Sebagai penjaga, keupayaan ibubapa untuk mengenali dan bertindak terhadap gejala autisme adalah penting untuk menyediakan penjagaan kesihatan yang optimum kepada kanak-kanak autisme. Kajian ini dijalankan untuk menentukan tahap pengetahuan ASD dalam kalangan ibubapa di Hospital Universiti Sains Malaysia. Kajian keratan rentas deskriptif digunakan dalam kalangan ibubapa yang tidak mempunyai anak autistik dan bukan profesion perubatan. Saiz sampel sebanyak 94 ibubapa telah dipilih. Skor pengetahuan dikategorikan kepada tahap rendah, tahap sederhana dan tahap pengetahuan tinggi. 63.8% daripada responden mempunyai pengetahuan sederhana tentang ASD dan 2.1% responden mempunyai tahap pengetahuan tinggi. Terdapat 34% responden mempunyai tahap pengetahuan rendah. Tahap pengetahuan mengenai ASD dikaitkan secara signifikan dengan jantina (p=0.008), tahap pendidikan (p=0.002) dan pendapatan bulanan (p=0.004). Penemuan ini menekankan peranan penting yang dimainkan oleh tahap pendidikan dan status sosio-ekonomi dalam membentuk pemahaman ibu bapa tentang autisme. Batasan dalam kajian ini adalah kaedah persampelan yang mudah. Selain itu, kebanyakan responden adalah ibu. Sebahagian daripada responden melaporkan soal selidik terlalu panjang. Kajian masa depan harus mempertimbangkan untuk mengurangkan bilangan item dan memasukkan soalan tentang status sosiodemografi, seperti kawasan luar bandar atau kawasan bandar, untuk

meneroka pembolehubah yang mempengaruhi pengetahuan ASD. Kajian masa depan harus bertujuan untuk menangani batasan ini dengan menggunakan sampel yang lebih pelbagai dan mewakili, memastikan keseimbangan jantina dan menggunakan reka bentuk membujur untuk meningkatkan kesahihan penemuan. Kesimpulannya, menangani jurang sosio-demografi adalah penting untuk meningkatkan pemahaman ibu bapa tentang autisme. Penggubal dasar, petugas kesihatan dan pendidik harus bekerjasama untuk merangka intervensi yang berfokus yang memastikan akses yang saksama kepada maklumat dan sumber.

KNOWLEDGE OF AUTISM SPECTRUM DISORDER AMONG PARENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRACT

Autism spectrum disorder (ASD) is growing increasingly common around the world. As primary carers, parents' capacity to recognise and respond to autism symptoms is crucial for providing optimal healthcare to autistic children.This study was conducted to determine the level of ASD knowledge among parents at Hospital Universiti Sains Malaysia. A descriptive cross-sectional study was used among parents who did not have an autistic children and not a medical profession. A sample size of 94 parents was selected. A knowledge score was categorized into low level, medium level and high level of knowledge. Result showed 63.8% of the respondents had medium knowledge about ASD and only 2.1% respondents had high knowledge. There was 34% of the respondents had low level of knowledge. The level of knowledge regarding ASD was significantly associated with gender (p=0.008), educational level (p=0.002), and monthly income (p=0.004). The findings underscore the significant role that educational level and socio-economic status play in shaping parental understanding of autism. The limitations in this study was a convenient sampling method. Besides, most of the respondents were mothers. Some of the respondents reported the questionnaire was too long. Future studies should consider reducing the number of items and include questions about sociodemographic status, such as rural areas or urban areas, to explore variables that influence ASD knowledge. Future studies should aim to address these limitations

by employing more diverse and representative samples, ensuring gender balance and utilizing longitudinal designs to enhance the validity of the findings. In conclusion, addressing socio-demographic gaps is critical for increasing parental understanding of autism. Policymakers, healthcare providers, and educators should work together to create focused interventions that ensure equitable access to information and resources.

CHAPTER 1

INTRODUCTION

1.1 Background of the study

According to the American Psychiatric Association, autism spectrum disorder (ASD) refers to a complex developmental condition involving persistent challenges with social communication, restricted interests and repetitive behavior (American Psychiatric Association, 2024). It affects how a person acts and interacts with others, communicates, and learns (Andoy Galvan et al., 2020). ASD is a neurodevelopmental disorder that appears before the age of 3 years (Wetherston et al., 2017).

