

Exploring the Barriers and Expectations Towards Health Care Services Among Parents/Caretakers of People with Intellectual Disability in Kuantan, Malaysia: A Qualitative Study

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ABSTRACT

Backgrounds: People with intellectual disabilities (PWID) are often characterized by challenges in learning and difficulties in performing daily activities. These difficulties can have an impact not only on the individuals themselves but also on the people around them, especially their parents, caregivers, and healthcare workers. Therefore, establishing a positive relationship between parents or caregivers and individuals with disabilities is crucial as a key factor in promoting positive healthcare experiences and outcomes. **Aim:** This study aims to explore the barriers and perceptions toward healthcare services among parents or caretakers of people with intellectual disability, including the challenges and their expectations toward healthcare services. **Materials and Methods:** This was a qualitative study using purposive sampling. Thirty participants were contacted at the initial stage and invited to participate in the study. Semi-structured in-depth interviews were done among parents and caretakers of PWID who attended Special Care Dentistry and Paediatric Dentistry clinics in Sultan Ahmad Shah Medical Centre, Kuantan, Pahang. Topic guides were generated from literature review and expert opinions, followed by pilot interviews to refine them. However, after the interviews were done for the first 13 participants, we have reached data saturation, and no new themes emerged. The interviews were recorded, verbatim transcribed, and analyzed using Braun and Clarke's guidelines for thematic analysis. **Results:** The satisfaction of parents or caretakers toward healthcare services for PWID and positive experiences in receiving healthcare services were noted. However, the results revealed several barrier themes in seeking healthcare services: lack of availability of parking, longer waiting time, appointment time, crowded environment, limited information on the availability of the services, and longer travel duration. Furthermore, expectation themes emerged from this study: continuous follow-up, accessibility to healthcare services, and staff attitude.

KEYWORDS: Barriers, expectations, healthcare, intellectual disability

INTRODUCTION

Intellectual disability (ID) can be generally represented as a problem in learning and difficulty in doing daily activities. ID is defined as a significant impairment of mental abilities in intellectual functioning and adaptive behavior, which mainly

includes conceptual skills, social skills, and practical skills.^[1] This, to some extent, has an impact not only

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on the individuals but also on the people surrounding especially the parents, caretakers, and also healthcare workers. The limitations forced people with intellectual disabilities (PWID) to always be in need of specialized and integrated treatment provided by health care services. The exact etiology of ID is uncertain; however, it may be caused by genetic abnormalities and environmental exposure.^[2] Lee *et al.*^[11] stated that genetic abnormality will lead to an inborn error of metabolism, neurodevelopmental defect, and neurodegeneration, while maternal exposure to toxins, infectious agents, uncontrolled maternal condition, and birth complications are the environmental factors. A few studies suggested that ID is routinely associated with other diseases that need special care from the professional, thus requiring a longer hospital stay.^[3-5] PWID have a higher prevalence of oral health problems, such as increased caries rates due to poor oral hygiene and soft diets, altered salivary flow due to the use of numerous medications, resulting in an increase in the formation of plaque and calculus, and abnormal jaw growth and space loss, leading to malocclusion.^[6] As stated by Lee and Chang^[7], although some of the oral problems may not be significant, these can lead to more complex and poor overall health status if continuously being neglected.

Social Statistics Bulletin Malaysia 2018 revealed that as of 2017, there were 453,258 people with disabilities registered with the Malaysian Department of Social Welfare, and the persons with learning disabilities category accounted for the second highest number, which was 34.8%.^[8] PWID patients are frequently being marginalized by society due to the social stigma toward people with IDs, thus forcing the parents to face difficulty in establishing a good rapport with healthcare providers.^[5] Thus, “Akta Orang Kurang Upaya 2008” was enacted to increase health access for this demographic, and it stipulated that those with disabilities should have equal access to healthcare services.^[9] In most studies, the authors highlighted the importance of having a positive relationship between parents or caretakers of people with IDs and healthcare professionals as a key factor in positive healthcare experiences and outcomes.^[4,5,10,11] The parents or caretakers of children with IDs preferred healthcare workers to communicate directly with their children rather than talk to them during the treatment; however, they claimed that it is hard to find this type of communication in every health institution.^[12] The same study revealed that the lack of communication leads to irritation and tension between parents or caretakers and staff.^[13] On the other hand, parents also emphasized

the development of supportive relationships with individuals with ID. Parents and carers of people with IDs need to face discrimination in society, including from health care services, as they only receive low-standard care and often being neglected.^[4] As a consequence, the delayed treatment will only cause their health condition to worsen since most people with ID have a higher prevalence of physical health problems.^[4] PWIDs require long-term care and support from their parents or other carers.^[14] Throughout this phase, the parents or carers have a higher duty toward these individuals, which has a significant impact on their physical, mental, and emotional well-being.^[15] This is because parents or carers of PWID have to face some challenges and obstacles, especially when seeking healthcare services. Nonetheless, there is no local study exploring the perception toward health care services among parents or caretakers of PWID. Thus, it is critical to explore the perceptions of parents or carers of PWID regarding current healthcare services, the challenges and barriers faced by parents or caretakers when seeking health services, and their expectations toward the healthcare system.

