



A Qualitative Exploration Of Self-Care And Health Management Experiences Of Adult Manual Wheelchair Users

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ABSTRACT:

BACKGROUND: Wheelchair is one of the commonest mobility devices for improving functional independence and active participation among persons with mobility limitations. However, there is limited understanding of how a wheelchair affects self-care and health management. The aim of this research is to understand the perspective of manual wheelchair users in completing self-care and health management.

METHOD: This study used the Qualitative Research method. In which Focus Group Discussion (FGD) was used. Wheelchair users with manual wheelchairs were selected as participants. A convenient sampling was adopted for the study. A total number of 7 manual wheelchair users were placed in the group. The duration of discussion lasted for 1 hour 30 minutes which included a warmup session, discussion session, and feedback session. The sessions were audio recorded and Recordings were transcribed in the Tamil language and translated into English for study purposes. Data collected during the focus group discussion was analysed using inductive thematic analysis.

RESULTS: Three themes- wheelchair product, barriers, and personal factors were found, along with nine subthemes- wheelchair durability, problems in day-to-day activities, suggestions for modification, environmental and non-environmental, environmental adaptation, condition-specific challenges, and economic condition. Offering a comprehensive understanding of the challenges and adaptive strategies of wheelchair users.

CONCLUSION: The study concluded the importance of a holistic approach for wheelchair users, highlighting barrier removal, inclusive wheelchair design, and customized interventions. The government, healthcare professionals, and designers can work together to create an environment that supports wheelchair users' independence and improves their quality of life by incorporating user perspectives.

KEYWORDS: Wheelchair User, Self-Care, Health Management, Focus Group Discussion.

I. INTRODUCTION:

The ability to move around is essential to human health and well-being. An appropriate wheelchair is essential for individuals who depend on them for mobility; it is required to guarantee their physical and mental well-being as well as their ability to function, participate, and be included. ⁽¹⁾

Approximately 15% of the world's population has some type of disability, and 1% of the population globally needs wheelchairs for increased mobility. ⁽²⁾ According to the last census in India, out of the 121 Cr population, 2.68 Cr persons are 'disabled' which is 2.21% of the total population. 20% of disabled persons are having disability in movement and its prevalence is steadily growing. ⁽⁴⁾

Wheelchairs provide mobility, postural support, and freedom to those who cannot walk or have difficulty walking, enabling them to move around, participate in everyday activities, and live life on their own terms. Wheelchairs, one of the most widely used assistive devices, are a valuable asset that allows access to places and tasks that would not be possible without them. ⁽¹⁾

1.1 Wheelchair user

Wheelchair user a person who has difficulty in walking or cannot walk, and uses a wheelchair for their mobility. ⁽⁵⁾ Many people with disabilities experience mobility impairments, requiring access to an appropriate wheelchair.

Wheelchair services must be able to meet the specific requirements of the individual, with regard to the specific condition that the individual is experiencing. conditions such as amputation, cerebral palsy, stroke, multiple sclerosis, muscular dystrophy, arthritis, spinal cord injury, neurodegenerative diseases, acquired neural/ brain injuries and other mobility related conditions. ⁽¹⁾

1.2 Appropriate wheelchair

An appropriate wheelchair meets the user's needs and environmental conditions, provides proper fit and postural support, is safe and durable, is available in the country and can be obtained and maintained and services sustained in the country at an affordable cost. ⁽¹⁾ Individuals with similar health conditions may not be similarly disabled or share the same perception of their disability, depending on their environmental adaptations the wheelchair should be made. ⁽³⁾

Access to suitable wheelchairs continues to be a major challenge, and standard practice within the wheelchair provision industry is uneven globally. There are a number of obstacles that prevent wheelchair users from having one or from using one without professional assistance, which increases the risk that they will use an improper wheelchair. Yet there is a significant and expanding demand for appropriate wheelchairs. ⁽¹⁾

1.3 Difficulties faced by wheelchair user

Adults who use wheelchairs have difficulty accessing physicians and receive less preventive care than their able-bodied counterparts. ⁽⁶⁾

Wheelchair-using individuals with disabilities frequently find it difficult to get from one place to another because public spaces are not accessible to them. ⁽⁷⁾

An individual with limited mobility has fewer opportunities to engage in education, training, and employment in an inaccessible built environment. Also, their exposure to positive life situations is limited. ⁽⁸⁾

When using a wheelchair indoors, a walker is typically used along with it. This is because it is inherently challenging to move a wheelchair in a typical home design, which has small doors, and stairs. ⁽¹⁰⁾

2.1 Difficulties in selfcare and health management

Research by Sushil Kumar Sahoo et al., highlighted challenges such as inaccessible healthcare facilities, limited availability of medical equipment, and inadequate training of healthcare professionals in addressing the specific needs of wheelchair users. He mentioned that further investigation is required to understand the long-term impact of wheelchair accessibility on the health outcomes and overall well-being of individuals with mobility limitations. This includes assessing the effects of accessibility on physical health, mental health, social participation, and overall quality of life. ⁽¹¹⁾

In the study conducted by Marianna S. Wetherill et al., concluded that reduced mobility can significantly impair one or more instrumental activities of daily living (IADLs), like grocery shopping, meal preparation, and household (kitchen) cleaning, as well as activities of daily living (ADLs), like walking and eating. These restrictions on ADLs and IADLs may have a negative effect on dietary intake by lowering the frequency of shopping outings, limiting access to necessary food items at stores, lowering the amount of fresh food available at home, and making it harder to prepare or eat healthful meals at home.⁽⁹⁾

2.2 Selfcare

Self-care has been an important concept throughout the profession of occupational therapy's history. Self-care has traditionally referred to activities of daily living (ADL), or personal activities such as eating and grooming. ADL, as defined by the Occupational Therapy Practice Framework: Domain and Process (the Framework), are "activities oriented toward taking care of one's own body".⁽¹²⁾

In OTPF-4 selfcare include Bathing, showering, Toileting, Dressing, eating, swallowing, feeding, functional mobility, personal hygiene and grooming and sexual activity.⁽¹³⁾

Bathing and showering: Getting bathing supplies and using them; washing, rinsing, and drying body parts; staying in the bathing position; and moving between bathing positions.

Toileting and toilet hygiene: Getting and using toileting supplies, keeping clothes in order, moving to and from the toileting position, cleaning the body, attending to menstrual and continence needs (such as colostomy, catheter, and suppository management), maintaining bowel movements and urination under intentional control, and, if required, using bladder control tools or agents.

Dressing: Dressing and undressing in an arranged manner; choosing clothes and accessories based on the time of day, the weather, and the desired appearance; acquiring clothing from the storage area; securing and modifying footwear and clothing; putting on and taking off splints, prosthetics, or personal devices.

Eating and swallowing: Keeping food or liquid in the mouth, adjusting it, and swallowing it.

Feeding: Gathering, positioning, and bringing food or liquid from the container to the mouth.

