

# Challenges in Healthcare Management of Individuals with Special Needs in Malaysia: Perceptions of Caregivers

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**ABSTRACT** **Aims and Objectives:** A “caregiver” is responsible for managing the basic needs of others, including individuals with special needs (IWSNs). Caregivers play an important role in the well-being of IWSNs, though caring can lead to a decline in health and quality of life. This qualitative study aimed to investigate the perceived healthcare challenges faced by caregivers of IWSNs in Malaysia. **Materials and Methods:** Thirty-two primary caregivers were interviewed via audio-recorded semistructured focus group discussions to investigate their perceived barriers and challenges in caring for IWSNs. The qualitative data were then analyzed via thematic analysis. **Results:** Thirty-two participants took part in a total of nine discussion sessions, where the majority were females ( $n = 29$ ; 90.63%) and from the Malay race ( $n = 30$ ; 93.75%). Most of the IWSNs under their care had autism ( $n = 11$ ; 34.38%) and were between 6 and 10 years of age ( $n = 13$ ; 40.63%). The main themes identified were related to healthcare services, support systems, caregivers’ personal factors, and IWSN issues. Within the healthcare services domain, themes regarding the accessibility and appropriateness of healthcare facilities and the attitudes of staff were uncovered, whereas in the support system domain, themes pertaining to community and peer, family, and governmental support were discussed. In the domain of caregivers’ personal factors, themes regarding stress with the burden of care and feelings of guilt were noted, and in the area of IWSN factors, the theme of behavioral difficulties exhibited by IWSNs was discussed. **Conclusion:** Primary caregivers in Malaysia face challenges with healthcare facilities and staff, gaining support from the community, family, and government, burning out, and feeling guilty as well as behavior issues of their IWSN. Thus, understanding these challenges is vital in providing healthcare services that cater to not only IWSNs but also their caregivers to ensure the success and well-being of all involved.

**KEYWORDS:** Barriers, caregivers, disability, healthcare

Received : 13-12-22  
Revised : 03-03-23  
Accepted : 20-03-23  
Published : 28-04-23

## INTRODUCTION

A “caregiver” is a person responsible for caring for an individual’s basic needs and performing or assisting in daily activities while caring for themselves. In most circumstances, they also care for other family members, such as their spouses or other children.<sup>[1]</sup> Studies have reported a decline in the health status of caregivers, both physically and mentally, in developed countries. Recently,

more caregivers have been suffering from depression, anxiety, and a decline in their general health within the first year of caregiving, highlighting the need for more attention to be given to the welfare of caregivers.<sup>[2]</sup>

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**How to cite this article:** Omar AF, Mokhtar IW, Ahmad MS. Challenges in healthcare management of individuals with special needs in Malaysia: Perceptions of caregivers. J Int Soc Prevent Communit Dent 2023;13:148-56.

### Access this article online

#### Quick Response Code:



**Website:** <https://journals.lww.com/jpcd>

**DOI:** 10.4103/jispcd.JISPCD\_234\_22

A factor contributing to the stress or burden faced by caregivers has involved poor accessibility to healthcare facilities, which is a core part of their responsibility. Studies have also noted financial burdens, ill-equipped facilities and professionals, limited access to psychological support, a lack of family planning information, and time constraints as some of the barriers caregivers face in accessing medical care in several countries.<sup>[3-5]</sup> Such studies have not been conducted in the context of Malaysia, though, thus inhibiting healthcare providers from improving their services or patient management and centering them on the effective roles of caregivers in caring for individuals with special needs (IWSNs). Furthermore, previous studies have only focused on caregivers of a specific cohort of IWSNs, based on their age group, medical conditions, or types of disability.<sup>[1,6-9]</sup> An exploration of issues related to healthcare management concerning caregivers of a wider group of IWSNs is, therefore, warranted, especially in Malaysia where such information is currently lacking. This study aimed to explore the challenges in healthcare management experienced by primary caregivers of IWSNs who attend community-based rehabilitation (CBR) centers in Selangor, Malaysia.