MATERIALS AND METHODS

STUDY DESIGN

A cross-sectional qualitative study was performed on parents or caretakers of patients with ID who attended special care dentistry or pediatric dental clinics at Sultan Ahmad Shah Medical Centre (SASMEC) and Kulliyyah of Dentistry (KOD) in International Islamic University Malaysia (IIUM), Kuantan, Pahang.

ETHICAL APPROVAL

Application and approval of the study from IIUM Representative for Ethical Committee (IREC) IREC 2021-063 and Department of Education and Research (DEAR), SASMEC @IIUM was obtained. On top of that, the procedures were fully explained to the subjects, and verbal and written consent was obtained prior to the research, which was in accordance with Helsinki Declaration 2008.

SAMPLING CRITERIA

Purposive sampling was used in this study. The estimated sample size was based on saturation for qualitative research. The minimum is 5 and the maximum is 50 participants. Thirty parents or caretakers of PWID were contacted and invited to participate in the study.

The inclusion criteria were parents/caretakers aged 18 years and above, able to understand both Malay and English, and all of the participants need to know the individual with ID well for at least 2 years. The

exclusion criterion was parents/caretakers who have an intellectual or learning disability.

METHODOLOGY

A qualitative research method was conducted. Prior to commencing the interview, two of our researchers (AIM and ANR) underwent training and were provided with a script to ensure that the questions asked would facilitate the generation of meaningful data. A pilot interview was conducted to refine the topic guides. The topic guides were developed from previous literature and expert opinions, which include questions on their sociodemographic background, overall health status, experiences and challenges with healthcare services, satisfaction as well as expectations from the healthcare services.

The semi-structured, in-depth interviews were conducted with each participant through face-to-face or online platforms via Google Meet in order to understand the perceptions of caregivers about the experiences, challenges, and expectations while seeking healthcare services. Interviews were conducted in either the Malay language or English language. Initially, 30 participants were selected from among the parents and/or carers of patients who attended Special Care Dentistry and Paediatric clinics at SASMEC and KOD in IIUM. However, we found that the data had been saturated with no new emerging themes after 13 participants. In this interview, probing questions were used in the last remark of the respondents to get further details regarding that particular question.

The interviewer took detailed notes on respondents' answers by using field notes. Field notes help researchers to document the observations. The entire interview was audiotaped using a recorder with the consent from the participants and was transcribed verbatim.

STATISTICAL ANALYSIS

The interviews were audio-recorded, transcribed, and analyzed in accordance with Braun and Clarke's guide to thematic analysis. Thematic analysis was used as it is helpful to explore parents with PWID views on seeking healthcare. Analysis of the qualitative data involved line-by-line coding by two people (ANR and AIM) by reading the transcripts repeatedly. A coding list was identified early in the coding process. The codes were reduced to account for overlap and redundancy. The initial sets of code from the data were created, and the research team members used the remaining codes to create categories as identified early in the coding process. The common patterns among the codes that have been created were identified to generate themes that were relevant to the research objectives.

RESULTS

A total of 50 respondents were contacted via phone by two researchers (ANR and AIM). Only 13 participants agreed to be interviewed. Table 1 shows the sociodemographic background of the respondents. Three parents and one caretaker were among the four participants in the male group, whereas in the female group, six parents and three carers were present in the female group. Autism was the most common condition among PWID, followed by cerebral palsy and Down syndrome. All of the respondents are of Malay ethnicity, which works as either professional or nonprofessional, and one respondent was unemployed [Table 2]. In this study, the parents or caregivers of PWID were observed in terms of their perception of healthcare services in Kuantan, barriers in obtaining treatment, and expectations toward healthcare services. The summary of findings can be seen in Table 3. These findings are explained throughout this paper using direct quotations.

