

ORIGINAL ARTICLE

Exploring the Personal Experiences, Barriers and Expectations Among Caregivers and People With Physical Disabilities in a Teaching Hospital in Kuantan, Malaysia

Abdul Hadi Said¹, Farah Natashah Mohd², Mohamad Zairi Bahrom³, Aznan Md Aris¹, Mohamad Afiq Mohamad Shahrin¹

¹ Department of Family Medicine, Kulliyah of Medicine, International Islamic University Malaysia, Kuantan, Pahang, Malaysia

² Special Care Dentistry unit, Kulliyah of Dentistry and Sultan Ahmad Shah Medical Centre, International Islamic University of Malaysia, Kuantan, Pahang

³ Faculty of Mechanical & Automotive Engineering Technology, Universiti Malaysia Pahang Al-Sultan Abdullah, Malaysia

ABSTRACT

Introduction: Improving healthcare services for people with physical disabilities (PWPD) is critical to health achievement worldwide. The caregivers of PWPD play a pivotal role in facilitating early diagnosis, participating in treatment decision-making, and selecting suitable service providers. Therefore, this study aims to explore the personal experiences, barriers, and expectations of PWPD and their caregivers in receiving healthcare services at a teaching hospital in Kuantan. **Method:** A total of 18 participants, including PWPD and their caregivers attending the hospital, were purposely selected to participate in individual in-depth interviews following a generic qualitative study design. These interviews were conducted in Malay using a topic guide, and the sessions were recorded, transcribed, and subsequently analyzed. The data analysis process followed a qualitative data analysis framework. **Results:** The findings of our analysis revealed that most participants expressed satisfaction and shared positive experiences with the healthcare services they received. They emphasized that improved facilities and high-quality equipment played a significant role in enhancing their satisfaction. However, several barriers were identified, primarily related to physical limitations. These barriers included insufficient parking availability, deteriorated wheelchair conditions, long distances between different areas, overcrowding in the pharmacy, heavy doors, the absence of automatic beds, excessively high emergency buttons, limited shopping options, and restricted operating hours. Participants also expressed expectations for improved transparency in doctor-patient communication and enhanced hospital promotions. **Conclusion:** To enhance future healthcare provision, it is essential to understand and address the expectations of PWPD and their caregivers at various levels within the healthcare system.

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Corresponding Author:

Farah Natashah Mohd, MSc SSCD(KCL)

Email: fasha@iiium.edu.my

Tel: +609-591 2596

INTRODUCTION

According to the Department of Social Welfare Malaysia, the number of registered 'People with Disabilities (PWD)' in 2021 was 621, 248 individuals. Among the PWD categories, the physical category accounted for the highest percentage at 35.2%, followed by the learning disability category at 34.8% and the visually impaired category at 8.9% (1). Additionally, in 2008, the Malaysian government ratified the Convention on the Rights of Persons with Disabilities at the UN Headquarters. This ratification establishes comprehensive safeguards for individuals with disabilities, encompassing the rights to life, equality before the law, and access to justice,

education, employment, and healthcare. The treaty became effective in Malaysia on August 18, 2010 (2). The primary objective of this act is to facilitate the registration, protection, rehabilitation, development, and overall well-being of persons with disabilities, with the aim of eliminating barriers that hinder their full and active participation in society.

People with physical disabilities (PWPD) face greater healthcare challenges than the general population (3). Research indicates that approximately 40% of this population experienced unmet medical needs due to difficulties in accessing healthcare services (4). A Canadian study revealed that PWPD were more socially disadvantaged and more likely to rely on emergency departments, suggesting unmet health needs (5). Moreover, people with disabilities have higher rates of premature death and preventable chronic conditions and are less likely to receive timely screenings (6-12).

Sometimes, their access to diagnosis and treatment is limited (9,13). The reasons for this include financial constraints, transportation issues, structural barriers, and the lack of appropriate equipment, such as lifting devices, accessible scales, and suitable examination tables (14-15). Furthermore, healthcare professionals' attitudes also have been identified as additional barriers to healthcare access for people with disabilities (16). Previous studies conducted abroad have highlighted physical barriers, transportation limitations, communication challenges, attitudes of both clients and providers and care coordination as factors affecting the quality of healthcare received by individuals with disabilities (13,15,16,17).