## MATERIALS AND METHODS

The current study is qualitative in nature and employed semistructured interviews, involving 32 caregivers of IWSNs, conducted via face-to-face focus group discussions. Ethical approval was obtained from The Ethics Committee, Universiti Teknologi MARA-REC/08/2021 (MR/739)—and the Department of Social Welfare, Ministry of Women, Family and Community Development, Malaysia, via their online platform *MyResearch* (JKMM 100/12/5/2: 2021/252).

The study involved caregivers of government CBR centers in Selangor, Malaysia. Based on purposive sampling, one center was selected from each of the nine districts: Gombak, Hulu Langat, Hulu Selangor, Klang, Kuala Selangor, Petaling, Sabak Bernam, Sepang, and Kuala Langat.

The study utilized a semistructured focus group interview, containing open-ended questions developed in a previous study.<sup>[3]</sup> The content of the questionnaire was validated by specialists in the fields of special care dentistry and public health. Translation and adaptation processes were applied to produce bilingual semistructured questions (in English and Malay), which were deemed vital as the respondents of this study predominantly did not speak English. The translation and adaptation processes included the following steps.

The first involved forward translation by the principal investigator, whose mother tongue is Malay and who has a good command of the English language. In the second step, an expert panel consisting of clinical specialists involved in caring for people with disability as well as experts in qualitative reviewed the translated questions and provided necessary comments, and the third stage involved backward translation of the questions to English by a professional language expert who had no knowledge of the original English version. In the fourth step, also considered content validation, an expert panel reviewed both the forward and backward versions, discussing, and finalizing the questions. Fifth, face validation or pretesting was conducted via online and face-to-face interviews involving caregivers external to the study's data set attending our dental clinic using convenience sampling. Finally, these results were reviewed by the expert panel to ensure that both versions of the questions (in English and Malay) were equivalent regarding the concepts, items, semantic content, measurement, and operation.<sup>[10]</sup>

The managers of the nine centers were provided with subject information sheets, explaining the objectives and conduct of the study, via an invitation e-mail; they then disseminated the information to the caregivers. Those who showed interest (approximately three to five caregivers from each center) were contacted by the managers. Interview dates and times were confirmed; the interviews were carried out at the centers, each session was audio-recorded, and field notes were taken for further analysis.

Verbal consent was obtained and recorded before a bilingual focus group discussion was conducted by the principal investigator who is a PhD student who has attended courses on qualitative studies and is a special care dentist. She also conducted the pilot to this study and was trained to do interview surveys. Each session was carried out in a private room and lasted between 30 and 45 min, consisting of between three and five participants per session where a code was assigned to each subject for anonymity and identification. All participants completed the interview with no dropouts, and interviews were carried out in a single visit.

## DATA ANALYSIS

The data were analyzed via thematic analysis involving open and closed coding, followed by the identification of emerging themes. The validation of codes and themes was conducted by having a coresearcher debriefing session and team vetting, which provided an external check on the data collection process and credibility determination, where themes and codes were agreed upon.<sup>[11]</sup> These themes and codes were returned to the participants to seek for their agreement on the findings.

## RESULTS

### SOCIODEMOGRAPHIC CHARACTERISTICS

All nine CBR center managers agreed to participate in the study. The sociodemographic characteristics of the study participants are presented in Table 1.

### CHALLENGES IN HEALTHCARE MANAGEMENT FACED BY CAREGIVERS OF INDIVIDUALS WITH SPECIAL NEEDS

The caregivers expressed various challenges in the healthcare management of their IWSNs, which are categorized into four domains: healthcare services, support systems, caregivers' personal factors, and IWSN factors. The excerpts from subjects pertaining to each theme are presented in Table 2.

#### Domain 1: Healthcare services

##### Theme 1: Accessibility of healthcare facilities

Three caregivers expressed issues with accessibility to wheelchairs or walking aids in healthcare facilities, which affected their ability to efficiently attend appointments.

##### Theme 2: Appropriateness of healthcare facilities

Concerning priority access, most participants were unhappy with the long waiting times that they had to endure despite arriving timeously for their appointments. They preferred an express lane to avoid their children throwing tantrums and further complicating the visits

for both them and the clinicians. In addition, some respondents were not satisfied with the waiting room facilities provided in healthcare establishments and felt that they would benefit from designated areas for their children to sleep and play or where the parents could manage their children's tantrums.