The prevalence of ASD has risen dramatically in children lately, from one in 110 (Accordino, Kidd, Politte, Henry, & McDougle, 2016) to one in 88 (Zablotsky, Bramlett, & Blumberg, 2017) and most recently, to one in 59 (Cheryl Bodiford Mcneil, Lauren Borduin Quetsch, & Anderson, 2018). However, the prevalence of ASD in Malaysia remains unknown. There is no updated official statistic on ASD in Malaysia (Eow, Gan, Lim, Awang, & Mohd Shariff, 2020). There is no local epidemiological study on ASD prevalence in Malaysia. However, in a feasibility study on the use of Modified Checklist for Autism in Toddlers (M-CHAT) among children of 18 to 36 months of age in child health clinics by the Ministry of Health Malaysia, the prevalence of ASD in Malaysia was approximately 1.6 in 1,000. In the USA, the overall prevalence of ASD is 14.7 per 1,000 (one in 68) (Ministry of Health, 2014). Compared to previous studies in 2017, 2018, and 2019, there is an increasing trend in the prevalence of ASD due to increasing awareness among parents.

Autistic children are different from children with typical development (TD) in terms of social interaction, communication, food selectivity, and feeding patterns (Sharp et al., 2013). ASD is categorized under learning disabilities along with other cognitive and developmental disabilities but not as an individual disorder in Malaysia (Jabatan Kebajikan Masyarakat, 2017). Early diagnosis and intervention are critical for improving outcomes in children with ASD. Parents play a pivotal role in recognizing early signs and seeking timely professional help, making their knowledge and awareness of ASD vital. Raising an autistic child can be overwhelming for parents and families. An autistic child may require lifelong support and services to improve their ability to function at home, school, or the community (Russa, Matthews, & Owen-DeSchryver, 2014).

In Malaysia, awareness and understanding of ASD among parents vary significantly, influenced by factors such as educational level, socio-economic status, and access to healthcare resources. Despite efforts to increase public awareness, many parents still lack adequate knowledge about ASD, leading to delays in diagnosis and intervention.

Previous studies have highlighted the importance of parental education in understanding and managing ASD. However, there is limited research specifically focusing on the Malaysian context, particularly within the setting of a major healthcare institution like HUSM. This study aims to bridge this gap by assessing the level of ASD knowledge among parents attending the pediatric clinic at HUSM.

By identifying knowledge gaps and their associated factors, this research will contribute to the development of targeted educational programs and support services. Enhancing parental awareness is essential for promoting early detection, improving intervention strategies, and ultimately bettering the quality of life for children with ASD and their families.

1.2 Problem Statement

Understanding the level of knowledge about ASD among parents is crucial for early diagnosis and intervention. This study explores parents' awareness at HUSM, aiming to identify gaps and improve educational outreach efforts. Prevalence of ASD has increased rapidly include more awareness and understanding of ASD, resulting in better diagnostic tools and more parents seeking ASD evaluations for their children (Rice et al., 2012). Opposite with middle- and low-income countries, ASD was late diagnosed that cause delays in treatment, and resulting the increasing of medical costs, long term special education needs and a greater reliance on continual living support (Montiel-Nava, Chacín, & González-Ávila, 2017).

A previous study conducted in Malaysia among parents showed that the majority of respondents had good knowledge of ASD. Females were more prone to having good knowledge rather than men (Kaman, Ishak, & Muhammad, 2023). However, a study conducted in Malaysia among public by Azmi et al. (2022) showed that the knowledge of ASD in the moderate level. A study conducted by Chu et al. (2021) in general public in Malaysia showed that by enhancing knowledge about ASD could increase the awareness regarding ASD. There were many studies have done to determine the knowledge of ASD however it appear only a few studies that specify to parental population.

Therefore, this study was conducted to determine the level of knowledge of ASD among parents in Hospital USM. Moreover, this study also provided an overview of demographic characteristic that associated with the level knowledge of ASD in Malaysia. Hence, improvement could be done in order to provide awareness about ASD in future. The knowledge about the disease, understanding about sign and symptoms, risk factors and complication allowed parents to assess their children and report any

abnormalities to the healthcare provider. Besides, it could enhance involvement in disease management and improve positive outcomes.

1.3 Research Question

i) What is the level of knowledge of ASD among parents in Hospital USM ?

ii) Is there any association between demographic characteristics with the level of knowledge of ASD among parents in Hospital USM?

1.4 Research Objective

1.4.1 General Objective

To determine the knowledge of ASD among parents and factor associated with knowledge in Hospital USM.

1.4.2 Specific Objective

The specific objectives of this study are :

i)   To identify the level of knowledge of ASD among parents in Hospital USM.

ii) To determine the association between demographic characteristics (gender, education level, monthly income and marital status) with the level of knowledge of ASD among parents in Hospital USM

1.5 Hypothesis

Ho – There is no significant association between demographic characteristics with the level of knowledge of ASD among parents in Hospital USM

Ha - There is significant association between demographic characteristics with the level of knowledge of ASD among parents in Hospital USM

1.6 Significant of study

While there is extensive research on ASD, there is limited information on the specific knowledge levels among parents in Malaysia. This study will fill this gap by providing current data on parental knowledge and understanding of ASD within the local context. The alarming signs of ASD include delayed language development, repetitive behaviour, non-responsiveness to their names, and communication delays. The awareness of ASD needs to be adequate (Anwar, Tahir, Nusrat, & Khan, 2018). There is a high chance of misdiagnosis or late diagnosis if there is a lack of awareness about the sign of this disorder (Anwar, Tahir, Nusrat, & Khan, 2018).