Functional mobility: Transferring between positions or locations (while carrying out daily tasks), including in-bed mobility, wheelchair mobility, and transfers (e.g., wheelchair, bed, car, shower, tub, toilet, chair, floor); this includes functional ambulation and object transportation.

Personal hygiene and grooming: Getting supplies and using them; shaving or using tweezers to remove body hair; applying and taking off makeup; washing, drying, combing, styling, brushing, and trimming hair; taking care of the hands and feet's nails; taking care of the skin, ears, eyes, and nose; putting on deodorant; cleaning the mouth; brushing and flossing teeth; taking out, cleaning, and reinstalling dental orthotics and prosthetics.

Sexual activity: Participating in the wide range of sexual expression and experiences with oneself or other people.

2.3 Health management

Activities that focus on developing, managing, and preserving wellness and health habits, such as self-management, in order to enhance or preserve health and enable participation in other occupations.⁽¹³⁾

Health and Well-Being: Maintaining wheelchair accessibility is essential for improving the mental and physical health of wheelchair users. Accessible environments encourage mobility, exercise, and leisure activities, improving cardiovascular health, muscular strength, and general fitness. Additionally, wheelchair accessibility facilitates access to medical facilities, ensuring prompt medical care and support, enhancing quality of life and health outcomes.⁽¹¹⁾

Social and emotional health promotion and maintenance: Finding jobs and social interactions that promote health and well-being, recognizing one's own talents and assets, controlling emotions, effectively expressing demands, creating a sense of self, and making decisions to enhance one's quality of life.

Symptom and condition management: Managing mental and physical health needs, such as using coping mechanisms for illness, trauma, or social stigma; controlling pain; managing chronic illness; identifying symptom fluctuations and changes; developing and using techniques for managing and controlling emotions;

scheduling time and creating behavioural patterns for restorative activities (such as meditation); using social and community supports; navigating and obtaining health care

Communication with the health care system: Expressing and receiving verbal, written, and digital communication with health care professionals and insurance providers, including understanding and advocating for self or others.

Physical activity: completing strength, balance, and cardiovascular exercises to enhance or preserve health and lower the risk of health episodes, such as making walks a regular part of the day.

Nutrition management: Implementing and following the medical team's recommendations regarding nutrition and hydration, cooking meals to support health objectives, and engaging in diet regimens that promote health.

Personal care device management: Purchasing, using, maintaining, and cleaning personal care items such as glucometers, pessaries, adaptive equipment, glasses, contact lenses, hearing aids, orthotics, prosthetics, and contraceptive and sexual devices.

3.1 Qualitative study

Qualitative research is any type of study that yields findings that are not derived from quantitative methods or various types of measurements. This can contribute to work on person's life, observations, attitudes, perceptions, and opinions. ⁽¹⁴⁾ Research that understands phenomena, investigates problems, and provides answers is known as qualitative research.

3.2 Focus group discussion

Focus groups are used to gather information about shared opinions and the meanings that lie behind those views. They also help to create a deep understanding of the beliefs and experiences of participants. ⁽¹⁸⁾ Focus group discussion is more beneficial because they offer more genuine settings where participants can both influence and be influenced by one another. ⁽¹⁹⁾ Focus groups are considered as an efficient method of gathering information from a wide range of people, and they would be a helpful attempt to bring participants with similar experiences together to examine a particular topic of interest. ⁽¹⁸⁾

II.METHODOLOGY:

The study used a qualitative approach with Focus Group Discussion as the method. It was conducted at the Mary Varghese Wheelchair Trust, Bagayam, Vellore. The sample population included manual wheelchair users, and a convenient sampling technique was used. The sample size was seven (n = 7).

Inclusion criteria were: Person above 18years ⁽³⁵⁾, Long-term wheelchair Users ⁽³⁶⁾, manual wheelchair users, and both genders. Exclusion criteria included: persons who are not able to understand commands, short-term wheelchair users due to orthopaedic conditions and acute care, and people who don't know the regional language.

III. DATA COLLECTION METHOD:

Participants were identified according to the selection criteria and invited to take part in the study. The study's objective was described. They consented to participate and provided signed consents. Detailed, semi-structured focus group discussions were used as the data collection method. To conduct the focus group discussion (FGD) the wheelchair users were gathered in the Indoor space where the users take tailoring training and sports practice, the place is wheelchair accessible environment. As the place is situated away from the main road and confined room space it was made sure that no external distractions were present. I had a volunteer with me for helping to circulate forms and take photographs and videos. Semi-structured theme (guiding) questions were used to conduct the focus group discussions. Questions were asked to the participants after a brief ice-breaking session in order to learn more about their perceived knowledge, lived experience, and opinions regarding self-care and health management. The guiding topics prepared in English were questioned in Tamil. The session was audio recorded using two mobile phones which were placed on the table and the wheelchair users gathered around the table. The participants were assured and respected throughout the conversation. The participants were free to express their ideas, emotions, beliefs as well as their views and opinions. Each participant waited until others shared their views and answered. Everyone in the group facilitated to share their experience.

In general, once the focus groups cease to provide you with new information, then don't need to conduct any more sessions, one and a half hours often is the ideal length.⁽³⁷⁾ The time taken for FGDs was totally of 1 hour 35 minutes. The first 15 minutes of the session is utilized for providing a consent form, an explanation about the forthcoming sessions, and demographic details were collected, after an ice-breaking activity was given. Which is a paper-based activity, each participant is given time for completing the task and explained the purpose of the activity the theme is 'think outside the box'. Then next hour the session was recorded, the guiding questions were asked and data were collected, the Last 15 minutes, the collected data was repeated-made sure that all their points were collected; were given time to add any points if they've missed earlier and finally, Feedback form where given and feedback were obtained, through pen and paper and also verbal. The FGDs continued until the level of saturation was reached, at a point where no new concepts or ideas were contributed. Participants' comments on the topics of discussion were written down and gathered on audio. Later the recorded audio was heard multiple times to transcribe and the notes taken during the session were also considered to add in the transcript and the transcript was read along the audio to ensure that the information written was appropriate. To understand the content and information of the writings it was read thoroughly. To comprehend the information/meaning of the texts mentioned or spoken about by the participants, the texts were sorted, structured, tagged, and categorized. The transcripts were carefully examined to identify the refined themes and categories by inductive thematic analysis.

IV. DATA ANALYSIS:

The analysis was carried out after the focus group discussions were completed. The recorded audio was transcribed verbatim, and the discussions conducted in Tamil were translated into English. A thematic, line-by-line analysis was used to review the transcripts.

The transcripts were read several times to get a clear understanding of the data. Themes were then identified and categorized. Key points from the data were highlighted and coded with meaningful labels. These labels were used to compare other parts of the data to find similarities and differences.

Through this process, patterns within the categories were connected, and recurring themes emerged. Codes with similar meanings were grouped together into thematic statements to capture the core experiences. Finally, the themes were presented along with supporting quotes from the transcripts.