##### Theme 3: Attitudes of healthcare staff

Regarding the attitudes of healthcare staff, the participants felt that the staff in healthcare facilities lacks professionalism and empathy toward IWSNs and their caregivers. One had been threatened to be removed from therapy sessions, whereas others had experienced cold and insensitive encounters during their visits. They also felt that appropriately trained staff should be assigned specifically for IWSNs such that they would not have to be grouped with other patients.

#### Domain 2: Support systems

##### Theme 1: Community and peer support

Four participants felt that their community's awareness was important to help keep them informed and inspired. One respondent also expressed feeling that society has yet to accept their children as a part of it. In contrast, four respondents felt that the community has helped by giving them guidance and advice on how to care for their IWSNs.

With regard to knowledge sharing among caregivers, four respondents noted feeling grateful for having a support system where they could share their opinions or useful tips about caring for IWSNs. Nevertheless, two respondents felt more stressed after engaging in messaging platform groups as these made them feel worse about their situation or led them to unveil the negative aspects of their IWSNs.

##### Theme 2: Family support

In this subtheme, four respondents felt acknowledged by their extended families, where help was also offered, and had good support from their nuclear families, specifically their husbands. A participant reported that their family was able to guide her as she had a similar child. However, negative feelings were also present where the participants felt that they were not understood by their extended or nuclear families. One was even judged and advised harshly by their own extended family without them acknowledging her effort.

##### Theme 3: Governmental support

Concerning governmental support, the respondents had varied feelings regarding the financial aid provided; two respondents felt that it was adequate and were grateful for the aid. Others, however, felt that the costs of maintaining a household with an IWSN and

**Table 1: Sociodemographic characteristic of participants**

Data details	Number, n (%)
Gender	
Male	3 (9.37)
Female	29 (90.63)
Ethnicity	
Malay/Bumiputra	30 (93.75)
Indian	2 (6.25)
Types of disability cared by participating caregivers (according to Department of Social Welfare Classification of Disability [Kementerian Pembangunan Wanita, 2019])	
Physical	1 (3.13)
Learning	
Autism	11 (34.38)
Slow learner	10 (31.25)
Syndromic disorder	5 (15.63)
Global developmental delay	3 (9.38)
Combination	2 (6.25)
Duration of care	
1–5 years	4 (12.5)
6–10 years	13 (40.63)
11–15 years	1 (3.13)
16–20 years	7 (21.88)
21–25 years	2 (6.25)
26–30 years	3 (9.38)
31–35 years	1 (3.13)

**Table 2: Excerpts, subthemes, and themes derived from discussions**

Excerpts	Theme
<b>Domain 1: Healthcare services</b>	Accessibility of healthcare facilities
For some elder parents, we get tired easily from preparing for hospital visit so it would be good to have wheelchairs available to use at the hospital.	
<i>Subject 1</i>	
When attending hospital visits, the long waits are difficult. It would be good if there could be a place for my child to play, sit and run so he won't get bored or throw a tantrum.	
<i>Subject 2</i>	
A special room would be good because our children are different. They may want to sleep while waiting.	
<i>Subject 3</i>	
For my child's hospital visit, I come at 8 a.m. but the doctor only comes at 10 a.m. It happens almost every visit.	
<i>Subject 8</i>	
Hospitals should give priority like a special lane for IWSN. Sometimes, we wait for an hour and by then my child would have cried and rolled around.	
<i>Subject 9</i>	Appropriateness of healthcare facilities
Some doctors or therapists complain about parents. They threaten to stop helping us if our child does not progress as they expect and they use hurtful words.	
<i>Subject 4</i>	
Nurses and doctors in Malaysia have a lack of understanding on autism. They are also insensitive to the parents and ask questions harshly.	
<i>Subject 5</i>	Attitudes of healthcare staff
We want to do what the doctor asks us to, but it is sometimes hard, but we try. Doctors do not want to get to know both the family and their patient because we both matter. Multiple appointments get set in a day, morning, and afternoon, which tires my son out inducing tantrums.	
<i>Subject 6</i>	
It would be good to have a special department and designated staff to deal with special needs patients, so we do not have to be with other patients.	
<i>Subject 7</i>	
<b>Domain 2: Support systems</b>	
<b>Positive responses</b>	Community and peer support
There are a lot of groups on messaging platforms that we can choose from nowadays. It is better now than it was because there is more information and groups to help.	
<i>Subject 7</i>	
As my husband works overseas, when I need advice, I share it with my women's community group, and they will usually give me advice and motivate me. They advised me on how to apply for the disability card and where to send my son for therapy.	
<i>Subject 9</i>	
Community involvement is important. Hearing others' stories is motivating me to be a better parent.	
<i>Subject 14</i>	
The community center has a support group where we can talk and share as well as organize get-togethers.	
<i>Subject 17</i>	
<b>Negative responses</b>	
At my medical visits, I see other parents of patients who do not accept us.	
<i>Subject 10</i>	
People are aware of special needs, but they can not accept it. Like when my son has a tantrum, they should leave us and back off.	
<i>Subject 7</i>	
I try not to read support group information and stories on social media because it makes me compare their children with mine and it makes me stressed.	
<i>Subject 15</i>	
Support groups are not necessary as it reveals the negative sides of our child.	
<i>Subject 18</i>	Family support
<b>Positive responses</b>	
I usually ask my sister for advice because she has a child like mine which is helpful.	
<i>Subject 5</i>	
I like sharing with my family more because others can just listen, but family can help physically and financially.	
<i>Subject 6</i>	