The author aims to assess the level of knowledge of ASD in parents with typically developing children in Hospital USM, Kota Bharu, Kelantan, especially since the estimated number of autistic children incidence is as high as one in 68 children (Christensen et al., 2016). The findings would identify areas where parents might lack knowledge, allowing healthcare providers and educators to design targeted educational programs. These interventions can enhance parents' ability to recognize early signs of ASD, seek timely diagnosis, and access appropriate interventions, ultimately improving outcomes for children with ASD.

The results can inform healthcare policy by highlighting the need for resources and support systems for parents. Policymakers can use this information to allocate funding, develop training programs for healthcare providers, and create public awareness campaigns about ASD. The result in knowing regarding the awareness and knowledge are up to the mark, thus helping in decreasing the burden of parents and teachers and eradicating any confusion and discomfort regarding the child's behaviour (Anwar, Tahir, Nusrat, & Khan, 2018).

By understanding the knowledge levels of parents, healthcare professionals at Hospital USM can tailor their communication and support strategies to better meet the needs of families. This study added to the global body of research on ASD, offering insights that may be applicable to other regions with similar socio-cultural contexts. It provides a basis for comparative studies and contributes to the broader understanding of ASD awareness and education worldwide. By addressing these aspects, this study aims to make a meaningful contribution to the field of ASD research, with practical implications for education, policy, and clinical practice.

1.7 Conceptual and operational definition

Knowledge	According to Cambridge Dictionary (2019), knowledge means the understanding of or information about a subject that someone gets by experience or study, either known by one person or other people generally. In this study, knowledge refers to information or understanding about autism spectrum disorder. The source of information is through experience, media social or others.
Parents	According to Cambridge Dictionary (2019), parents refer to a mother or father of a person or an animal, or someone who looks after a person in the same way that a parent does. In this study, parents refer to a person or caregiver or father or mother who take over or responsible to the child.

Autism spectrum disorder	Based on the Diagnostic Statistical Manual of Mental Disorders, 5th edition (DSM-5) American Psychological Association (2013), autism spectrum disorder is a summary term used for a combination of social communication deficits and repetitive and restricted behaviours.
	In this study, autism is a lifelong neurodevelopment condition that affects how a person acts and interacts with others, communicates, and learns (Andoy Galvan et al., 2020).

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviews a series of literature regarding the characteristic of ASD, knowledge of ASD and the association between selected demographic characteristics variable (gender, education level, monthly income and marital status) with knowledge of ASD. The general findings of the literature review presented in several sections according to the key aspects of the research. The recent articles and related issues were included in this chapter. The chosen conceptual framework to guide this proposed study was discussed.

2.2 Autism spectrum disorder

ASD described a condition complex congenital disorder characterized by neurological deficits that manifest prior to the age of three years, with core symptoms of impairment in social interaction and communication, as well as restricted and repetitive behaviours of varying severity (Casey & Strain, 2016). Besides, Diagnostic and Statistical Manual of Mental Disorders (DSM-5) also classified ASD into three levels of severity, which are level one is requiring support, level two is requiring substantial support and level three is requiring very substantial support (Casey & Strain, 2016). The level three of ASD severity is based on social communication impairments and restricted repetitive patterns of behaviour. On the other hand, restricted and repetitive behaviour may include stereotypes or repetitive motor movements, use of objects or speech, insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or nonverbal behaviour, highly restricted interests with high intensity or focus,

and hyper or hypo-reactivity to sensory input or unusual in sensory aspects of the environment (Deka, Feeley, & Lubin, 2016). Global epidemiological data indicate that about one to two percent of the world's population has ASD, which corresponds to about 50 million individuals with the disorder (Baxter et al., 2015). Nevertheless, uncertainty exists in the incidence of ASD, particularly as it pertains to its causes and significance, with no definite answer available as to why the incidence of ASD increased rapidly during the 1990s and has continued to do so in the 2000s (Neggers, 2014).

The cause of ASD is multi factorial and even though it is thought that both genes and environment may play important roles, the previous studies focused on obstetric, mode of delivery, birth order, parental age and parental age gap (Andoy Galvan et al., 2020). Obstetric mode of delivery has a significant impact in both early and late outcomes in a child's life. Although the causal relationship between the type of obstetric delivery and ASD is not established, there was some evidence of association between the two. It has been observed that Caesarean section tends to increase the risk of ASD (Al-Zalabani, Al-Jabree, & Zeidan, 2019).

Many studies showed strong evidence that advancing paternal age at the time of birth offspring increased the risk of autism (Sandin et al., 2015). Parental age gap showed that moderate-to-large (10 years or more) difference between the parental age resulted in an increased risk of ASD (Sandin et al., 2015).