V. RESULTS:

This research was conducted to explore the difficulty encountered by adult manual wheelchair users in self-care and health management. Based on the results of the thematic analysis that has been carried out, three themes related to wheelchair users were emerged, namely:

- Wheelchair product with three subthemes, namely, wheelchair durability, problems in day-to-day activities, and suggestions for modification.
- Barriers with three subthemes, namely environmental and non-environmental, and Environmental adaptation.
- Personal factors with three subthemes, condition-specific challenges, and economic condition, and Managing emotions.

Table 1 Emerged Themes and Sub-themes

Theme	Sub-themes
Wheelchair product	Wheelchair durability
	Problems in day-to-day activity
	Suggestions for Modification
Barriers	Environmental barriers
	Non-environmental barriers
	Environmental adaptation
Personal factors	Condition-specific challenges
	Economic condition
	Managing emotions

Table 2 Participants' details

NAME	AGE	GENDER	DIAGNOSIS	ADAPTED PROFESSION	WHEELCHAIR TYPE	SELF-PROPELLED OR ATTENDED-PROPELLED	HOW LONG USING A	USING INDOOR /OUTDO OR / BOTH
WCU 1	41 y	Male	Spinal Cord Injury	Tailorin g/sports	Manu al	Self-propelled	4y	Both
WCU 2	27 y	Male	Spinal Cord Injury	Sports coach	Manu al	Self-propelled	7y	Both
WCU 3	37 y	Femal e	Spinal Cord Injury	Tailorin g/sports	Manu al	Self-propelled	4y	Both
WCU 4	38 y	Femal e	polio	Tailorin g/sports	Manu al	Self-propelled	2y	Outdo or
WCU 5	36 y	Femal e	polio	Tailorin g/sports	Manu al	Self-propelled	2y	Outdo or
WCU 6	31 y	Male	Spinal Cord Injury	Tailorin g/sports	Manu al	Self-propelled	2y	Both
WCU 7	24 y	Male	Spinal Cord Injury	Tailorin g/sports	Manu al	Self-propelled	1y 6m	Both

WCU* – Wheelchair User, y- years, m- months

Table 3 Abbreviation of the participant code

Example: WCU1 41, M	
WCU	Wheelchair user
1	Number of the participants (1 – 7)
41	Age of the participant
M	Gender (M-Male, F- Female)

5.1 Wheelchair product:

In this theme, we will discuss the problems with wheelchair durability and suggestions for modification by wheelchair users for their betterment, as well as the difficulties they face while using the wheelchair.

5.1.1 Wheelchair durability:

Under the heading of 'bathing and maintaining body posture', wheelchair users expressed that they faced many problems related to the grip of the break. Because the chances of falling are high, they face this issue often while transferring to take a bath.

"After buying a new wheelchair and using it only for 3-4 months, there will be some fault in the break. When applying the brakes and shifting from the wheelchair in the bathroom, wheelchair will go back suddenly due to the slippery surface and the chance of falling is very high, we face this problem often." (WCU2 27, M)

Wheelchair user 1 added some modifications in the wheelchair that will be helpful for them while transferring and avoids the chance of falling. This was added under the next sub-theme.

In the heading of 'toileting under cleaning after use', the wheelchair user stated that fall chances are high while transferring from the commode to the wheelchair due to the slippery surface. They also said they don't have any problems in cleaning, only while transferring they have troubles.

"We have no issues in cleaning the parts after toilet." (WCU1 41, M)

After cleaning while shifting to a wheelchair fall can happen often due to the slippery floor. wheelchair can move or we won't get a place to hold and shift. that is our major issue." (WCU2 27, M)

In both the above contexts the common problem is the grip of the wheel and brake on the slippery surface.

Wheelchair user shared that the most common problem they face in their wheelchair is while completing their hair cut, which comes under the personal hygiene and grooming subheading of self-care.

"I would sit in the wheelchair for hair cutting so the wheelchair would become full of hair and after taking bath, while shifting back to the wheelchair all the hair sticks to me again so, so I need to take bath again.

Nowadays I remove my cushion and sit on the wheelchair and get my hair cut done, after which I first clean my wheelchair and bathroom then I take a bath and shift to a wheelchair though I had cleaned, the hair would stick in the wheelchair which is a problem to me.

After the haircut the hair gets stuck in the wheel bearing which makes the wheel tight for propelling, so I need to clean that after every haircut. Even when I cover the wheelchair and cut my hair, It will get to the bearing and gets stuck. Every time we are getting these issues." (WCU2 27, M)

They mentioned that, after the hair cut the hair gets stuck in the wheel bearing which makes it difficult for the user to propel the wheelchair and the wheel becomes tight and even sometimes won't rotate so, they have to spend extra time in removing and cleaning the bearing to make the wheel free for propelling.

Also, wheelchair user 1 stated that they are often facing the same issue and all other participants agreed to his statement.

"When hair or thread gets stuck in the bearing, the wheel won't propel properly or it becomes tight. so I should remove and clean the bearing. Often, we face this issue." (WCU1 41, M)

This is a main issue that not many people are addressing when it comes to wheelchairs. The wheelchair users expressed it would be helpful if they get any solution for this problem.

In the 'personal device management' heading wheelchair users expressed how often they clean the wheelchair, the common problem they face in a wheelchair.

"I clean my wheelchair whenever I'm using it. Before using the wheelchair, I clean the dust and I will do full cleaning weekly once." (WCU3 37, F)

"Every week or once in 10 days I clean my wheelchair. if not, the wheels may become tight to propel" (WCU6 31, M)

From the responses, we know that they clean their wheelchair once in 10 days or once in a week. Everyone takes care of their device properly to avoid problems in propelling the wheelchair.

One of the wheelchair users stated that he would clean only if any tightness while propelling or any fault in the wheelchair is felt.

"I won't clean or remove until I notice any fault in the wheelchair. If there is any fault then I will clean it fully by removing all parts and oiling all the parts, especially the bearing and wheel". (WCU2 27, M)

Here they also have mentioned that the bearing problem and how they procure the bearing when they need a replacement.

"In the bearing, due to water while bathing or hair after cutting it gets stuck and makes, it difficult to propel sometimes the wheels won't rotate. At that time, we need to remove and clean them all or need to change the new one."

"Most of the time it's the bearing problem that we are facing. If that happens, I ask nearby wheelchair users if they may have spare bearings, we just buy among ourselves if not I buy from online with the bearing number." (WCU1 41, M)

Wheelchair users get bearings from other wheelchair users or they buy it from online. For repairing the wheelchair and removing the parts, they help among themselves and teach new users how to do the repairs.

"If there is any problem or repair in the wheelchair, we try to do it by ourselves. Those who don't know or new, we help them to do it and teach them." (WCU2 27, M)

If they have some problem in their wheelchair that needs to be fixed, they can do it by themselves but only when the parts are available nearby, if not they have to go to the place where they bought the wheelchair. One of the users shared that he wanted to go, but due to work he kept on postponing that.