Table 2: Continued

Excerpts	Theme
<p>I sometimes go on holidays with my other child sometimes while my husband cares for my special child.</p>	
<p><i>Subject 10</i> My family emotionally supports me, and my husband will take over my duties when I need. They will help me find solutions</p>	
<p><i>Subject 14</i> <b>Negative responses</b> I can not even explain what I feel to my husband. He never understands.</p>	
<p><i>Subject 8</i> Sometimes, family can not understand us and do not provide support. They instruct me to do things and overlook the efforts that I have put in.</p>	
<p><i>Subject 13</i> I want to share with my family, but they do not understand so I look for people with similar situations as mine.</p>	
<p><i>Subject 16</i> When I speak to my family, they are not kind with their advice and blame me for pampering my child if my child acts out.</p>	
<p><i>Subject 17</i> <b>Positive</b> I get monthly contributions from the social welfare department as well as the political representative in the form of grocery vouchers on my daughter's birthday.</p>	Governmental support
<p><i>Subject 11</i> The alms board has given my son finances for a hearing aid.</p>	
<p><i>Subject 12</i> <b>Negative</b> The government does help but it is not enough as things are expensive now. We have a family to support and special children cost more. This affects our other kids as they may not be able to go to school or work.</p>	
<p><i>Subject 13</i> The money given is for my child, but I also need money to replace what he has destroyed due to tantrums at home.</p>	
<p><i>Subject 2</i> <b>Domain 3: Caregivers' personal factors</b></p>	
<p>My challenge is more mental. I must always be strong and patient especially now that he is an adult. I worry when he showers if he would have a fit as he is sensitive to water, so I am scared if he stays too long in there.</p>	Stress with burden of care
<p><i>Subject 8</i> If he goes out for a while and does not answer his phone when I call, I will go around the village looking for him. He is at the age where he likes to go out now and does not listen to me.</p>	
<p><i>Subject 21</i> I worry as I am getting older now and have been diagnosed with hypertension. What happens to my child when I am gone and how will he provide for himself? I can not predict the future for him.</p>	
<p><i>Subject 17</i> As my son has cerebral palsy, I need to always carry him which was easy when I was younger but now that he is already 16 years old, it is a problem. It gets worse when he is angry or throws a tantrum.</p>	
<p><i>Subject 6</i> I had my daughter in my 40s and I have asthma so I am easily tired and that's makes me more stressed.</p>	
<p><i>Subject 19</i> <b>"ME-TIME"</b></p>	
<p>I used to be able to leave my son with my parents when I needed some me-time but now I do not get that as much due to the pandemic. We have been at home more.</p>	
<p><i>Subject 20</i> As a housewife, I must bring my son with me everywhere. I do not have any me-time. I also can not be out for long because of him.</p>	
<p><i>Subject 21</i> I sometimes feel lonely and need friends because my husband is working abroad. But I find it hard to be social and spend more time at home with my family which can be stressful.</p>	
<p><i>Subject 15</i></p>	