2.2.2 Knowledge of ASD

The level of knowledge about ASD among parents can significantly impact the early identification, intervention, and overall management of the condition. Early

diagnosis and intervention are critical, as they can greatly enhance developmental outcomes and improve quality of life.

There were limited studies conducted regarding knowledge of ASD among parents in Malaysia. A previous study conducted among parents in Malaysia showed that majority of the respondents had good knowledge of ASD and females were more prone to having a good knowledge rather than men (Kaman, Ishak, & Muhammad, 2023). However, a study was conducted in Malaysia among general public by Azmi et al. (2022) showed that majority respondents had a medium knowledge regarding ASD (71.17%). Similar finding in a study by Md Shamsudin and Abd Rahman (2017) showed (76.7%) of respondents reported familiarity with the word autism but they did not know the physical appearance of the autistic children. In fact, most of the respondents did not know about the actual characteristics of autistic children and confused with the characteristic of hyperactive children (Md Shamsudin & Abd Rahman, 2017).

Based on the study (Wetherston et al., 2017) in Nigeria, shows the prevalence of parents that unfamiliar with the treatment of ASD were 53.3% and there were only 13.4% of prevalence shows that parents had a practical understanding of the treatment for ASD. There are 69% of prevalence shows that parents defaulted on the treatment of ASD because they stated that the treatment was ineffective. Parents felt that treatment for ASD was costly. 73.6% of prevalence shows that parents stated that the services for ASD are extremely expensive and there is a lack of government support.

A study by Anwar, Tahir, Nusrat, and Khan (2018) in Karachi, Pakistan showed parents represented poor knowledge regarding the ASD. The lack of adequate knowledge about ASD can adversely affects early identification and intervention of ASD (Hui et al., 2021). Lower education level and lower socioeconomic status are

among the main reasons which had caused inadequate knowledge about ASD in the community (Pickard & Ingersoll, 2015).

A study conducted in Kingdom of Saudi Arabia by Alsehemi, Abousaadah, Sairafi, and Jan (2017) among parents showed that there were 88% of the respondents responded positively about ASD, however, the rate degree of knowledge about ASD, only 9% of the respondents were high knowledge, and the majority (41%) of the respondents were low knowledge.

Previous study was conducted by Waddah M. Alalmaei Asiri et al. (2023) among parents in Southwestern Saudi Arabia showed that majority of the respondents (85.5%) had poor knowledge regarding ASD and only (14.5%) of the respondents had good knowledge. Parents were the first observer of any unusual behaviour compared to other children or siblings of the same age group. Poor knowledge regarding the ASD increased the chance of misdiagnosis or late diagnosis (Liu et al., 2016).

Previous study was conducted among nurses in Ghana showed that majority of the respondents had low knowledge in identifying characteristics of ASD (Sampson & Sandra, 2018). Psychiatric nurses showed a good knowledge in ASD (61.9%) after encountering previous autistic children compared to paediatric nurses (58.5%). This finding showed that there was a statistical difference between the previous encounter with ASD and knowledge of ASD. However, the overall knowledge level about ASD among both nursing groups was very low (Sampson & Sandra, 2018).

If the parent recognized the symptoms of autism in their child, like lack of eye contact, hyperactivity, increased attachments to toy, no reaction to verbal cues, etc., then they could seek medical help (Anwar et al., 2018). More knowledge and understanding of ASD had led to better diagnostic techniques and a rise in the number of parents seeking ASD examinations for their children, which were some potential explanations

for why the prevalence of ASD had increased so quickly (Rice et al., 2012). While there had been global effort to educate the public and raise awareness about ASD, particularly in the United Kingdom (UK) and the United States (US), less had been done in middle- and low-income nations (Scherzer et al., 2012).

2.2.3 Factor contributing the knowledge of ASD

2.2.3.1 Gender and the knowledge of ASD

A previous study conducted in Malaysia showed that female has statistically significant higher score for knowledge of autism respectively (Anwar et al.2018) and same finding with the other studies that conducted in Karachi that had a greater number of females identified correct opinions regarding autism in comparison to males (Ellias & Shah, 2019).

A study was conducted by Alsehemi, Abousaadah, Sairafi, and Jan (2017) in Kingdom of Arab Saudi showed that females (57%) were more knowledgeable about the ASD compared to males which may reflect improved exposure or their interest. Similar finding with a study conducted in Ghana showed that 84.6% were females had a good knowledge and 15.5% were males had a poor knowledge (Sandin et al., 2015).

2.2.3.2 Educational level and the knowledge of ASD

Higher educational levels were also associated with increased levels of knowledge about ASD (Liu et al., 2016) and more positive attitudes towards communication disorders (Jones et al. 2021). This prediction was made since the evidence in the current study and past studies Mitchell and Locke (2014) had proven that ASD knowledge was closely related to one's educational level.