Theme I: Barriers when seeking healthcare services

Lack of availability of parking

One of the main problems experienced by the parents of PWID when seeking healthcare services for their children is the availability of parking [Table 3]. There is no problem in terms of transportation to bring the children to the hospital. However, the parents complained regarding the difficulty of finding available parking due to limited parking spaces. Only vehicles displaying a People with Disability (OKU) sticker, with an official OKU identification card issued by the Social Welfare Department (JKM), are allowed to use disabled parking spaces:

"If possible, provide parking not only for the OKU driver, but also for the OKU child we want to bring." (R2)

The distance from the parking to the entrance is quite far, making the process of getting treatment difficult due to unpredictable behavioral problems of PWID:

Table 1: Participant sociodemographic information

| Sociodemographic | Numbers (n) |
|------------------------|--------------|
| Gender | |
| Male | 4 |
| Female | 9 |
| Relation to the PWID | |
| Parents | 9 |
| Carer | 4 |
| Others | 0 |
| Age (mean, range) | 49.1 (33–59) |
| Occupational category | |
| Professional | 10 |
| Nonprofessional | 3 |
| Operational technician | 0 |
| Unemployed | 1 |

Table 2: Participant sociodemographic information

| ID | Age | Gender | Occupation | Relation to the PWID |
|-----|-----|--------|-----------------|----------------------|
| R1 | 53 | Female | Professional | Mother |
| R2 | 58 | Female | Professional | Mother |
| R3 | 43 | Female | Professional | Sister |
| R4 | 54 | Male | Professional | Father |
| R5 | 53 | Male | Professional | Father |
| R6 | 36 | Male | Professional | Brother |
| R7 | 61 | Female | Professional | Mother |
| R8 | 46 | Female | Professional | Sister |
| R9 | 59 | Female | Nonprofessional | Mother |
| R10 | 53 | Female | Nonprofessional | Mother |
| R11 | 52 | Male | Professional | Father |
| R12 | 37 | Female | Nonprofessional | Sister |
| R13 | 33 | Female | Professional | Mother |

Table 3: Summary of findings

Barriers when seeking healthcare services.

1. Lack of availability of parking
2. Longer waiting time
3. Unsuitable appointment time
4. Crowded with other patients
5. Limited information on the availability of the services
6. Longer travel duration

Expectations toward our healthcare system

1. Continuous follow-up for health check-ups
2. Accessibility to healthcare services
3. Staff attitudes toward patients with intellectual disability

“We can’t park in the parking lot for the disabled. Because he’s not the one driving, mom and dad are... I really have to drag her sometimes, when she doesn’t want to walk.” (R13)

Longer waiting time

The treatment outcome and behavior of PWID were affected by the length of time patients waited before being seen. Parents or carers of PWID reported they had to manage their child’s rage if the waiting period was too long:

“He used to cry when he was a child. He was crying all the time. That’s why sometimes we feel angry if our turn is too late.” (R4)

On the contrary, more than half of the respondents reported that they had been prioritized with a shorter waiting time:

“PWD has been given priority in terms of waiting time... I think everything is good and has improved.” (R8).

Parents of PWID stated that they often received special treatment that eased their process of seeking treatment for PWID. As mentioned by a respondent:

“... all of the staff are very concerned when they see a special need and then they do give special treatment, they will help to speed it up the process.” (R6)

Appointment time

Most of the respondents are working parents and struggle to bring their children for treatment due to their tight schedules. They found it difficult to fit their working schedules to suit the appointments for their children, leaving them missing the appointments. One of the respondents mentioned:

“... My wife and I are both working. Sometimes it is quite difficult for us to come to the given appointment... The appointment time given sometimes prevents us from sending the child to the hospital because we have to go to work.” (R4)

Other than that, working parents had to apply for leave in order to bring the children to healthcare appointments, which was mentioned by one respondent:

“If the treatment is more than 4h, I need to apply for leave.” (R1)

Crowded with other patients

Parents or carers of PWID found that it is difficult to bring their child to seek treatment due to the crowded atmosphere in most of the government hospital settings. Most wards in government hospitals feature rather close bed spacing to accommodate more patients. As mentioned by a respondent:

“... if you go there, there are beds which close to each other and then become crowded.” (R6)

Parents also reported that it is unsuitable for PWID as they might be uncomfortable and start to act out of control by disturbing other patients.