**Table 2: Continued**

Excerpts	Theme
<p>I decided to stop working because my wife could not handle our son. Since then, I have not gone for a coffee with my friends or gone to town to see my friends. I can not have time on my own because my son will want to come along.</p> <p><i>Subject 7</i></p> <p>It is stressful to maintain the house, take care of the children, and face the pressure of work. As I work from home, my employers still expect work to be done so I sometimes sacrifice sleep. This is more difficult as my children have different sleeping patterns, which means I work at all hours.</p> <p><i>Subject 4</i></p> <p><b>Neglect of other kids/family members</b></p> <p>It is tough when I try to explain to my daughter that I pay more attention to her brother because he can not tell me what he wants but she feels I do not care about her as much.</p> <p><i>Subject 4</i></p> <p><b>Cause of disability</b></p> <p>I was in accident with my son at the age of 2 months. The impact was so great that our car split in half. After that, he could no longer speak or make sounds like he used to.</p> <p><i>Subject 5</i></p> <p>Family has said my child became this way because I pampered him and that makes me feel bad.</p> <p><i>Subject 8</i></p> <p><b>Domain 4: IWSN factor</b></p> <p>She sometimes scolds me and complains constantly. The tasks will not get done and she does not allow me to help her. If I ask, she gets angry and throws things.</p> <p><i>Subject 13</i></p> <p>If he does not want to listen, we do not proceed with the task because he will self-harm or start crying and screaming.</p> <p><i>Subject 4</i></p> <p>It sometimes depends on how he feels. Some days the tasks can be done independently but, if he is not in the mood, he will not do it, or we will have to argue first.</p> <p><i>Subject 23</i></p> <p>Usually, she will get angry when I ask her to do something but, now that she is older, it has been a bit better.</p> <p><i>Subject 8</i></p> <p>I must persuade him for daily tasks otherwise he will pinch or scratch me.</p> <p><i>Subject 19</i></p> <p>She used to be able to take care of herself but since the pandemic, I can not ask her or raise my voice. She will tend to want to be alone and neglect her tasks.</p> <p><i>Subject 24</i></p> <p>I sometimes ask him to do the task on his own like hold his toothbrush which he can but struggles. He still wants me to do the task.</p> <p><i>Subject 5</i></p> <p>If I monitor, he will do the task well but otherwise he will just do parts of it.</p> <p><i>Subject 1</i></p>	<p>Feelings of guilt</p> <p>Behavioral difficulties</p>

IWSN = individuals with special need

inflation were not considered; thus, the help offered was insufficient.

**Domain 3: Caregivers' personal factors**

**Theme 1: Stress with the burden of care**

The caregivers experienced stress over issues causing them constant anxiety; this was apparent in those with older IWSNs. They worried about their children's well-being at home but also for the stage when their child would become independent or for their future. Two participants were stressed not only about their own physical limitations as they aged or due to their medical

conditions but also regarding their ability to care for their children as they physically grew.

Other caregivers expressed that they needed some time for activities for themselves, especially after home confinement during the pandemic or having to bring their IWSNs to their self-care sessions. Moreover, the respondents have had less time or opportunities to socialize, be it with family or friends, which has led to feelings of loneliness in some. A caregiver also felt stressed with the overwhelming responsibilities of being a working parent with an IWSN.

## Theme 2: Feelings of guilt

In addition to stress with the burden of care, one participant felt guilty regarding their other child (without special care needs) who felt that they did not pay as much attention to them, whereas another even felt that they had caused their IWSN's condition or disability.

### Domain 4: Individuals with special need factors

#### Theme 1: Behavioral difficulties exhibited by individuals with special needs

Some respondents expressed the occurrence of tantrums or self-harming behaviors when their IWSN was asked to perform tasks, whereas others had issues with their IWSN being moody or performing tasks depending on their mood. A caregiver even had issues with their IWSN harming them when they would try to help. In addition, others expressed having issues with dependence, where some of their IWSNs had regressed due to the pandemic or required more assistance when carrying out daily tasks. In describing the behavior of their IWSN, one respondent claimed.