Previous study conducted in United Kingdom showed that children of mothers with higher education status (A-level or above) were twice as likely to have a diagnosis of ASD recorded when compared to children of mother with lower levels of education (Kelly et al., 2017). A study conducted in National University Hospital in Singapore showed that family socio-economic status and parental education were more strongly associated with symptoms of ASD among children than intensity of early therapeutic intervention (Nye, 2021).

A case-control study, using hospital-based data in Zhengzhou, a central city in China, found that lower socioeconomic status, measured by parental education, was related to higher risk of childhood ASD (He et al., 2018). These studies proved that the level of education had a statistically significant associated with knowledge of ASD in providing for early intervention. The highest prevalence of childhood ASD was in low-education families. Higher household income and family adults' education was each associated with lower likelihood of ASD (He et al., 2018).

2.2.3.3 Monthly income and the knowledge of ASD

The increasing number of ASD cases resulted in higher healthcare expenses for parents who seek consultation and treatment at various facilities (Eow et al., 2020). Many public and private autism centres were established to accommodate the assessment and intervention needs of the children with ASD. Autistic children required a higher frequency of healthcare service visits and special educational services apart from prescription drug use (Eow et al., 2020). Families raising autistic children contributed significant amounts to the cost of care. Apart from the financial burden and time spent on special care required, the diagnosis of ASD might also subject the parents

to stigmatisation in the form of peer rejection, stereotyping, and exclusion. These stigmas represented further challenges for the parents to raise autistic children.

According to the previous study conducted by Pickard and Ingersoll (2015) in New York found that parents of autistic children that have high socioeconomic status were more aware of service options for their children in comparison to parents of a lower socioeconomic status. Parents from the upper class identified more signs and symptoms of ASD compared to parents with lower socioeconomic status. This showed that socioeconomic status has significant for knowledge of ASD. Opposite with previous study in Denmark, there was no relationship between socioeconomic status and knowledge of ASD (Kelly et al., 2017). On the other hand, studies in European and other countries revealed a negative or no relationship between SES and childhood autism. For example, an increased risk of ASD was associated with lower socioeconomic status in Sweden, France, and Japan (Delobel-Ayoub et al., 2015). In many parts of the world, autistic children were not being diagnosed until three or four years old. This was late diagnosis detected, which frequently occurs in middle- and low-income countries, caused delays in treatment, resulting in increased medical costs, long term special education needs, and a greater reliance on continual living support (Bello-Mojeed et al., 2017). Previous study conducted in China showed that children in families with socioeconomic disadvantage, in the form of lower family income and education, had greater risk of ASD (He et al., 2018).

Thus, increased knowledge and awareness of a specific disorder such as mental illness may positively affect people's attitudes and behaviours, reducing fear, avoidance, and discrimination (Chu et al., 2021).

2.2.3.4 Marital status and the knowledge of ASD

Marital status can significantly influence the level of knowledge that parents have about ASD. Parental conflict, divorce, and separation are likely to make the diagnostic journey more difficult.

A study was conducted in United States showed that children whose parents were not together, whether it was secondary to divorce, separation or never being together had demonstrated a large disparity in age at diagnosis about 1 year and 4 months (Huang et al., 2014). For children whose parents were present during the diagnostic journey, there was an obvious urgency for examination around the age of three, with the age of diagnosis rapidly reducing after that. For parents of children who were not together, the first increase in age at diagnosis occurred around the age of four. This showed that divorced parents had poor knowledge regarding ASD due to face greater time and financial constraints, which can limit their ability to seek out information and resources about ASD. The later age of diagnosis could be related to the interference of relationship strife, either between partners or over the child's developmental state (Huang et al., 2014). It could also result from difficulties buying and arranging services, particularly for single parents, due to a lack of support with daily activities (Huang et al., 2014).

The dynamics of single-parent households, dual-parent households, and blended families each offer unique challenges and opportunities that affect how parents understand and manage autism. In dual-parent households, responsibilities related to child-rearing and seeking information about developmental disorders can be shared. This can lead to a more collaborative approach to understanding ASD, as both parents can contribute to research, attend medical appointments, and participate in support groups (Kalb et al., 2021).

2.3 Conceptual Framework of the Study

Health belief model (HBM) is utilized as conceptual framework in guiding this study. HBM is an instrument developed 1950s by a group of social psychologists, Irwin M. Rosenstock, Godfrey M. Hochbaum, S. Stephen Kegeles and Howard Leventhal at United States (U.S). HBM is a psychological framework that explains and predicts health behaviors by focusing on the attitudes and beliefs of individuals. When applied to understanding parents' knowledge of ASD, the HBM can offer valuable insights into how parents perceive and respond to information about ASD. HBM is composed of components which are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action and self-efficacy.