To date, no specific study has been conducted in Malaysia to assess the experiences, barriers, and expectations of people with physical disabilities (PWPD) and their caregivers in receiving healthcare services. Therefore, this study aims to fill this knowledge gap by exploring these aspects within the context of Sultan Ahmad Shah Medical Center (SASMEC). By conducting this research, we aim to gain a comprehensive and accurate understanding of the healthcare experiences of PWPD and their caregivers in this specific setting. Additionally, the findings of this study will not only improve the services in our hospital but also provide valuable insights into the overall healthcare system in Malaysia. We hope this study's outcomes will guide policymakers, healthcare professionals, and stakeholders in identifying and addressing the barriers faced by PWPD in accessing healthcare services.

MATERIALS AND METHODS

Study setting

This study was conducted at Sultan Ahmad Shah Medical Centre (SASMEC), Kuantan, Pahang, Malaysia. This hospital is a teaching hospital certified Shariah-based, which consists of up to 70 subspecialties (18). From these subspecialties, we choose several clinics in SASMEC which were Special Care Dentistry, Surgical, Medical Rehabilitation and Orthopedic clinics to conduct this study. These clinics were chosen as there were the main clinics visited by PWPD.

Study design, recruitment of participants and data collection

The study was an in depth, exploratory qualitative study aimed to explore the personal experiences, barriers, and expectations of PWPD and their caregivers in receiving healthcare services at SASMEC. The study was conducted from January to June 2023, allowing participants to express their views and share their experiences. A total of 18 participants, including PWPD and their caregivers, were selected using a purposive sampling technique. The recruitment process involved contacting potential participants through respected clinics, and criteria such as language proficiency and exclusion of untreated

psychiatric illness were applied. Data collection was stopped once there was no new information gain and the data saturation achieved.

Data collection involved conducting face-to-face, semi-structured, one-on-one interviews in a private room at the rehabilitation clinic. The interviews were conducted in Malay language (the first language of the researcher and participants) which include socio-demographic background, overall health status, healthcare experiences, satisfaction levels, and expectations. The themes used in this study were generated from the literature review (3,9,13,14,15). Each interview lasted between 45 minutes to 1 hour, and field notes were taken during the interviews. The interviews were audio recorded with participants' consent and later transcribed verbatim. No repeated interviews were conducted, and there was no pre-existing relationship between the researcher and participants. Participants received a token of appreciation at the end of the interviews for their participation.

Data analysis

The interviews were audio-recorded and transcribed verbatim into coding sheets prior to analysis. The analysis for this paper was conducted in Bahasa, and later the relevant quotes were translated into English. In order to secure the trustworthiness, PI went over and corrected each transcription to ensure that the recording was accurate. Subsequently, during a follow-up peer debriefing session, researchers independently coded the transcripts and cross-referenced replies to ensure the reliability of interpretations (19). This methodology was considered optimal for two key reasons. Firstly, the interviewer who conducted the interviews is a native Malaysian and proficient in Bahasa, which ensured a higher level of credibility in interpreting and coding the data using the participants' language. Secondly, translating the interviews into English before analysis poses inherent risks of losing both the exact meanings and the cultural meanings, as certain Bahasa terms may not have direct translations and require understanding within their cultural context (20) The analysis was conducted following the guideline outlined by Braun and Clarke for thematic analysis (21,22). Thematic analysis was chosen as it allowed for an exploration of the perspectives of PWPD and their caregivers regarding healthcare services. Firstly, we read the transcripts repeatedly to become familiar with the data. Secondly, initial codes were generated, and efforts were made to reduce overlap and redundancy in the codes. Initial sets of codes were created based on the data, and the research team members used the remaining codes to establish categories, as identified early in the coding process. Common patterns among the codes were identified to generate themes that were relevant to the research objectives. Lastly, the English translated themes were reviewed by 2 supervisors and defined to make sure they were cohesive and distinguishable from each

other.

