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Md Jahangir Alam & Wendy Bryant |

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*Corresponding author: Md Jahangir Alam, SEPT (South Essex Partnership NHS Trust), Essex, UK
E-mail: Mohammad.alam@sept.nhs.uk

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PHYSIOLOGY & REHABILITATION | RESEARCH ARTICLE

Access to water and sanitation for people with paraplegia living in rural communities in Bangladesh

Md Jahangir Alam^{1*} and Wendy Bryant²

Abstract: *Purpose:* To explore how people in rural Bangladesh with paraplegia accessed water and sanitation in their home environment. *Method:* Based on a qualitative design, semi-structured interviews were used to gather direct experiences. Six people with complete paraplegia were recruited and their interview data were subject to thematic analysis. *Findings:* There were different ways of accessing water and sanitation. Experience varied depending on accessibility within the home environment, design of assistive devices, and individual skills. The dynamics between these factors determined how much time and energy were required. Easier access was associated with higher life satisfaction and a sense of occupational balance. Barriers to access have serious implications for health and wellbeing, but independence can be achieved through environmental adaptation or modification, appropriate design of assistive devices and development of individual skills. *Conclusions:* Community-based rehabilitation and other campaigns could use these findings to advocate for improved access to water and sanitation for people with paraplegia. At an individual level, occupational therapists can address barriers to access, by enabling people to gain skills, and adapt their environment and routines. Combining individual and community approaches could have many benefits for occupational balance, health and well-being.

ABOUT THE AUTHORS

Md Jahangir Alam and Wendy Bryant are occupational therapists whose research is focused on exploring the experiences of people with disabilities in everyday activities or occupations, using participatory and qualitative methods. This enables us to gather data directly from people with disabilities and where possible, involve them in analysing and presenting the findings. This approach recognises their expertise in their own lives and as citizens with rights to participate in their communities. It also values occupation, or doing everyday activities, as being centrally important to health and wellbeing, and also an effective focus for collaborative research.

PUBLIC INTEREST STATEMENT

People who rely on wheelchairs following a spinal injury can face considerable barriers in accessing water and toilets. This article reports the findings of research carried out in rural Bangladesh. Interviews with disabled people revealed that facilities for washing and using the toilet were not easily accessible, requiring more time and help to use them. Getting water to drink and to wash involved using plastic bottles and jugs to carry water from a community tubewell. Their lives were adversely affected. Family members could not work because they had to help with everyday activities which could have been managed with simple adaptations such as ramps. These adaptations are provided by occupational therapists elsewhere, overcoming discrimination towards disabled people. Focusing on adapting the environment, for personal independence in everyday activities, could improve the health and productivity of disabled people and their communities in developing countries.

Subjects: Allied Health; Health & Society; Health Conditions

Keywords: Asian toilet; assistive technology; self-care; wheelchair users; tubewell; occupational balance; paraplegia; disability; accessibility; water & sanitation

1. Introduction

Worldwide, 90 million people have experienced spinal cord injury and about half of them are paraplegic (Dawodu, 2006; Hoque, Grangeon, & Reed, 1999). Of these people, 80% live in developing countries such as Bangladesh and have limited or no access to basic services at home, including clean water and sanitation (Bain et al., 2012; WHO, 2012). This has an impact on the health and well-being of these individuals, their families and their communities (Gleick, 1996; Groce, Bailey, Lang, Trani, & Kett, 2011; WHO, 2012). In rural Bangladesh, water for bathing, toileting, washing and most importantly drinking, often has to be accessed from an outside source and transported home. As wheelchair users, people with paraplegia face challenges in collecting water from different water points and taking it home (Hannan, 2005; Jones, Parker, & Reed, 2002), affecting daily activities (Gleick, 1996). Occupational therapists aim to promote health and well-being through occupations of everyday life, so it was important to explore the experiences of people with paraplegia. This research had potential to inform future local development and the practice of occupational therapists in similar settings.