"Mostly we get parts from other users or from online. if it is not available then we should go to the dealer or organization where we got the wheelchair. Past one month I have had a problem with my footrest and I can't fix that. At the same time just for this, I can't travel to Chennai. if there is any work at that time I will repair it." (WCU2 27, M)

Other users expressed that if they don't know to repair then they can't use the wheelchair, and added other common problems.

"For cleaning or repairing the wheelchair parts, if the person knows then no problem if not then it is a problem, they can't use the wheelchair until it gets fixed."

"The second common problem we face in wheelchairs is wheel puncture but this we can fix in nearby puncture shops. Some wheels are made of anti-puncture material which is useful for us." (WCU6 31, M)

They mentioned a user should have some knowledge of how to do basic repairs and clean the parts if not they have to wait until someone fixes that. The second problem other than bearing is tyre puncture but that can be easily fixed from nearby shops and they mentioned that because of the cheaper price they can even change to a new tyre.

5.1.2 Problems in day-to-day activities:

Under the topic of 'undressing in toileting and hygiene', wheelchair users expressed they had problems only in undressing the lower half, especially removing the pants.

"I don't have any problem in upper body dressing and removing but removing pants in wheelchair is a problem, we remove it slowly." (WCU1 41, M)

Wheelchair user 2 added some more points regarding this

"Our main problem is removing pants; by holding the armrest and leaning to one side, we remove the other side gradually. It takes time to remove pants and while doing this fall can happen. even though we have small wheels at the back, due to weight we may fall. Fall is our main concern". (WCU2 27, M)

In this the user expressed removing pants takes a longer time and the user explained how he removes his pants step by step and their main concern is falling from the wheelchair when leaning to one side while removing the pants and backward tipping is possible while they lean more back for removing the pants.

In menstrual caring user 3 expressed the concerns and trouble they face during menstrual hygiene.

"During periods time it is a problem to change the sanitary pad frequently and while changing we should clean the area which is a major problem while doing in a wheelchair. often cleaning and changing the napkins takes longer time." (WCU3 37, F)

The other two Female users agreed to this and their main concern is, that it takes longer time to change the napkins because undressing and cleaning the area in a wheelchair takes a longer time.

When wheelchair users feed children in their homes, they face issues due to their condition and wheelchair, so most users avoid participating in this activity.

"Feeding the children is tough as they are naughty and move here and there. I can't hold them and at the same time balance while giving food. Due to injury, it is very difficult to balance and at the same time to hold the children while feeding" (WCU6 31, M)

The user stated that he was not able to balance the wheelchair and feed the child. It is very difficult for them to feed kids. Another user adds other aspects of the problem in feeding.

"I used to feed my niece, for that I make her sit on my lap and hold her with my left hand and with my right hand I feed her. Suddenly, if I want to move or she moves, I have to hold the rim in my right hand and my hand gets dirty. so, I need to wash it, which is difficult for me to keep on washing my hands." (WCU2 27, M)

This user's main concern is whenever he is feeding and wants to hold the rim to maintain the balance his hand will get dirty and he wants to wash again and again.

"In my home there are no kids so I don't have any problem in that." (WCU7 24, M)

Other users stated the same that they don't have any children at home to feed so they don't know the practical difficulties of feeding. One user expressed, in home mostly they won't let her to do any work like this.

"My sister takes care of all house hold works and don't let me to do any works because I'm already in wheelchair." (WCU3 37, F)

5.1.3 Suggestions for modification:

In maintaining the 'posture and transferring heading', a user suggested it would be helpful if they add this feature in the wheelchair.

"For shifting inside bathroom, it would be helpful if they provide a pad like structure for transferring (I told like sliding board?) ah yes, that can be placed inside the wheelchair near the armrest so we can open the board and shift using that and fold it back inside. no need of a large height, just half feet will be okay to transfer from one place to another. if wheelchairs have this it will be comfortable for us to transfer and prevent wheelchair from moving while shifting." (WCU1 41, M)

They have stated that it would be helpful if they had a sliding board attached to their wheelchair. It would give the user a grip and prevent the wheelchair from moving while transferring for bathing. Another wheelchair user also agreed to this proposal.

"It would be helpful attaching sliding board inside a wheelchair for transferring." (WCU2 27, M)

Others stated that for transferring, they need grab bars attached in the bathroom so that they won't fall and get good support when they are shifting to take a bath.

"In-wall an angle (grab bars) kind of thing should be placed. By holding that in one hand while other hand in wheelchair, we can shift" (WCU6 31, M)

"In the bathroom, compulsory grab bars should be placed for shifting inside. (WCU7 24, M)

All agreed that attaching grab bars is mandatory and after the injury, everyone want to do some modifications in their homes, one of the users has built a seat with bricks in the bathroom to avoid falling.

"I have a problem in sitting and bathing in the bathroom so I have built a seat with bricks inside the bathroom. While bathing it won't be slippery." (WCU5 36, F)

From all this, we know that wheelchair users try modifications at their level to make their activities more convenient to perform. Other users said it would be easier for them if they have a Western commode than an Indian one.

After the injury, compared to the Indian toilet If the bathroom has a western toilet, it will be easy for us to use. We won't face much issue with that. Also, it is helpful in transferring by ourselves (WCU1 41, M)

Here the user stated that after spinal cord injury, they should modify the bathroom to attach the western commode which is easier for them to use, and no need for other's help to perform the activity. They can't use an Indian commode without a commode chair so they prefer a Western commode compared to this.

Most users stated that it would be helpful if the company provides cushion with the wheelchair.

"You know the main problem in wheelchairs is none of the companies' providing cushions except 1 or 2. if the company provides cushion, then it will be useful for everyone. (WCU1 41, M)

Other users also agreed with this,

"According to me, If the company provides wheelchairs with cushions, it will be helpful and if not also, all users should need to buy cushions." (WCU2 27, M)

They told, backside light should be placed in the wheelchair for traveling at night.

Backside compulsory light should be placed if we are traveling in the night time. If we ask the company, they are providing only stickers with that we don't have any use. (WCU6 31, M)

They are asking for a light attachment in the back of the wheelchair to prevent any accident while traveling at night.

5.2 Barriers:

5.2.1 Environmental barriers:

In the bathing component, wheelchair users don't have any problems in taking and using the supplies because they have modified everything to their heights.

"We have no problem in taking the supplies at home, we have placed all necessities at our height level and others said the same no issue in that." (WCU4 38, F)

They have issues with the architectural barriers like the size of the door and space inside the bathroom and have issues entering the bathroom and using it.

"In our homes, we all have readymade doors that are only 2 feet wide, so entering and coming out of the bathroom is a problem for us. Before the injury, we had small-width doors. After the injury, we have to modify the door for going inside and coming out."

"In addition, all bathrooms have a threshold which is at least 1 inch high to prevent water from coming out of the bathroom, so crossing that and going inside is another problem with a wheelchair."