Ethical consideration

Application and approval of the study from IIUM Representative for Ethical Committee (IREC) IREC 2022-202 and Department of Education and Research (DEAR), SASMEC @IIUM was obtained. On top of that, the procedures were fully explained to the subjects and written consent was obtained prior to the interview.

RESULTS

Sociodemographic profile of the participants

The sociodemographic profile of the participants in this study provides a comprehensive view of their background and characteristics. The study included a total of 18 participants, comprising 11 patients and seven caregivers. Table I shows the sociodemographic background of the respondents while table II shows their clinical background. Table III summarizes the findings.

Personal experiences with healthcare services

Positive experiences with healthcare workers, staff and students

The attitude of healthcare workers and supporting staff is important in shaping the healthcare experience for PWPDP. It not only contributes to patient satisfaction but also has a significant impact on health outcomes and emotional well-being. The majority of respondents expressed their satisfaction with the attitude of the healthcare workers, staff, and students, highlighting their positive experiences with the healthcare services they received from our hospital.

One of the notable aspects appreciated by patients was the friendly and caring nature of the healthcare workers. Patients describe the staff as approachable, using soft voices that create a warm and welcoming environment. The level of friendliness exhibited by the healthcare workers makes patients feel like they are among family members rather than in a clinical setting.

"The doctor is excellent, top-notch. As soon as we enter the consultation room, they greet us in their own way. They don't just put on a blank face. The ENT doctor is particularly friendly, always asking if there is anything we want to inquire about or any other problems we have." (Patient 1)

The attentiveness of the doctors was another aspect that patients valued. The doctors take the time to thoroughly explain procedures, address patients' concerns, and answer their questions. This patient-centred approach instils a sense of trust and allows patients to actively participate in their healthcare decisions.

"I usually visit the orthopaedic clinic. I come around 8 am, and by 10 am, I can already see the doctor. Last

Table I: Sociodemographic background of participants

Socio demographic		Numbers (n)
Status	Patients	11
	Caregivers	7
Gender	Male	7
	Female	11
Age (mean,range) in years		49.25, 20-70
Race	Malay	15
	Chinese	2
	Indian	1
Level of education	Secondary school	11
	Diploma/Degree	5
	Master/PhD	2
Occupational category	Government	1
	Private sector	5
	Pensioner	3
	Self employed	2
	Unemployed	5
	Student	2

Table II: Clinical background of participant

ID	Status	Age	Gender	Diagnosis	Beneficiary
R1	Patient 1	60	Male	Right sided stroke	No
R2	Caregiver 1	63	Female	-	-
R3	Patient 2	48	Female	Right sided stroke	Yes
R4	Caregiver 2	50	Male	-	-
R5	Patient 3	28	Male	Prolapsed intervertebral disc (PID) L4,L5	No
R6	Caregiver 3	28	Female	-	-
R7	Patient 4	70	Female	Right knee osteoarthritis	No
R8	Caregiver 4	72	Male	-	-
R9	Patient 5	20	Female	Tumour T8-T12	No
R10	Caregiver 5	40	Female	-	-
R11	Patient 6	47	Female	Left sided stroke	No
R12	Patient 7	65	Female	Right diabetic foot ulcer with below knee amputation	Yes
R13	Patient 8	15	Male	Left tibial and fibula fracture	No
R14	Caregiver 8	58	Male	-	-
R15	Patient 9	39	Female	Multiple sclerosis	No
R16	Caregiver 9	35	Female	-	-
R17	Patient 10	41	Male	Spinal cord injury	Yes
R18	Patient 11	33	Female	Spinal cord injury	Yes

time, the duration was about 30 minutes to 1 hour because the doctor wanted to explain the procedure for the operation. Plus, I had a lot of questions to ask as well." (Patient 11)

Involving patients in decision-making was another aspect that contributed to a positive healthcare experience. Both groups express satisfaction with the healthcare providers who seek their opinions and involve them in the decision-making process. This patient-centric approach empowers individuals to actively participate in

their care, ensuring that their preferences and concerns are considered.

"They will ask for our opinion first." (Caregiver 3)
"When something is needed, the doctor will provide suggestions." (Patient 3)

Patients also appreciate the helpfulness of the hospital staff and students. The level of support and care demonstrates the dedication of the healthcare team, creating a positive and supportive atmosphere for patients.