Limited information on the availability of the services

PWID requires specialized healthcare services to address their unique needs. However, parents and caregivers may not be aware of the healthcare services that are available to them. This lack of information can result in delayed or inadequate healthcare services, leading to negative health outcomes. Delayed or inadequate healthcare services can also result in decreased quality of life and increased healthcare costs. One of the respondents reported:

“It was tiring me out to search healthcare services until one clinic suggested a IIUM hospital at that time... I never thought there would be dental services provided for disabled people like my sister.” (R8)

Longer travel duration

Some respondents had to endure long journeys that cost a lot of money when they traveled to Kuantan for

medical care from nearby areas. They were justified by the lack of facilities and training for PWID in their region:

“If he has a high fever, I will take him to Kuantan, because the situation will be more difficult in Jerantut.... It’s because the small town doesn’t have many facilities for the disabled, and you have to go to the big city.... Especially in terms of dental treatment, there really isn’t. Not all clinics are willing to accept it. That’s why I have to travel every month to get treatment for her... It’s just that if we go far, it costs to go back and forth from home.” (R13)

THEME II: EXPECTATIONS TOWARD OUR HEALTHCARE SYSTEM

Continuous follow-up for health checkups

In this study, we found out that parents are really concerned with their children’s health. Continuous follow-up for PWID is important to ensure that they receive the support they need and to improve their quality of life [Tables 2 and 3]. By having continuous follow-ups, it can help identify any issues or concerns they may have so that they can receive coordinated and comprehensive care:

“For people who are like my son, it is very important to have regular health check-ups periodically.” (R1)

Accessibility to healthcare services

Parents perceived PWID may require additional support and assistance to access healthcare services:

“The service is okay. Nice. Because they already have sent reminders, that’s all...I think it’s easier not to put the clinic near places where it is difficult for people to go.” (R5)

One of the respondents emphasized the need for increasing awareness about healthcare services available for PWID. They can provide resources and support to individuals with IDs and their families to help them navigate the healthcare system effectively:

“Maybe you should promote the available services to people.” (R8)

We found that accessibility to healthcare facilities for people with ID meets the majority of respondents’ expectations. Healthcare facilities should be physically accessible to individuals with IDs. This means ensuring that the building is wheelchair accessible, there are appropriate signs and markings for those with visual impairments, and that there is adequate space for individuals with mobility aids:

“For now, everything is okay. They have provided a ramp for wheelchairs... They also provide wheelchairs to use if you do not bring them.” (R8)

Staff attitudes toward patients with ID

In this study, parents of PWID have high expectations of healthcare staff attitudes toward their children. Parents expect healthcare staff to show empathy and compassion toward their loved ones and to understand the challenges they may face in accessing healthcare:

“If possible, even the staff and doctors need to be more understanding... It means you need to have expertise. At least they understand how special needs children behave.” (R2)

Besides, parents expect healthcare staff to have the knowledge and expertise to provide high-quality care for PWID, as well as expertise in communication strategies and behavior management:

“I hope most of the medical practitioners that will become new dental officers will try to be more emphasize in satisfying the feeling of this special needs guardian of this patient and to be more affectionate with them... I think there is need to be some sort of training for doctors and general practitioners to be more integrated or affectionate toward patients because small words, very encouraging words, it’s given a lot to us.” (R6)

DISCUSSION

Parents and carers of PWID had favorable impressions of healthcare services in the current study, which is consistent with a study conducted in Sydney in which the parents spoke well of the clinic.^[10] They had a positive experience overall because they were not stigmatized or subjected to discrimination by the staff, although stigmatizing attitudes toward PWID were also found in previous studies.^[11] Stigma and discrimination can hinder the efforts of healthcare providers to deliver services to individuals with ID and reduce access to treatment. Therefore, to promote effective healthcare and optimal health, it is necessary to address stigma among PWID.

Parents of PWID had difficulty in accessing healthcare services due to the lack of available parking, making it challenging for them. PWID are often associated with mobility impaired, which found medical facilities and services more inaccessible.^[16] Other studies showed similar findings in which weekly and monthly barriers to health care were experienced by a higher percentage of disabled people.^[17] In order to overcome this barrier, parents use public transport to save time to find parking. However, other findings found parents with disabled children struggle to bring their children to treatment due to lack of access to cars and public transportation.^[18]

The findings of the present study revealed reduced wait times while seeking treatment for PWID, which contradicted the trends of similar studies indicating longer waiting times for PWID to be seen by health professionals. A study in 2022 revealed that longer waiting times have been demonstrated to predict whether a person will not show up for their scheduled appointment.^[19] An increase in the length of waiting times increases the likelihood of a patient not attending the appointment and hinders PWID from gaining primary access care.^[20] Individuals with intellectual impairments may benefit from shorter wait times for healthcare services as they may need additional assistance and accommodations to receive services and may have a harder time navigating the healthcare system.

Parents of PWID also highlighted the issue of unsuitable appointment times, particularly during working hours. The extended period required for appointment attendance was viewed as an impediment to appointment adherence, creating a contradiction between their dedication at work and appointment attendance. This is particularly worrisome because evidence reveals that service users who are repeatedly missing appointments are at an elevated risk for preventable health problems and premature death.^[21] Thus, it may demand additional flexibility in appointment scheduling.^[22] To enhance appointment attendance and accessibility to services for PWID, policies and strategic plans should be focused on the important findings from these factors.