## DISCUSSION

This study focused on caregivers, as they were deemed to be the most appropriate subjects to bridge the gap between healthcare providers and IWSNs.<sup>[12]</sup> Important factors that contribute to the mental health of caregivers, such as friendships, work, and good family support, must be nurtured as an imbalance could affect their ability to care. This, in turn, could compromise the quality of life of the IWSNs. Understanding the issues affecting them could help maintain caregivers' lifestyle dynamic and allow healthcare professionals to provide more appropriate care according to those needs.<sup>[12]</sup>

The majority of caregivers in this study were the mothers of the IWSNs and primarily homemakers, as per previous studies.<sup>[13]</sup> Regarding the years of care, previous studies have only focused on disabled children, cancer patients, elders with Alzheimer's disease, or palliative care patients, and studies on the caregivers of disabled adults or adolescents have not been conducted. Therefore, the findings in this study include a more diverse age group, with caregivers experienced in caring for different types of IWSNs.

Healthcare facilities have been criticized in past studies for having limited physical spaces for IWSNs and lacking flexibility with their scheduling. Families have also felt that professionals have not allowed caregivers to speak openly and have, thus, been unable to customize their plans, especially in home care. Moreover, reports have indicated that healthcare professionals lack the skills to

manage caregivers or IWSNs in an optimal manner.<sup>[7,12]</sup> As with previous studies, our participants felt the same, but they also expressed their preferred system, which includes both designated staff and facilities and a fast lane service to prevent stressful appointments. The study revealed that having healthcare staff who are trained in managing IWSNs would encourage patient attendance and their eventual health outcomes. Having a conducive physical environment that caters for the needs of IWSNs was also related to an improvement in patients' compliance with professional health services, thus resulting in a higher quality of patient care.<sup>[5]</sup>

In this study, the respondents had mixed opinions on the need for financial assistance. The Department of Social Welfare provides a monthly allowance for each child in their care, and some parents receive assistance from external parties.<sup>[14]</sup> Many of them felt that this was adequate, whereas some stated that they preferred additional assistance. This finding is in accordance with previous studies, revealing that financial constraints are notably felt in families with only one source of income.<sup>[15]</sup> Even with the provision of funds, previous studies have reported similar issues where funds have been allocated for care but not for the maintenance or renovations required to care for IWSNs.<sup>[12]</sup> The lack of financial support from governing bodies, as expressed by the participants in this study, therefore calls for improvements in the current policies and healthcare system to support the needs of IWSNs in receiving quality healthcare. Such efforts are important to support the rights of IWSNs in Malaysia to gain equitable access to healthcare services, as stipulated in the Persons of Disabilities Act 2008 (Act 685).<sup>[16]</sup>

While legislations exist to promote the well-being of IWSNs, communities also play an important role in assisting the caregivers of these individuals in multiple respects, including providing social support. However, the respondents in this study reported that they noted difficulties in integrating themselves within the community while having to manage or care for an IWSN. Previous studies have revealed a similar situation, where caregivers have reported feelings of isolation due to the lack of understanding or sympathy toward being a full-time caregiver.<sup>[13,15]</sup> The respondents herein felt that they did not have the time or opportunity to socialize, which is similar to the findings of a past study revealing the lack of social relationships due to the burden of care.<sup>[13]</sup> The lack of acceptance of IWSNs as part of society was also felt by the respondents herein, leading them to feel more isolated and unsupported. The roles of community members in disability care should, therefore, be enhanced and the members

empowered such that they can serve as useful agents or media to assist caregivers in providing psychological support. In addition, the community at large, including those with disability care and professional healthcare backgrounds, may play an active supporting role through the sharing of knowledge and skills that could help caregivers overcome difficulties in performing the activities of daily living (ADLs).

In addition to insufficient support from the community, a lack of understanding and assistance provided by family members was highlighted as one of the challenges faced by caregivers of IWSNs in this study. The respondents perceived that they lacked support from their spouses and close relatives, resulting in stress and caregiver burden. In Western culture, a nuclear family signifies a more biological structure, consisting of a set of parents and their offspring. In contrast, members of a nuclear family in Asian cultures include relatives and in-laws, who collectively play an important role in developing the values, practices, and traditions of the members.<sup>[17]</sup> Despite these differences, it is pertinent to acknowledge that family members play a significant role in the overall daily management of IWSNs. Therefore, the awareness of family members should be enhanced such that they play a more supportive role, not only for IWSNs but also for primary caregivers.