"There's one (nursing student), who I treated like an adopted child. Initially, when I need to go to the eye department, I sometimes don't remember which floor to go to. She was the one that guided and accompanied me. In return, she always calls me to ask for prayers." (Patient 4)

The waiting time for consultations was also one of the important factors in patient satisfaction. Patients described the waiting time as appropriate and well-balanced. This efficient management of waiting times creates a positive impression and reflects effective communication between the healthcare teams.

"There are no issues here. There is a two-way communication. It's not too long or too short, just nice." (Caregiver 8)

Professionalism and competence in healthcare workers inspire confidence in patients and their families. When healthcare providers and supporting staff exhibit expertise in their roles, patients perceive them as trustworthy and capable of delivering high-quality care. This professionalism encompasses qualities such as reliability, accountability, and ethical conduct.

"The nurses here are more experienced in terms of skills. They are the ones who draw blood and insert intravenous drips. It's different from other hospitals. There was also a time when a staff nurse checked my urine volume using ultrasound. It was good." (Patient 3)

Treating patients with respect and preserving their dignity is fundamental in healthcare settings. Respecting patients' dignity positively influences their healthcare experience and instils trust in the decisions made by the healthcare team. A female respondent expressed appreciation for the consideration given to gender segregation and privacy during specific times of the day:

"After 10 pm, there are no male staff members. Even in the morning, they only open the curtains at 7 am, before that, there's nothing." (Patient 5)

Better facilities and adequate equipment

The availability of proper facilities and equipment in healthcare settings plays a crucial role in enhancing the

overall experience of patients, particularly for people with physical disabilities. Throughout the interview, some respondents highlighted several aspects related to the infrastructure of SASMEC. Firstly, the spacious hospital areas were appreciated by wheelchair users, offering comfort and easy navigation for both patients and caregivers.

"It's comfortable and spacious. If I need to stay for a while, he can push himself to the elevator and anywhere else. Other government hospitals are narrow, I have to wait for him." (Caregiver 1)

Furthermore, a few respondents also emphasized the importance of cleanliness within the hospital environment. Positive feedback regarding cleanliness indicates a high standard of maintenance and hygiene practices being implemented in SASMEC. Additionally, maintaining clean and well-maintained toilets is another essential aspect of healthcare facilities.

"Everything here is clean and beautiful." (Patient 10).
"The restroom is clean, tidy, and odourless. It seems like they always keep it clean. I only use the accessible toilet, never the regular one." (Patient 10)

Apart from cleanliness, they were also concerned about the accessibility of toilets in the hospital. The availability of accessible toilets which cater for the needs of individuals using wheelchairs or walking frames promotes independence. One patient praised the accessible toilets around the hospital:

"The toilets are very helpful. Even with the regular toilets, I can sit on them." (Patient 6)

Furthermore, the provision of buggies within the hospital premises was also appreciated by patients. This service allows caregivers and PWPD to move around the hospital especially when they need to go to different clinics or departments. The availability of buggies demonstrates the hospital's commitment to ensuring the convenience and well-being of patients with mobility challenges.

"I used to come here before when there was no buggy, but now they have it. If I arrive there and feel tired, I just wait for the buggy." (Patient 4)

Moreover, the hospital is also equipped with some specialized equipment such as physiotherapy machines. The availability of this equipment helps PWPD to have a comprehensive and continuous therapy in just one hospital. One caregiver of a stroke patient highlighted the advantage of a better machine at SASMEC compared to the previous hospital experience:

"The physiotherapy machine they use is not available there (refer to previous hospital). They have it here.

So, my husband's hands and legs can work together."
(Caregiver 2)

In this current study also, we found that several participants emphasized on a computerized system (I-Pesakit) that has been used by SASMEC. Quick access to patient data through an efficient computer system was mentioned as a positive attribute of the healthcare services provided. This digital infrastructure enables healthcare providers to access and retrieve patient information promptly, resulting in more efficient care. As a result, this computerized system eventually reduced waiting times and improved coordination among healthcare professionals, ultimately enhancing their overall healthcare experiences.