Many people with paraplegia live in communities where everybody struggles to access clean water, due to weak infrastructure and unimproved water sources like ponds and rivers (WHO, 2012). This is despite a United Nations Sustainability Development Goal to halve the proportion of the population without access to clean water and sanitation by 2030 (Gleick, 1996). Until recently the issue had received very little attention in Bangladesh, despite the government signing the Universal Declaration of Human Rights, which acknowledges the right to a standard of living adequate for health (United Nations, 2006).

In Bangladesh many people access water from tubewells while surface water like ponds and rivers are used for bathing (Kafiluddin, 2005). Tubewells consist of an iron pipe extending to underground water sources and releasing water through a suction pump. They are located outside between people's homes, without consideration for access by disabled people. Tubewells provide drinking water as well as water for self-care. Surface water is mainly used for toileting. Accessing water in a public space can be easier as there is more room to manoeuvre a wheelchair, but there is no privacy and there are still challenges in managing paths to the tubewell and transferring in and out of the wheelchair to bathe (Hannan, 2005; Jones et al., 2002). Recommendations have been made for accessible and private commodes, but transfers and access to water for washing after using the toilet were not considered (Hannan, 2005).

In addition, people with paraplegia often face stigma because of community beliefs that they contaminate water sources, making a public toilet dirty or simply take too long to use shared toilets (Kendra, 2008; Pradhan & Jones, 2008; Tesfu & Magrath, 2006). If it is not possible to enter a public toilet cubicle, then there is further stigma associated with open defecation (Water Aid, 2006). All these difficulties make people with paraplegia dependent for help, impacting on their well-being and dignity (Hannan, 2005). Water intake through the day may be restricted so the need to go to the toilet is limited to the evening when help is more available (Bailey & Groce, 2009; Tesfu & Magrath, 2006).

There is a widespread misconception that people with paraplegia cannot engage in paid work and so work environments do not welcome disabled people (Momin, 2004). Inaccessible toilets are often a major barrier to people with paraplegia seeking, taking and keeping jobs (Snider & Takeda, 2008). In addition, a caregiver may also be unable to work, because of the need to provide assistance, compounding the impact on the family (Jones & Reed, 2004). Such families may then be unable to afford to make necessary adaptations or modifications to their homes.

This is an example of occupational injustice, where people are prevented from participating in occupations by external factors (World Federation of Occupational Therapists, 2006). A focus on occupational aspects of participation is important to occupational therapists, who use a number of strategies based on assessment of individual need, including teaching wheelchair skills and environmental adaptation or modification such as providing a ramp to a water point (Jones & Reed, 2004). Most people receive and many expect practical assistance from their own family, not always recognising possible benefits of being independent (WHO, 2012). There have been initiatives to address these issues, taken forward by a growing number of national and international non-governmental organisations (NGOs), but mostly focused on the general population rather than disabled people, possibly because of a lack of knowledge about disabled people's everyday lives (Water Aid, 2006).

Therefore there is a particular need to understand more about the experiences of people with paraplegia, since this has been relatively under-researched. This research aimed to find out how people with paraplegia accessed water and sanitation in a community setting in Bangladesh, identifying methods of access and the impact of barriers to water and sanitation.

2. Method

Since access to water and sanitation involves a complex interaction between environmental and individual factors, quantitative research methods were believed to be unlikely to provide a sufficiently rich understanding of the participants' experiences. A qualitative design was developed, as managing washing and toileting is a potentially sensitive and personal issue. Individual semi-structured interviews were chosen to protect the participants' privacy and dignity (Bowling, 2002). The interview questions were developed by the first author, who had direct experience of working as an occupational therapist with people with paraplegia in Bangladesh. While drawing on his experience, questions were open so participants could answer in whatever way they felt was relevant (Bailey, 2004; Patton, 2002).