"Our bathroom size is small so moving around this space, using it and turning inside the washroom with wheelchair is a difficult task for us." (WCU1 41, M)

The user clearly explained that their problem related to the bathroom is the width of the door which is small and many houses have readymade doors which are of small width. Also mentioned that the threshold is a hindrance for entering the bathroom and the overall size of the bathroom is small, so turning inside and using it is a trouble for them.

Also, one of the users mentioned the difficulty in reaching for the tap for handwash. It would be helpful if the wash basin had the clearance to accommodate the wheelchair.

"For handwash, the tap is too far and not reachable from a wheelchair, and rotating the tap is also a problem. if that is nearby and if the wheelchair can be accommodated under wash basin, then it won't be a problem, we can wash our hands easily". (WCU6 31, M)

while eating they face issues when the table has a table stretcher which doesn't allow the wheelchair to fit properly in the table, so they can't keep food on the table and eat.

"I can't go onto the table because of the structure (table stretcher) so I have to turn to one side and eat my food but that is uncomfortable for me while eating." (WCU7 24, M)

Another user followed some strategy to overcome this problem while eating, and he expressed other problem he faced while eating.

"While eating at home we can keep pillows on our laps and eat, but outside I when hold the plate in one hand and eat with the other hand. While holding a plate in one hand and eating, food may fall and create a mess which I have to clean. It is uncomfortable for us that time, we can't even move immediately even if we want. We won't have a problem if the table is without a table stretcher, then a wheelchair can go inside and we can eat comfortably." (WCU2 27, M)

At home user keeps pillows as a lapboard and eats, but outside he faces trouble in holding the plate and eating, and it would be easier to eat when the table is without a stretcher.

In personal hygiene and grooming, wheelchair users have difficulty reaching to the saloon or beauty parlours because of the inaccessible buildings.

"Going to a saloon in itself a problem because in most of the saloons, we can't use wheelchairs because there won't be ramp. All the shops are only built with steps. Even if shops have one step, we need to ask help from others to cross it and also for shifting into the hair cutting chair" (WCU6 31, M)

Most of the places have staircases but won't have ramps or accessible features. Wheelchair users face trouble entering the place. While shifting from a wheelchair to a barber chair they need help from others and the user shared about an accessible shop.

"One person has opened a shop designed for differently abled people with an inbuilt ramp, which is accessible for us. Every Tuesday he cuts hair for us and the rest of the days for other people. He has designed this shop for us." (WCU7 24, M)

One person has built an accessible saloon in their locality, especially for the disabled population so many are benefiting from that, but other user said his concern for them they don't have any shops like these.

"Nearby people can go for such accessible shops but for us no such shops are available."

"After seeing the 4 steps I won't go inside, instead I will get their number and ask them whether they can come to my home in their lunchtime for a haircut for that they will charge at least 50 rupees extra or more." (WCU2 27, M)

Due to the inaccessible structure, the user contacts the barber to come home for a haircut but in this case, the barber asks for extra charges and other user added that some barbers won't come.

"I can't cut my hair at my convenience. if suppose I go to a saloon I know after 2-3 people they will cut mine but if I call them home then there won't be any assurance that they will come. Once I waited for the whole day till evening, but the person came the next day, this happens often." (WCU1 41, M)

As the shops are inaccessible, they call barbers to home but they don't have assurance the person will appear or not, and for their convenience, they can't cut hair whenever they want to do so, they need to plan early to avoid problems like these.

In personal hygiene and grooming, a female user has expressed her concern regarding the inaccessibility of beauty parlors, it is not comfortable for them to do at home in a normal chair which causes neck pain and they worry about the makeup chair and equipment which would be present only at the shop.

"I want to do eyebrow threading but most of the shops are on the 1st floor or have many steps in the entrance which is tough for me to go. If I contact them to come home there will be another issue with equipment and makeup chair which will be available only at their place. At home we have a normal chair or wheelchair in which if we do makeup or even eyebrow threading it won't be comfortable and bending our neck for a long time causes neck pain to us. (WCU3 37, F)

Another user expressed problems with dental cleaning

"The issue with dental cleaning is that the clinic has stairs at the entrance and while waiting in the waiting area for the dentist I feel uneasy because all are sitting in normal chairs and I am the only one in a wheelchair. At the back of my mind, I will be thinking whether it would be okay or not to shift to the dental chair and will I able to enter the dentist's room as most consultation rooms are small and few hospitals are not accessible at all like small clinics." (WCU2 27, M)

The user stated that most of the dental clinics are not accessible and the consultation rooms are small many small clinics are not accessible and he feels uneasy because in the waiting room, he will be the only person in the wheelchair and others are in normal chairs. He worries whether he will be able to shift in the dental chair and whether the place will be accessible or not.

In health management, most of the users shared that compared to meeting the doctor in person they try home remedies and contacting the doctor to get a cure. They won't prefer going to the new hospital because they don't know whether it is accessible or not.

"Recently I got a fever, I was not able to enter the clinic because of the steps at the entrance then I called my friends for help and entered the place due to these problems, I usually prefer a previously treated hospital to a new one." (WCU1 41, M)

Other agreed to this,

"I am also like that, for fever or any health issue, going to the clinic and entering will be a problem so I try home remedies." (WCU5 36, F)

"Instead of taking risks and traveling to the hospital I prefer not to go" (WCU6, F)

"Instead of meeting the doctor in person I will call them and ask if they don't respond then with the help of my friends I will reach there and consult the doctor". (WCU7, M)

From home, till they reach the place, it is a huge task so they prefer not to go or they contact them via mobile.

"Instead of going, I will contact the doctor but I don't know whether they will respond or they are busy so I message them. later they will reply and prescribe me the medicine for which I send my dad or mom to buy the medicine for me." (WCU2 27, M)

Most users prefer contacting the doctor, if not they get help from others and reach the place. Some users try home remedies and later they try to reach out the doctors.

"I try with everything at home to get a cure if not I will go and check with the doctor" (WCU3 37, F)

One of the users tries alternatives like searching on the internet when the doctors are not responding.

I will try to contact the doctor if they don't respond I will search on the internet with symptoms and search for remedies on YouTube or I will think about what changes I made recently and what food I had. After injury, in the training they teach the different locations of pain and its causes so it will be easy for me to detect. if all this didn't work then I will consult the doctor. (WCU2 27, M)

All wheelchair users prefer meeting the doctor as the last option. They try everything at home at their level to get a cure or they try contacting the doctor to get the prescriptions or a few try searching on the internet. If all this doesn't work, they reach the hospital and meet the doctor.

In 'community participation' like attending a function in the family, the building is not accessible for wheelchair users.

"Going to a place like a function hall or marriage hall itself a problem for us. All these places are designed for normal persons not for us. Entering the hall itself is a huge task. We can enter only with the help of others." (WCU1 41, M)

Most of the places are not accessible for the wheelchair user so entering the hall is a problem. Other users shared that the workplace is also inaccessible.