"Moreover, all the follow-ups are done using a computer system, so it's more efficient." (Patient 11)

Barriers when seeking healthcare services

Inadequate parking lot

One prominent issue voiced out by PWP and the caregivers was the inadequate availability of parking spaces within the hospital premises. Throughout the interview, several respondents mentioned the need to arrive early just to secure a parking spot. They need to wake up early and prepare themselves which takes a longer duration compared to a normal person.

"Finding parking is always difficult. You have to arrive early to secure a spot, and usually, my sister drops me off." (Patient 5)

This situation is further exacerbated by the fact that some individuals disregard parking regulations, occupying designated parking spaces for people with disabilities (OKU parking) without the necessary permits or stickers.

"There are only four OKU parking available at the main entrance. Yet, other people often park there. Previously, luxury cars would occupy those spaces. But now, normal people without the OKU sticker park there." (Patient 1)

To address this problem, it is essential to prioritize the expansion and enhancement of parking facilities. By creating additional parking options, the hospital can cater the needs of patients, visitors, and staff, allowing for a smoother and more convenient experience when arriving at the facility. One respondent shared her view on a solution regarding this problem.

"Increase the size of the parking area and consider constructing multi-level parking." (Caregiver 1)

Limited and restricted operating hour of the shop lots

One aspect that poses challenges within the hospital is the limited availability of shopping options, accompanied

by restricted operating hours. This poses inconvenience and difficulty for both PWP and their caregivers who may need to purchase essential items or refreshments during their stay. This situation becomes particularly problematic during extended hospital stays or when patients are unable to leave the premises, which was mentioned by one respondent:

"During my previous hospitalisation in Klang Valley, there were 3 to 4 cafes were open at night. However, during my 10-day hospitalisation here, I couldn't go out. It was a bit challenging, especially during the weekend, because all the cafes were closed. Only 1 cafe opens until 10pm" (caregiver 3)

Deteriorated wheelchair condition

Based on the interview, most PWP use the wheelchairs available in SASMEC. However, there was a noticeable problem with the condition of the wheelchairs. Most wheelchairs were in poor condition with unusable wheels and missing footrests. For example, a patient of spinal cord injury mentioned:

"There is just one issue; many wheelchairs in the ward are damaged. The wheels are unusable, and some lack footrests. Some wheelchairs have rust due to improper storage" (Patient 11)

Addressing this issue requires regular maintenance and proper storage practices to ensure functional and safe wheelchairs are readily available.

Heavy doors

Although not a major concern, the weight of some doors within the hospital poses challenges for wheelchair users. This is particularly noticeable in areas where manual doors are used instead of automatic ones. For example, in the radiology department,

"There is a slight problem in radiology. The door to Room A gets stuck when I push it all the way, getting caught on the adjacent door." (Caregiver 8)

To improve accessibility, they suggested installing automatic doors: *"It would be better to have automatic doors instead of manual ones, as it can be challenging to push them."* (Caregiver 1)

Absence of automatic beds

One notable issue within the hospital is the absence of automatic beds. It becomes a major challenge particularly those with limited mobility where they require assistance with adjusting their bed positions. Due to this problem, they often rely on the assistance of healthcare personnel or family members to raise or lower the bed according to their comfort level. This dependency on others not only affects the patient's sense of independence but also places an additional burden on the hospital staff. One respondent mentioned:

"During my stay in the ward, there were no automatic beds, although I noticed some in other ward. However, the bed I had was a manual one. So I had to ask for assistance when it was time to eat. Even when I wanted to eat by myself, I had to rely on someone else to raise the bed. I have a spinal problem, and if I could adjust it myself, it would be more convenient." (Patient 5)

Excessively high emergency button

Another concern is the placement of emergency buttons in the wards. The emergency buttons were too high to access especially when there is any emergency or when they require immediate assistance.

"Another issue was that reaching the button at the back of the bed was difficult because it's placed too high." (Patient 5)

Even worse, other respondent reported that some of them were not functioning. As a consequent, this can cause delays in receiving prompt medical attention or aid, potentially compromising patient safety and well-being. The placement of emergency buttons at a more accessible height would greatly enhance patient comfort and ensure their ability to quickly get assistance whenever needed.