The questions and other aspects of the research were subject to ethical approval, which was given by a university ethics committee and the local evaluation department in the rehabilitation unit in Bangladesh. A convenience sampling method was used, selecting people known to the rehabilitation unit who could be approached easily (Bailey, 2004). All participants had received rehabilitation at the unit and had returned home. People living in villages rather than urban areas were included, because of the particular difficulties with accessing water in rural areas. A sample size of six was selected for this study, which was considered to be realistic for practical reasons. Using the rehabilitation unit records, 20 participants were invited for an interview on a first come first serve basis. Interviews were carried out at a time and venue that was most convenient for participants in a private, quiet place. All participants gave their signed consent before starting the interview. The first author conducted the interviews, using local languages and an informal approach to encourage the participants. With their permission, the interviews were recorded and additional information recorded in field notes and by taking photographs to capture relevant details of the environment. The first participants were invited to comment on the questions, as a pilot study. Minor revisions were made to reduce repetition and the data from these interviews were included in the final data set.

Each interview was transcribed verbatim, giving participants pseudonyms and re-checking for accuracy. The interview transcripts were all translated into English and then analysed using thematic analysis. This approach was chosen because it allowed for social interpretations, being a rigorous and transparent method of data analysis which allowed complex associations (Green & Thorogood, 2004; Ritchie, Lewis, & Elam, 2003). This process of transcription and translation increased familiarity with, and immersion in, the data, further informed by the photographs and fieldnotes (Green & Thorogood, 2004; Holloway, 2005). Attention was focused on the participants' direct experiences (Finlay & Ballinger, 2006). Units of analysis containing similar experiences were compared and contrasted for underlying patterns, concepts and association via a process of highlighting, cutting and pasting (Lewis & Ritchie, 2003). Patterns, concepts and associations were grouped under broader unifying themes once the researcher was satisfied that all alternatives explaining the relationship

between the data had been accounted for and ultimately exhausted (Green & Thorogood, 2004). The researcher kept detailed notes of this process. Findings were also discussed and checked with the second author, to support the trustworthiness and reliability of these processes (Patton, 2002).

3. Findings

The six participants shared their varied experiences of accessing water and explored the impact of barriers to water and sanitation. Three themes emerged from data analysis: water, home and impact on daily occupations, presented here with verbatim quotes from the participants.

3.1. Water

Participants drew and transported water in various ways, storing it at home for further use. They obtained water from ponds, rivers and lakes and a tubewell:

Around 15–20 years ago we drank water from pond to lake but now I collect water from tubewell as it is closer than ponds and lakes to our home. (Rajib)

Majority of the participants stated barriers to using the tubewell:

It is difficult for me to press tubewell from wheelchair, handle is not long enough and its surrounding concrete step is the main barrier to draw water. Also it takes more energy and time to draw water. (John)

Using a wheelchair meant steps were a barrier. The nearer participants could get to the water source, the easier it was to use as shown in Figure 1.

Threshold steps at the bathroom door were another barrier when transporting water home in a wheelchair. Participants also had to think ahead about what to fill with water and some stressed that they always used buckets:

I prefer to use bucket for drawing water because it contains much water so I don't have to come for drawing water so frequently. A bottle is very difficult to fill with the water because the mouth of the bottle is small and needs more time to fill from the tubewell. (Kabir)

One participant used a tap which had a narrower mouth than a tubewell and was suitable to fill either a bottle or a bucket:

I like to use bottle for drawing water from tap as it is easy access for me. (Liton)

The majority of the participants preferred to use both a bucket and a plastic bottle, known as assistive devices, for carrying water, using the footrest of their wheelchairs to carry the bucket (see Figure 2).

Carrying water depended on what the water was to be used for. For example, participants preferred bottles for carrying water as they could drink from them (see Figure 3).

I use two or three plastic coke bottles to carry water for me. Initially I fill it up then I close its opening, then I take one in my lap and two others by the side of my thigh. (Lotus)

These bottles were large and heavy to carry on their lap. Others used a jug, mug, glass or jar for drinking. Usually these were made of aluminium which was light and easy to carry. Half of the participants used a mug with a hooked handle to dip into a bucket for washing and cleaning. These items were also used to store the water at home, mainly for drinking, cleaning and toileting. Participants stored water for night-time use or for when the water point is busy.

Figure 1. Drawing water from tubewell.