PWID are stated to have behavioral issues such as aggression, violence, and stereotyping that could result in harm to oneself, others, or property destruction.^[23] The same study also reported that, as with emotional and psychological suffering, physical discomfort could lead to behavioral disturbance.^[23] The surroundings and environment often play a role in behavioral disruption. The likelihood of the patient lashing out in irritation or discomfort increases in situations where they feel uncomfortable.^[24] The results show that the hospital setting, crowded with other patients, adversely affects PWID service delivery outcomes.

Existing research reveals that PWID face a variety of difficulties when attempting to acquire health information and that their informational demands are not satisfactorily satisfied. Engagement of patients in healthcare management has the potential to improve health outcomes. The majority of people with disabilities claimed that their caregivers gathered data on their behalf, while only a small number did so from employees.^[25] This is consistent with a review that highlighted the preferences of caregivers to seek health

tertiary care hospitals due to a lack of specialized care in their areas.^[26] Hence, increasing awareness of the special care needs of PWID is crucial if help is to be given to them, and all healthcare professionals must be fully aware and respond to their specific needs in order to ensure service developments and improvements take place and positive hospital experiences are provided.

Longer travel durations can also be a substantial barrier to healthcare access for PWID and influence their health-seeking behaviors. This study indicated that some parents of PWID had to travel from their hometown to Kuantan in order to acquire healthcare services because they believed that Kuantan offered better healthcare services. They are justified by the fact that people are increasingly able and ready to travel further for healthcare services, including to foreign nations.^[27] Healthcare professionals and organizations should provide some strategies as a potential response to this issue. Mobile healthcare services for PWID can provide direct healthcare to individuals in their homes or communities, reducing the distance that PWID must travel to receive treatment.^[28] Local service delivery can guarantee that patients have access to health care services near their homes. This can be accomplished by providing community services or establishing partnerships with local healthcare experts.

In order to meet parents' expectations of Malaysia's healthcare system, it is essential that PWID's particular needs and perspectives are acknowledged. The inclusion of PWID in the creation and execution of specific policies and programs are essential. Parents may anticipate healthcare services to be more accessible in terms of location and schedule flexibility. This population must receive comprehensive healthcare services that address the complicated health demands of PWID.^[29] It is crucial to ensure that all healthcare practitioners involved in an individual's care communicate effectively and operate with respect and dignity, which can help avoid delays and improve the overall quality of treatment.

Finally, our limitation was the participation of the carers residing in Pahang state. Thus, we cannot generalize the PWID's carer the barriers and perceptions received in getting health care services. For future studies, the involvement of other hospitals or centers that are treating PWID is necessary to give more accurate results in terms of generalization.

FUTURE RECOMMENDATION/CLINICAL SIGNIFICANCE

Most of the articles at least mentioned the concerns of parents of PWID regarding the importance of communication between general practitioners,

patients, and parents. However, we can also see how social and institutional discourses that did not support the emotional and psychological needs of clients interfered with relationship building. Thus, it can cause parents to experience some difficulties in establishing trusting relationships with the physician for their child with additional needs. With the prejudice and stigmatization among professionals toward PWID can create discrimination in accessing healthcare services. All medical staff must undergo mandatory training that is competency-based and practice-relevant and includes educational materials that address stigma, labeling, stereotyping, and prejudice.^[30] Thus, future research should address these concerns to enhance the healthcare system and quality for children with ID.

CONCLUSION

The issue of health needs for individuals with disabilities persists in the community despite significant advancements in education and public access to healthcare. By recognizing and understanding the needs of parents of PWID can enhance the well-being of the family and their quality of life. There were six obstacles preventing parents of PWID from meeting their needs, and three expectations were mentioned and highlighted in this study. It is crucial to tackle and overcome these barriers in order to improve the health outcome among PWID.

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CONFLICTS OF INTEREST

All authors declared no conflicts of interest.

AUTHORS' CONTRIBUTION

All authors have fairly contributed in the research and reviewed the manuscript.

ETHICAL POLICY AND INSTITUTIONAL REVIEW BOARD STATEMENT

Application and approval of the study from IIUM Representative for Ethical Committee (IREC) IREC 2021-063 and Department of Education and Research (DEAR), SASMEC @IIUM was obtained.

PATIENT DECLARATION OF CONSENT

Verbal and written consent were taken prior to the interviews of the participants. This is in accordance with the Helsinki Declaration 2008.

DATA AVAILABILITY STATEMENT

Not applicable.

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