Perceived susceptibility refers to parents' beliefs about the likelihood of their child developing ASD. If parents recognize that ASD is a possible condition for their child, they may be more motivated to seek information and resources. Perceived severity involves parents' understanding of the seriousness of ASD and its potential impact on their child's life. Higher perceived severity can lead to increased awareness and proactive behavior in seeking diagnosis and intervention. Perceived benefit pertain to parents' beliefs in the effectiveness of actions available to reduce the risk or severity of ASD. If parents believe that early diagnosis and intervention can significantly benefit their child, they are more likely to pursue and value ASD related knowledge, perceived barriers are the obstacles parents believe they might face in seeking information or accessing services for ASD. Barriers can include a lack of knowledge, financial constraints, or limited access to healthcare professionals. Identifying and addressing these barriers is crucial for improving parental awareness and knowledge of ASD, cue of action is the component that includes external factors that trigger parents to seek

information about ASD. Cues can be events like observing symptoms in their child, receiving advice from healthcare providers, or public awareness campaigns. Self-efficacy is refers to parents' confidence in their ability to understand ASD related information and effectively manage their child's condition. Higher self-efficacy can encourage parents to engage more deeply with educational resources and healthcare services. By applying the HBM, interventions can be designed to enhance parents' perceptions of susceptibility and severity of ASD, emphasize the benefits of early intervention, and reduce perceived barriers. For instance, educational programs at HUSM could provide comprehensive information on the signs and symptoms of ASD, the importance of early diagnosis, and the effectiveness of interventions. Additionally, support groups and counseling services could help boost parents' self-efficacy and provide the necessary cues to action.

Understanding and utilizing the HBM can guide healthcare providers and educators in developing strategies to improve ASD awareness and knowledge among parents, leading to better health outcomes for children with ASD.
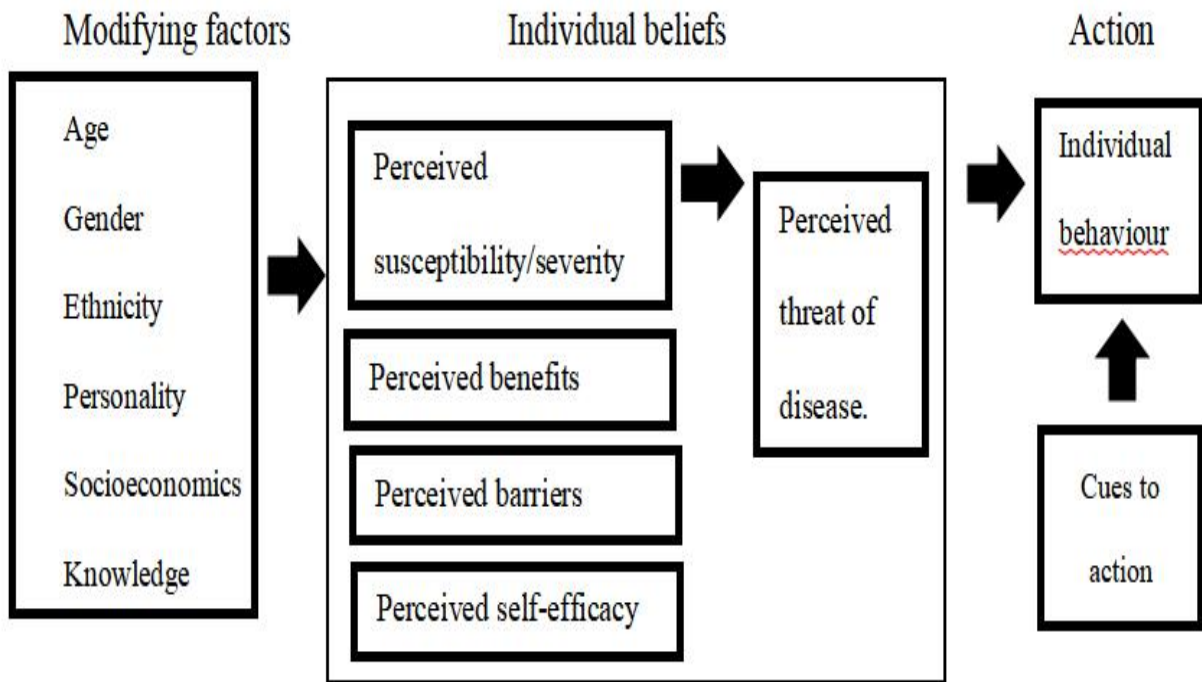
Figure 2.1 : Structure of the Health Belief Model (Pignone et al.,2011)

HBM explained the knowledge of ASD among parents to change their health beliefs through knowledge of ASD about the cause, sign and symptoms and interventions.

Modifying factors

Individual Beliefs

Action

Demographic chasracteristic (age,parents'age parents' gender, educational level, monthly income and marital status) and level knowledge in ASD.