In addition to the stress caused by a lack of familial support, this study also reported on multiple other forms of stress caregivers experience due to, for example, constant anxiety or feelings of guilt regarding the condition of their IWSNs, feeling guilty about or overburdened by their responsibilities to other family members, or simply feeling limited by their own physical issues. As reported in a previous study in the context of the United States, the declining health of caregivers is a source of stress but remains unaddressed; caregivers usually feel overwhelmed, which leads to a downward spiral of depleting mental health.<sup>[12]</sup> The physical limitations felt by caregivers have been previously documented but have been related more to the pandemic where help has been scarce.<sup>[13]</sup> The burden felt has also risen with increases in their responsibilities, including, for example, caring for other children or being solely responsible for their households (e.g., in the case of distant spouses or highly dependent IWSNs), as noted in previous studies.<sup>[13,18]</sup>

A limitation faced in this study involved response bias during the focus group discussions as they were carried out by a healthcare professional. This could have prevented the participants from being more honest and open about their opinions due to the interviewer's education level.<sup>[19]</sup> Cultural norms have consistently

been viewed as a limitation in group discussions involving Asian subjects.<sup>[20]</sup> In this study, specifically, the participants may have been reluctant to open up fully about the challenges pertaining to their families or IWSNs due to the need to "save face."<sup>[21]</sup> Nevertheless, the respondents herein were able to address some sensitive issues and mentioned some important points for further investigation.

Another limitation involved the limited diversity in the subjects in terms of their gender, socioeconomic status, and ethnicity. Therefore, the data obtained may only reflect the group of the study population. To diversify our data, future research can extend this study to include caregivers of a higher socioeconomic status, such as those with IWSNs in private institutions. Nevertheless, this study remains significant as it provides reflections on the population visiting CBR centers and their challenges, thus allowing policymakers to improve the services provided.

## CONCLUSION

The results of this study reveal that primary caregivers face challenges from their environment, personal issues, and IWSNs. Within the environmental domain, themes regarding healthcare services and policy and support systems were identified, addressing healthcare services and facilities and the lack of understanding and inclusivity from both society and caregivers' families. In the personal domain, themes pertaining to stress were discovered, focusing on feelings of guilt, anxiety, a lack of time, feeling overwhelmed, and facing physical limitations. In the IWSN domain, caregivers faced behavioral difficulties such as tantrums, mood swings, aggressive behavior, and ADL dependence. Understanding these challenges is vital in providing healthcare services that cater to not only IWSNs but also their care providers to ensure success in the caregiving process.

## FUTURE SCOPE/CLINICAL SIGNIFICANCE

This study will help to understand the challenges faced by caregivers and assist in improving healthcare services for IWSNs. These issues should be made known to policymakers to help improve the quality of life for both care and IWSN.

## ACKNOWLEDGEMENTS

The authors thank Dr. Nawwal Alwani and Dr. Yeoh Oon Take for their input during the content validation of the semistructured interview questionnaire. The authors also thank the respondents for their participation in this study.

## FINANCIAL SUPPORT AND SPONSORSHIP

Nil.



**CONFLICTS OF INTEREST**

There are no conflicts of interest.

**AUTHORS CONTRIBUTION**

A.F.O.: Study conception and design, literature search, data acquisitions and analysis, manuscript preparation. I.W.M.: Study conception and manuscript review. M.S.A.: Study conception and design, data analysis, manuscript editing and review. All the authors approved the final version of the manuscript publication.

**ETHICAL POLICY AND INSTITUTIONAL REVIEW BOARD STATEMENT**

Ethical approval was granted by the Research Ethics Committee at Universiti Teknologi MARA-REC/08/2021 (MR/739)-and the Department of Social Welfare, Ministry of Women, Family and Community Development, Malaysia via their online platform *MyResearch* (JKMM 100/12/5/2: 2021/252).

**PATIENT DECLARATION OF CONSENT**

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

**DATA AVAILABILITY STATEMENT**

The data used in the current study will be available up to 5 years after the date of publication.

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