"There's also the issue of the ward bell. In the medical ward, the bell rings, but no one comes. Some elderly ladies ended up crying while calling for the nurse. Recently, the bell broke as well." (Patient 9)

Overcrowding in the pharmacy

Pharmacy becomes one of the important departments for both inpatient and outpatient. Due to this, the pharmacy within the hospital encounters problems with overcrowding, resulting in inconvenience for patients. One caregiver shared her experience of being unable to retrieve their prescribed medications because the pharmacy unexpectedly closes earlier than anticipated: *"Sometimes, we cannot collect our medications because the pharmacy is already closed." (Caregiver 3)*

To tackle this issue, one respondent recommended: *"The pharmacy and payment counters should implement a counter replacement system. For example, during break time from 1pm to 2pm, there should be staff members to take over, like a shift system. This way, during the 1-2 shift, the staff who took a break earlier can return, ensuring uninterrupted service. I believe this approach could be beneficial." (Patient 3)*

By ensuring adequate staffing coverage throughout the day, the pharmacy can operate efficiently, avoiding any delays or inconveniences for patients.

Expectations towards our healthcare services

Improved transparency in doctor-patient communication

Participants expressed a strong desire for doctors to provide clearer explanations and ensure that their concerns and treatment plans are thoroughly understood. They emphasized the importance of having a meaningful and open dialogue with healthcare professionals, where information is presented in a transparent and accessible manner. One participant shared his experience:

"One thing I hope for is that when the doctor tells the story, maybe they can be more transparent, like my late father, who passed away due to pancreatic cancer and received treatment here. At that time, the doctor didn't fully disclose it to us. I didn't know the actual condition of my father. To put it simply, my father didn't have much time left at that time, but the doctor didn't say it. We understand their concerns, but maybe they could call and tell us the actual situation." (Patient 3)

Enhancing hospital promotion

In terms of enhancing hospital promotion, participants pointed out the need for more robust initiatives to raise awareness within the community about the services and facilities available at the hospital. Currently, many individuals rely on word-of-mouth or learn about the hospital through their children:

"I know this hospital from my younger sibling, because she brought her child here." (Patient 6) Hospitals should proactively engage in promotional activities such as public campaigns, community outreach programs, and partnerships with local organizations. By increasing visibility and disseminating accurate information, hospitals can ensure that the community is well-informed about the healthcare services offered, attracting more people to come.

DISCUSSION

In this study, we managed to explore both positive and negative experiences from the caregivers and PWP. The later experiences become barriers that they encountered. Our results indicate that positive experiences were built based on two bases: good interaction with the healthcare community and availability of facilities or equipment.

Effective communication plays a vital role in establishing strong relationships between patients, caregivers, and healthcare providers. In our study, we discovered that PWP and their caregivers expressed high satisfaction with the services, primarily due to the approachability and attentiveness of the doctors in which supported by a recent local study (23). These qualities are crucial in ensuring that the needs of PWP and their

Table III: Summary of findings

Themes	Subthemes	Main points
Experiences when seeking healthcare services	Positive experiences with healthcare workers, staffs and students	Friendly and approachable doctors
		Attentiveness of doctors
		Involvement in decision making
		Helpfulness of student and staff
		Worth waiting time
	Better facilities and good equipment	Professionalism and competence of staff
		Preservation of dignity
		Spacious hospital areas
		Cleanliness of hospital
		Accessibility of OKU friendly toilet
Barriers when seeking healthcare services	Lack of facilities	Inadequate parking availability
		Limited shopping options and restricted operating hours
	Equipment problems	Deteriorated wheelchair condition
		Heavy doors
		Absence of automatic beds
	Overcrowded	Excessively high emergency button
		Overcrowding in the pharmacy
Expectations towards our healthcare system	Improved transparency in doctor-patient communication	
	Enhancing hospital promotion efforts	

caregivers are adequately addressed. Interestingly, our findings differ from other studies, which highlighted communication as a significant barrier to accessing healthcare services (24-26). Furthermore, some previous studies have emphasized the importance of fostering positive relationships with healthcare providers (27,28). Patients that have positive relationships with healthcare providers were able to communicate better about the impact of their disability, navigate their care journey effectively, and receive appropriate accommodations (27). Consequently, PWPD and caregivers felt comfortable sharing their problems and challenges, as these positive relationships fostered an environment conducive to patient-centered care (27). This, in turn, empowered them to actively participate in their own care and decision-making processes.