Perceived susceptibility to ASD in parents. Perceived severity to ASD in children

Perceived benefits of knowledge in ASD

Perceived barriers

Perceived self-efficacy

Perceived threat of disease

Likelihood of positive behaviours

Cues to action, health education

Figure 2.2: Conceptual framework adopted from theory of Health Belief Model (HBM)

CHAPTER 3

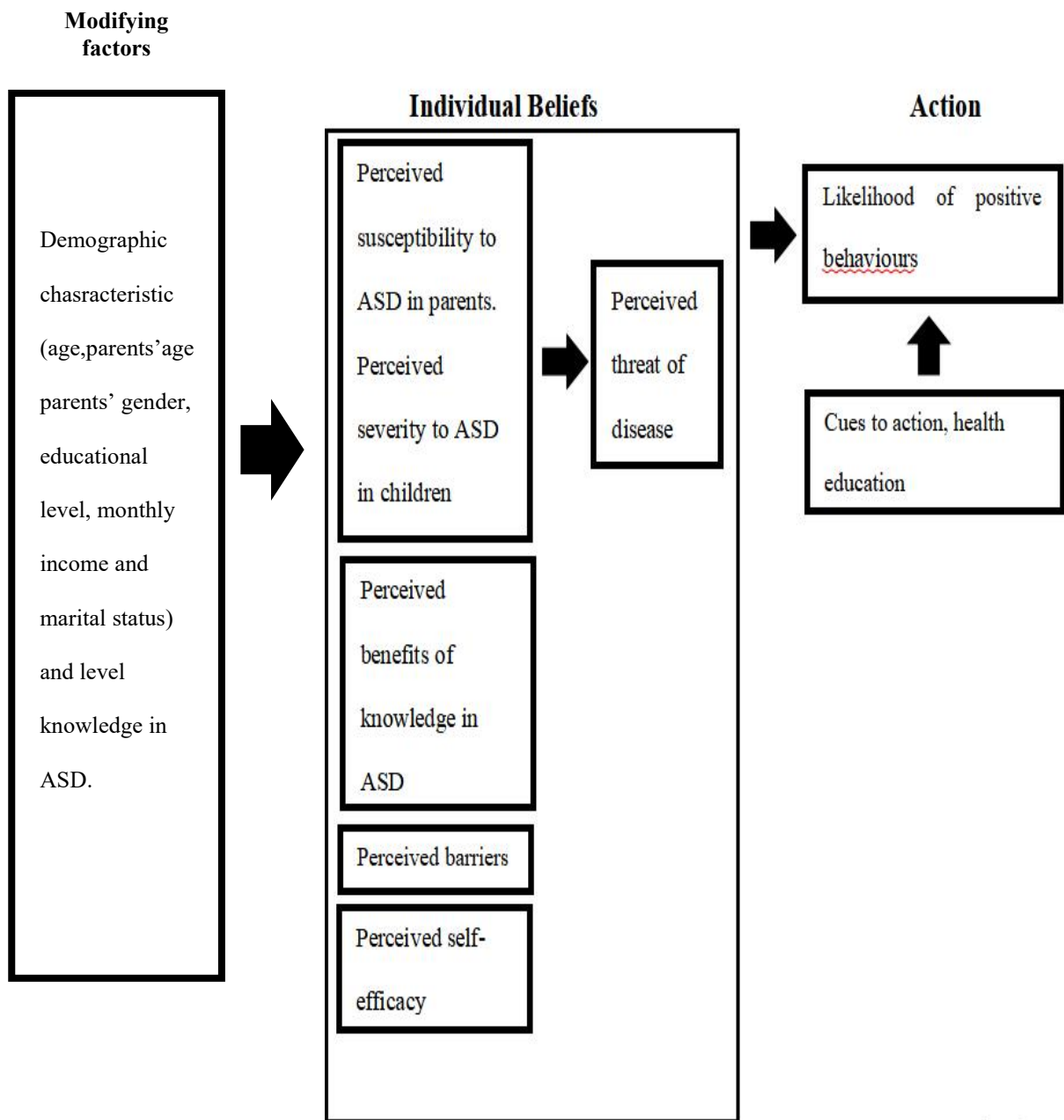# RESEARCH METHODOLOGY

3.0 Introduction

This section discussed the research methodology, included research design, duration, sampling strategy, instrumentation, data analysis, anticipated study results, and ethical considerations.

3.1 Research Design

In this study, the level of knowledge about ASD was assessed among parents who did not have autistic's child using a descriptive cross-sectional study design. A cross-sectional study provided a snapshot of the current level of knowledge about ASD among parents at a specific point in time. This study design was typically less time-consuming and more cost-effective compared to longitudinal studies. They could be conducted relatively quickly, allowing researchers to gather data and analyze results in a shorter timeframe. Besides, cross-sectional study was effective in identifying associations between variables, such as parental education level, socio-economic status, and knowledge of ASD. This can help highlight key factors that influence parental knowledge and understanding of ASD.