"if at all we work also the restrooms are tougher to use. Most of the offices are wheelchair accessible. we can work only if they are built especially for the handicapped. A normal washroom built for normal people it can't be used by us so we are not going for jobs that much, for us they won't change anything but they will keep on saying they will try to do it." (WCU3 37, F)

Workplace restrooms are inaccessible for wheelchair users. Even if they raise the issue to the management, they are not taking any action and changing the place for them. Because of this many of the wheelchair users are not working. They try working at their home by learning new skills like tailoring.

One of the user stated, that men can adjust, use the normal washrooms and can go for work when the offices is nearby.

"For men if the office is nearby then we can go and work, but for ladies it will be tough for traveling and working there. Also, we can adjust with the washrooms but they can't." (WCU2 27, M)

The users were unable to use wheelchairs in their home environment due to the small space and the type of landform. where they are living there are barriers to the wheelchair users.

"My house is in the first floor and inside we have steps also I can't use the wheelchair inside my house. For outdoors I will ask help from someone to place the wheelchair out, later I will transfer to it and go to nearby shops." (WCU5 36, F)

As the person's house is located in first floor, they are not able to use the wheelchairs and even inside the home due to the small space, they use the wheelchair as a seating device.

"I won't use a wheelchair much inside the house because of the small space so I prefer using it only outdoors and for sports purposes." (WCU4 38, F)

This user also uses a wheelchair only for the outdoors not inside the home, they can't move in their wheelchair, other wheelchair users agreed with this and stated the same.

"I am unable to use a wheelchair in home due to the size of the home and furniture all around. For the bathroom I will use a walker and move around." (WCU3 37, F)

One of the users can't use a wheelchair outdoor due to the landform where he is living.

"In my place I can't use wheelchair as it is in the mountain side and lots of small rocks are in road. Propelling even for a short distance the wheels direction gets changed and chances of fall are high." (WCU7 24, M)

Another user stated a problem with roads which is not uncomfortable for users to propel because of the slope structure.

"The main reason why we can't use wheelchairs on roads is because while constructing new roads they are elevating in the center and taper the side so water can flow in the side. Which makes propelling difficult for us. whenever I'm going, I should give one side more force compared to the other so I get more pain on one side of my hand. also, in between I can't rest, if I leave propelling then the front wheel will turn to one side so I should keep on propelling and it is painful." (WCU1 41, M)

Another user agreed with this and shared their view

"I went for a marathon the road was slope so while going I got pain in one hand and while coming, I got pain in another hand after that I couldn't do any work after that." (WCU2 27, M)

Other than this wheelchair users have trouble during the rainy season

"During the rainy season using a wheelchair is a problem, the wheels will get fully dirty and the roads won't be proper so, propelling the wheelchair is a problem. Going out and coming inside in those days are trouble." (WCU6 31, M)

In the rainy season, roads have potholes and are uneven to use the wheelchair (WCU1 41, M)

They face issue during the rainy season because of the potholes and stagnant water. they can't propel the wheelchair properly and it gets dirty while using in outdoors.

5.2.2 Non-environmental barriers:

Under 'social and health promotion and maintenance': wheelchair users expressed their feeling about a few areas about expressing feelings. Because of the societal stigma, the person stopped schooling and stayed at home.

In my place, I wanted to go to school but I didn't go because I was afraid that someone might mock at me and say you are a handicapped(nondii), I had this feeling always (WCU5 36, F)

Another user said how they were treated by their own family members in any family gathering

"They will tell face to face, why ma you came instead, you could have sent someone from your house." (WCU3 37, F)

"Sometimes our own family members say don't come, stay at home and avoid us in family gathering." (WCU4 38, F)

The users said that families are seeing them as burden and in function mostly they are alone and left out.

"For them (family) we are a burden and disturbance, so they say you better stay at home we will take care of the function and attend the function." (WCU5 36, F)

Other user added that they treat them as a third person and won't be part of the function.

"Even in my close friends or brother's wedding, they will treat me as a third person and when everyone is together and engaged, I will be in a corner alone."

"Even if I like to participate and work I can't, instead of me going and coming in wheelchair normal person do much faster and finish the work soon." (WCU2 27, M)

Even they like to participate and work but they feel, compared to them normal person can do faster so they don't get opportunities to participate so most of the time they are left alone in the family gatherings.

They face issues in the workplace from their fellow workers and by the management

"As a wheelchair user I had faced a lot of rejection. The first thing they ask is whether I can work for 8 hours" (WCU1 41, M)

Wheelchair user 2 added some people will talk behind their back that why they should attend the function.

"Even if they talk in front its fine but some people have this pity face reaction and say is that necessary for him to attend function in wheelchair." (WCU2 27, M)

A wheelchair shared their experience in a company and shared how their fellow workers treated her.

"I have worked in a shoe company. There will be lot of people saying why are you taking so much trouble to work here and also the restroom is very far so, they told even normal people like us can't go to restroom in summer time why are you suffering this much and why you want to continue here in spite of all this I worked there for 7 years." (WCU5 36, F)

She had to face this daily from them. Instead of motivating and appreciating her fellow workers discouraged her. But still she continued to work there. these are difficulties from their perceptive and others shared about how managers treat them.

"Some managers or owners behave differently to us they speak in a rude or harsh manner. we have faced this many times. After many struggles to support our family financially, we are going to work so when they speak harshly some people won't take it but some would feel very sad. we have to face the same situation at both home and work, where they are harsh to us". (WCU6 31, M)

Here he expressed that in both the workplace and home, people are being harsh to the wheelchair users and he feels that the higher authority behave rude manner, especially with wheelchair users.

5.2.3 Environmental adaptation:

In obtaining the dress from storage area, the wheelchair user have no issues and have modified for their comfort.

"Usually at the home, we will use lower shelves in the cupboard and upper shelves are used by normal people. In my home I kept all dress at reachable height so not much issue" (WCU1 41, M)

And all other participants agreed to this and they changed everything for their reachable heights.

"Yes, we have changed everything to our height, so selecting and taking the dress would be easy." (WCU6 31, M)

Also, for obtaining and using supplies both in toileting and bathing, the wheelchair users don't have much issues.

"We have no problem in taking the supplies in home, we have placed all necessities in our height level (WCU2 27, M) others said the same and agreed."

Physical activity

One user stated that he would engage in physical only if he comes for the sports practice if not, he will be idle.

"When we come for the sports practice then only, we are engaging in physical activity."

If not, my day will be like this at home, I would wake up at 12 pm and skip breakfast and watch my mobile till evening and I will meet my friends if they are doing any activity I get motivated to do, if not I will be sitting simply. (WCU2 27, M)

Most of the time wheelchair users spend time on their phone and by being idle. other used stated the same.