In addition to effective communication, participants also emphasized the significance of the attitudes displayed by supporting staff and students. The professionalism and competency demonstrated by the staff in their interactions with PWPD and their caregivers were highly valued. This was further reinforced by the actions of healthcare providers who prioritised and respected the privacy and dignity of patients throughout their treatment. Several studies have supported these findings by highlighting the importance of correct behavior and attitude affecting the accessibility to healthcare services (24,29). The quality shown by supporting staff

and students create an encouraging environment for PWPD to continue their treatment and rehabilitation in SASMEC.

Facilities and equipment are vital components of a healthcare setting, alongside the human factors involved in patient care. Based on our findings, spacious hospital areas and cleanliness of the hospital contribute to a comfortable and accommodating environment for PWPD and their caregivers. Studies have consistently demonstrated the positive impact of clean environments on patient satisfaction and well-being (31-32). In addition, the accessibility of hospitals for PWPD and their caregivers is crucial. They praised the availability of OKU-friendly toilets and the provision of buggies within the hospital premises. These facilities greatly improved their movement and provided convenience for them, ensuring that they feel included within the healthcare environment. Conversely, the absence of disability-friendly facilities can result in physical exclusion for PWPD (24). Furthermore, PWPD are also satisfied with the availability of specialised devices in SASMEC. As a consequence, they do not have to be referred to other tertiary hospitals, ensuring that they receive the necessary specialized care promptly (28). Some participants also believed that the implementation of computerized systems by SASMEC significantly improves healthcare delivery. These systems facilitate efficient management of patient records, enhance communication among healthcare providers, and minimize errors (33).

In our study, we also focused on the various barriers encountered by PWPD and their caregivers when accessing healthcare services at SASMEC. These barriers primarily revolved around physical obstacles, which have been consistently reported in previous research as well (34-38). One prominent challenge was the reliance on family support for appointments, primarily due to parking issues either due to inadequacy or insensitive provisions for disabled parking. This problem was also reported from the previous studies worldwide (36-38). In fact, the condition is even worse for them when the wheelchairs available at the main entrances have deteriorated. To address this, we recommend the implementation of more designated parking areas and regular maintenance of wheelchairs, which would significantly alleviate the burden on PWPD and their caregivers. Furthermore, we identified the weight of certain doors and the absence of automatic beds as additional challenges faced by wheelchair users and patients with limited mobility. To enhance accessibility and promote independence, we propose the installation of automatic doors and the provision of automatic beds.

Throughout our study, participants who had experienced hospitalization emphasized the importance of emergency buttons being positioned at a more accessible height. This adjustment would ensure prompt assistance in emergency situations, preventing any

delays that may compromise patient safety. Moreover, participants expressed frustration regarding the limited shopping options and restricted operating hours within the hospital, particularly during extended stays. Expanding the range of shopping facilities and extending operating hours would significantly improve the overall experience for patients and their caregivers, alleviating the inconvenience they encounter. Lastly, overcrowding in the pharmacy emerged as a prevalent issue raised by participants. To ensure efficient and timely service, we suggest the implementation of counter replacement systems and the provision of adequate staffing coverage throughout the day. By addressing these physical barriers and implementing our proposed solutions, it shall improve the overall healthcare experience as well as foster greater independence, accessibility, and patient satisfaction.

Regarding recommendations for the future, studies in the evaluation of healthcare access might make use of validated questionnaires that are based on the experience, challenges, and expectations from the present research.

CONCLUSION

In conclusion, this study identifies experiences, barriers and expectations among PWPDP and their caregivers when accessing healthcare services specifically in SASMEC. Positive experiences related to attitudinal aspects of healthcare workers, supporting staff and students as well as physical facilities may enhance them to continue their treatment in this hospital. However, a few barriers which were mainly related to physical accessibility should be improved in the future as proposed by local guideline. By tackling these issues, we can establish a healthcare system that is accommodating and accessible to all.

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