3.2 Research setting and population

The location of study was Paediatric Clinic in Hospital Universiti Sains Malaysia. Hospital USM was chosen for research location because Hospital USM's pediatric clinic offers specialized services and comprehensive care for children, including those with developmental disorders like ASD. This clinic served a diverse demographic, providing a broad spectrum of socio-economic and educational backgrounds, which is essential for understanding variations in knowledge and awareness of ASD. This ensures access to a

relevant patient population. Duration for this study was conducted for 1 year , starting from October 2023, and the data was collected from January 2024 to March 2024. The general populations of study were parents or caregiver in Paediatric Clinic in Hospital USM. The target populations of study were parents either father or mother or caregivers of children who were continuing for paediatric follow up in Paediatric Clinic in Hospital USM.

3.3 Sampling Plan
3.3.1 Subject Criteria – Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Parents either mother or father or caregivers of children aged between 11 – 30 months who came with child for continued the treatments (Shrestha, Dissanayake, & Barbaro, 2021).	1. Mother, father or caregiver belong to the medical profession. 2. Those who had autistic children. 3. Those who could not completely comprehend English and Bahasa Melayu (Anwar, Tahir, Nusrat, & Khan, 2018). 4. Respondents who involved in pilot study.

3.3.2 Sample size estimation

Single proportion formula was used to calculate the sample size estimation for first objective.

$$n = \left[\frac{Z}{\Delta}\right]^2 p(1-p)$$

n = Sample size

Z = 95 % confidence interval (CI) = 1.96

Δ = precision = 0.05

p = anticipated population proportion

Objective 1

For first objective, to determine the level of knowledge of ASD among parents. According to previous study, the prevalence of the level of knowledge of ASD among parents was 5.80% (Shrestha, Dissanayake, & Barbaro, 2021), thus

$$n = \left[\frac{1\cdot96}{0.05}\right]^2 0.058(1-0.058)$$

n= 84

After considering 10% drop out,

84 x 10%:10

n= 94

The minimal sample size was 84 and after considering 10% drop out, the calculated sample size was 94.

Objective 2

For second objective, to determine the association between demographic characteristics with level of knowledge of ASD among parents in Hospital USM, two proportion was used.

$$n = \frac{p1(1-p1) + p2(1-p2)(za + z\beta)2}{(P1 - P2)2}$$

n = required sample size

z_a = value of the standard normal distribution curve cutting off probability Alpha (α) in one tail for one-sided alternative or $\frac{\alpha}{2}$ in each tail for a two-sided alternative (z 0.05=1.96)

z_β = Power of study, 80% (z_β = 0.84)

p = estimated proportion of an attribute that is present in the population

p^1 = high educational level (Shrestha, Dissanayake, & Barbaro, 2021)

p^2 = low educational level (Shrestha, Dissanayake, & Barbaro, 2021)

$z = 1.96, \Delta = 0.05, p1 = 46.5\%, p2 = 22.9\%$

$$n = \frac{0.465(1 - 0.465) + 0.229(1 - 0.229)(1.96 + 0.84)2}{(0.465 - 0.229)2}$$

= 26

The minimal sample size was 26, and after considering a 10% drop out, the sample size calculated was 36.

The bigger sample size of 94 was taken as larger sample size to create a more significant result.

3.3.3 Sampling Method

The study was conducted by convenient sampling method by utilizing the inclusion and exclusion criteria demonstrated above. This study was carried out by distributing questionnaires to 94 parents either mothers or fathers or caregivers of children aged between 11 – 30 months, who came with the child for continued treatments.

The convenience sampling technique was one of the best methods of sampling distribution due to time, budget or logistical constraints. Participants were selected based on their availability and willingness to participate.

3.4 RESEARCH INSTRUMENT

Data was collected from the respondents by using a structured and self-administrated questionnaire to incorporate a range of information. This questionnaire was adopted and modified from Shrestha, Dissanayake, & Barbaro (2021) in an open access questionnaire.

3.4.1 Questionnaire

The questionnaire was divided into two sections.

Section A: Socio-demographic data

Section A consisted of information on the child's age, parents, parents' age, educational level, monthly income and parental status.

Section B: Knowledge of autism

Section B consisted of 22 modified items adopted from previous research in assessing parents' knowledge on autism symptoms, epidemiology, diagnosis, and intervention (Shrestha, Dissanayake, & Barbaro, 2021). The items related to symptoms including social communication and interaction behaviour, interests or activity were adapted from Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (DSM-5); (Casey & Strain, 2016).

Inclusion of the study items measured knowledge on epidemiology, diagnosis and intervention was based on previous research (Lynn Kern Koegel, Koegel, Ashbaugh, & Bradshaw, 2013). All items had three response choices: "agree", "disagree", and "do not know". Individual's responses were counted and displayed using percentages and frequency. A knowledge score was categorized to reflect a participant's opinions about ASD and its signs and symptoms by assigning one mark to each correct answer.