"I won't be involved much in any of the activities and for everything I need help but recently I started to get involved and do everything by myself." (WCU7 24, M)

"I will be simply sitting on the balcony and watching the roadside throughout the day if any tailor order comes then I will do that. (WCU1 41, M)

Both the users stated they wouldn't be involved in any activities and most of the time they are sitting simply

Other user stated she would do all household work and cooking and in free time she does tailoring to keep herself active.

I will do the cooking, my mother will keep all the necessities near me, I will cook sitting on the floor, and I help with household work after finishing all the work I will do tailoring in my free time to keep myself active in the home (WCU5 36, F)

Most of the users made changes in their home environment for completing their day-to-day activities.

5.3 Personal factors:

5.3.1 Condition specific challenges

Under the topic of 'bathing in rinsing and cleaning', wheelchair users stated that their condition differs, and according to the condition the difficulty changes. Compared to spinal cord injury polio person can do it easier.

"I can clean my body properly and I can bend and reach till my leg but people with more upper-level injury can't bend down. they won't have balance that much. so mostly they will put one leg on other leg and wash without bending." (WCU2 27, M)

The user mentioned that in more upper-level injuries they can't bend and wash so they use an alternate method by folding the legs and cleaning them, another user agreed with this and said he doesn't have issues with that.

"For Rinsing and bathing I don't have any problem and I can reach till my leg and clean it properly and also with upper body I have no issue." (WCU1 41, M)

Person with Polio said she doesn't have problem and can bath normal.

"Polio person like me can bath like normal individual but injury patient (spinal cord injury) has problem in reaching their leg depends on the level of injury" (WCU3 37, F)

Others agreed to this and said depending on injury and condition. It changes they mentioned that only people with more upper-level spinal cord injury face issues in this.

In dressing they have mentioned few points about the cloth materials and why they won't wear inner garments.

"Mostly we won't use lycra (spandex), tight fitting cloth and inners after injury because we won't feel any sensation below the injury." (WCU1 41, M)

As they have sensory loss below the level of injury, they are advised not to wear inner garments because of lack of sensations, pressure injuries can happen.

"In spinal cord injury the sensation won't be there so if we wear innerwear, we get redness and wound around the area when it is tight so, we use long trunk and loose wear." (WCU2 27, M)

Instead of tight inner garments they prefer loose ones and if they wear inner-wear they need to be sure that no redness or pressure sores are around the areas.

In grooming, they have issues in nail cutting especially when doing for lower extremities because of lack of sensation they can cut their skin.

"Yes, there is trouble in nail cutting because of no sensation there is a chance of cutting the skin recently also I had cut my skin, after which healing takes longer time" (WCU6 31, M)

Due to lack of sensation the user had cut his skin and the healing process took longer as he mentioned. Another user stated that mostly they won't do it by themselves, someone else will cut their nails to avoid any injury.

"I won't cut my nails, any one of my family members will do that for me." (WCU7 24, M)

In health management, a user stated for any underlying problem in their body the first symptom would be a fever. At that time wheelchair user will meet the doctor.

"Depending on the level of injury they won't feel pain for any problem, then first symptom will be fever. Even bone fracture or any injury we will get alerted by getting fever so at the time I will consult the doctor." (WCU1 41, M)

In the acute phase of the injury, training is given to them about the locations of pain and their causes and what to do when that happens. All agreed that normal fever or viral fever will be their first symptom of an underlying problem.

5.2.2 Economic condition:

In 'nutrition management', due to their home financial status, they are not taking the proper amount of nutritious food in their diet.

"We are not rich to take proteins and food which we like to eat. We eat food that they prepare at home. They won't cook anything special for us. In most villages, they take protein non-veg weekly once or monthly" (WCU4 38, F)

Another user said they can't ask for food that they want to have. They only eat what is provided at home.

We can't eat what we want because of the home situation, we won't ask what we like to eat. We will just eat what they prepare and weekly we will take non-veg as protein. (WCU3 37, F)

Another user's diet mostly has only rice and won't take protein.

"I eat only tiffin item and rice mostly I won't follow any diet or healthy just eat what they provide." (WCU7 24, M)

Only one user said he would take more protein and healthy food because of being in sports they provide good food.

"I will take protein food regularly at my home, they will provide good food with protein because they know I am in sports and want to maintain the body so they try to give healthy food always." (WCU2 27, M)

A wheelchair user needs a next bigger size wheelchair than the current one but due to the cost. He didn't change to a new one and is still using the old one.

"Currently I need a new wheelchair which is little bigger than my present one, but I can't burden my family more for 40-50 thousand for me. If they do anything with less money and an appropriate wheelchair it will be good for us." (WCU2 27, M)

Another user stated that a low-cost wheelchair is not appropriate and comes in one size fits all. Only by paying more money, they can procure an appropriate wheelchair.

"Normal Wheelchair of low-cost won't be the correct fitting and the backrest will be too high and other fitting issues. but high-cost wheelchairs will be good and appropriate it can be changed and all the wheelchairs should be appropriate for the user." (WCU2 27, M)

Other users stated that wheelchairs provided by the government are same size which is not a proper fit.

"Only by Paying more we get appropriate wheelchairs. the wheelchairs by the government are the same size for all which is not fitting for everyone. people who don't have knowledge about this using that which cause more problems." (WCU6 31, M)

He also mentioned people who don't have much knowledge regarding wheelchairs are using wheelchair provided by the government and facing the secondary problems.

On of the user has mentioned that for choosing different color they are costing more price than the usual one.

“Some wheelchair price depends on the color. I want to buy a black color wheelchair with all same feature as other colors but they charged me extra 2-3 thousand only for the black color.” (WCU2 27, M)

Just for black color the company is charging more price than the other color wheelchair. But the features are same in the other colored wheelchairs.

5.2.3 Managing the emotions:

A user stated all his sorrows went after coming to places like these seeing other wheelchair users and practicing sports.

“All sorrows are gone after some days of injury and after coming to place like this now, no sorrow regarding myself.” (WCU1 41, M)

Another user added how he felt when no one was around him and how he changed his happiness from his previous life and coping strategy.

Before the injury, I had 100s of friends, right now no one is there but now with 4 people in wheelchair users, I am happy. At home, I won't look at anyone's face and interact because we can't tell how long these people stay no one is forever.

At home, if they say something about me or when no one was there in home and everyone went out, I feel like why I want to live like this.

To cope with my stress, I will listen to music, or by seeing the nature I will change my mind if not I will call my favorite person and talk. (WCU2 27, M)

Others also use the same coping strategy and most users use listening to music to cope up with their stress

“To cope I will talk with my favorite person and share everything and they say it will be okay da leave. For me, it will be so much relieving.” (WCU6 31, M)

VI. DISCUSSION:

One of the primary challenges highlighted by many of the participants was the difficulty of performing self-care tasks, such as bathing, dressing, and mobility, due to the environmental barriers. participants mentioned that basic activities like using a bathroom or using the doorways were difficult because their home environments were not designed for wheelchair accessibility and also, they stated that they were dependent on others for help because their homes did not have the modifications, like ramps, accessible bathrooms, or wider doorways. The difficulties with moving around the house are consistent with findings from earlier research, by Patricia Herrera-Saray et al. (2012), who observed that wheelchair users' independence is limited by the design of ordinary homes, which often include stairs, small doorways, and other obstacles. Self-care tasks became more difficult, due to the inaccessible home environment. This observation aligns with Marianna S. Wetherill's (2021) findings, which show how the inability to perform activities of daily living (ADLs) is severely limited by physical disabilities, impacting not only physical function but also mental health because of the loss of independence. Wheelchair users also stated they have condition-specific problems in which spinal cord injury users face more problems compared to polio wheelchair users.

They face problems in personal factors such as economic condition and managing emotions. participants stated due to their economic status they are not taking healthy foods which is affecting their nutrition management and due to their family financial they prefer not to ask their needs to the family members. Other participants added that their financial status is limiting them from procuring new wheelchairs because of which they have to continue using the old ones. In the context of wheelchair durability, the Participants highlighted that the durability of the device is one of the major problems, especially with the bearing and brake of the wheelchair. Future researchers can focus on this area for a deeper understanding of the topic.

In the context of health management, the participants discussed the significant challenges they face with doctor's visits and obtaining healthcare services. Due to the inaccessible hospital environment, most users prefer for home remedies or by contacting doctors via mobile they get the cure for their problem. The difficulty in reaching medical facilities was one of the main obstacles found using this focus group. Many participants discussed how difficult it was to get to clinics, hospitals, and doctor's offices because of

inaccessible entrances, the absence of accessible lifts, or ramps, and not enough waiting room space for wheelchair users. These physical barriers to healthcare access make it very difficult to receive immediate medical treatment and regular health checkups. The findings from this study support the work of Tara Lagu et al. (2017), who emphasized that wheelchair users often experience difficulty accessing physicians and are more likely to face challenges in receiving medical care compared to their able-bodied counterparts". Some participants reported that their physical conditions were frequently missed because they were unable to obtain appropriate medical care. The study's participants highlighted the significance of having a healthcare system that is both physically accessible and staffed by experts who are aware of the details of treating individuals with disabilities.

The findings from the article by Sushil Kumar Sahoo (2023), expressed that a lack of wheelchair accessibility has a significant impact on users' mental health, contributing to feelings of isolation and distress. In addition, a common problem for the participants was social isolation and societal stigma. Many individuals discussed how social exclusion was frequently caused by the physical limitations of their living situation as well as a lack of accessible public areas. The of feeling social isolation is caused by the inability to engage in community activities, and access social settings due to the inaccessible environment and people who discourage and comment about wheelchair users' characteristics. Many users expressed their own families see them as a burden and they left them alone most of the time. According to Martha Banda-Chalwe et al. (2014), the literature has documented the significance of social participation for wheelchair users. They highlight how the absence of accessible environments significantly restricts opportunities for social interaction, work, and education, which increases feelings of loneliness and emotional distress. For those who depend on social interaction for emotional support and general well-being, this social isolation not only harms mental health but also lowers their quality of life.

Participants also shared their thoughts on solutions to these challenges and suggestions for wheelchair designs. They offered suggestions for improving their overall function and independent participation. Many participants wanted for more accessible public spaces, highlighting the importance of infrastructure changes such as ramps, wider doorways, accessible toilets, and public transportation systems that are wheelchair-friendly. Additionally, several participants highlighted the importance of better wheelchair designs that meet individual needs, particularly with comfort, mobility, and functionality. They have given a few ideas like adding a sliding board to the wheelchair adding backlights and other suggestions. These suggestions share the recommendations outlined in the Wheelchair Provision Guidelines (2008), which mentioned the importance of providing wheelchairs that are specifically designed to meet both the needs of the user and the environment in which they live. The need for customized and appropriate wheelchairs is an important solution, as the one-size-fits-all wheelchairs often fail to meet the needs of wheelchair users. Their concern was every wheelchair user should have an appropriate wheelchair meant for them. By which the overall function and independence will be improved.

This study highlights the challenges faced by manual wheelchair users in managing self-care and health management. The findings reveal the significant barriers to independence caused by environmental and physical limitations and other problems they face due to the wheelchair durability, and wheelchair design. The study highlights the significance of developing accessible environments, enhancing healthcare infrastructure, offering social inclusion, and avoiding societal stigma. In order to improve the overall independence and well-being for wheelchair users. To ensure that people with mobility impairments can live more independent, and healthy lives, society can try to create a more supportive and accessible environment by removing these obstacles

VII. CONCLUSION:

This study aimed to explore the experiences of manual wheelchair users in self-care and health management. The narratives of the seven participants who participated in the study explained their experiences in self-care and health management, through a focus group discussion. The perspectives of wheelchair users were gained regarding the problems wheelchair users face in their day-to-day self-care activities, managing their health, communicating with healthcare professionals, and other areas of health management. The findings of the study revealed the overall factors that affect the ability of wheelchair users to engage in everyday activities of self-care and managing their health.

Key findings highlighted the importance of wheelchair function and design to promote independence, while design flaws frequently result in restrictions on daily activities. These difficulties were made more difficult

by both environmental and non-environmental obstacles; problems like inaccessible infrastructure, societal perceptions, and financial limitations were commonly mentioned. Participants suggested adaptation to face these challenges, and they used few techniques to overcome the obstacles and maintain their mental well-being.

These results highlight the importance of a holistic approach to assist wheelchair users, highlighting barrier removal, inclusive wheelchair design, and customized interventions. The government, healthcare professionals, and designers can work together to create an environment that supports wheelchair users' independence and improves their quality of life by incorporating user perspectives.

Future research should build on these insights, examining the evolving needs of this population and exploring innovative solutions to address the barriers identified. This study serves as a foundation for advocating for better health management and self-care opportunities, highlighting the importance of inclusivity in designing systems and services that empower wheelchair users.

VIII. ACKNOWLEDGEMENT:

I am grateful to God Almighty for His grace and blessings throughout my journey. I would like to thank my parents, Mr. Sankar and Mrs. Vimala for the support, guidance and encouragement they have showered upon me throughout, which helped me to complete this study. I am deeply grateful for the valuable guidance and mentorship provided by my mentor and research guide Mr. Kurinji Chelvan S, MOT(DD)., PGDCBR., MBA., Principal, College of Occupational Therapy, NIEPMD for his insightful advice, feedback and helpful recommendations. I also thank him for helping me to work on my thesis with full freedom and complete this study successfully. My heartfelt thanks to my co-guide Mr. Harsha J, MOT (Neuroscience) Assistant Professor, at College of Occupational Therapy, NIEPMD for providing valuable guidance, suggestions and encouragement throughout this study. Last but not least, I would like to thank all seven participants who took part in the study. This research would not have been successful without their contributions.

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X. APPENDIX:

Image of the session