Figure 2. Transporting water in bucket.



Figure 3. Transporting water in bottle.



I always use my bucket or jar to store water. People keep always keep the tubewell busy and you never know when you need water to go for toilet and wash. (Liton)

3.2. Home

Participants who had access to a tap at home did not need to store water. Even if they did not have a tap, those who had a wheelchair-friendly environment and an appropriate assistive device such as a bucket of the right size for the wheelchair, could access water and sanitation independently, as illustrated in Figure 4.

I have a ramp in my house so that I can go with wheelchair for collecting water in bottle very easily. Moreover it helps to move me very easily, quickly and comfortably. At the beginning it was difficult without ramp but now it's easier for me with ramp to move wheelchair anywhere of my home. (Kabir)

However, there were other difficulties associated with water sources being out of reach:

Initially it [the tap] was installed too high for me so that I could not reach from wheelchair. But with the advice of sir (occupational therapist) it was adjusted for me so that I can turn it now more easily and comfortably. (Shaha)

If the water point was inside the home, they could access water in any season independently. Others had to cross muddy roads:

In rainy season, roads often become muddy and slippery so that it takes more energy to move my wheelchair. I often spill water which is dangerous for me so during crossing the steps and muddy road I need help of someone from behind. (Liton)

Figure 4. Successful ramp.



Half of the participants washed their clothes at the water point, using a plastered floor or wall by the side of the water point to rub the cloth with soap.

I wash my clothes in the water point so I don't have to carry extra water for washing. For drying I have to carry wet (or damp) clothes on my lap and put onto the washing line. (John)

Accessing toilets was difficult, with uneven floors, steps and limited space for turning a wheelchair:

It is too difficult for me that there is not enough space to manoeuvring wheelchair inside the toilet. Door is too tight, narrow and inaccessible for wheelchair user. Moreover using water and tissue after toileting is more difficult for me because there is not enough space to do that so I like to bath for cleaning purposes after each toileting into the water point where I get adequate space. (John)

Toilet paper is not normally available in poor Bangladesh households. Instead, water is used after toileting. In most latrines in the community, water is not stored in the toilet but is carried in a pot by the participants to the toilet. Since their hands are occupied with the wheelchair, it is a problem to also carry water.

3.3. Impact on daily occupations

Barriers to accessing water and sanitation impacted on all aspects of daily life, with participants describing how they had to plan ahead, focus on their need for water and accept help. The journey between Shaha's home, the toilet and the tubewell required him to be organised to be independent:

Distance between toilet and tubewell is far and it takes more time to carry water before toileting. Often I prepare and plan to allocate more time before going to the toilet as I don't have any other alternative options there. (Shaha)

Most of participants described how they stored water in a bucket or jar inside the toilet so they can use it after toileting, organising this as part of their daily routine, or with the help of carer/family member. Others prepared their wheelchairs in advance, placing an inner tube on the seat to avoid transferring.

I use Asian type of toilet as I have no other alternative options. It has not been modified since my problem. Usually I use inner tube on my wheelchair so I can flush water after toileting which is easy. However it is very difficult for me to wash after toileting so often I use the shower to clean myself. (John)

Very few participants had access to a shower, a tap with a long flexible pipe to clean and wash after toileting, which was easier to use independently.

Although all the participants had clean water available for drinking, they had to focus on how to get drinking water to meet their needs.

I don't know whether I [will] get available water or not but I drink water as much as I need to keep me fit. Usually I drink water three times per day as well as before going to bed. (Liton)

Others who used a tap within their compounds drank more frequently. They could travel to the water point quickly and did not have a particular set time for it:

Often I drink water as much as I need from my tap as it is in my house. I don't have to allocate extra time for drinking as it is easy and quick. (Rajib)

Bathing required more water than any other activity. To avoid having to carry large volumes of water, some participants had their bath alongside the tubewell, using a wide concrete space around the tubewell and transferring from wheelchair to floor:

I go near the tubewell and have bath there. I need a huge amount of water to bathe which is impossible for me to draw and carry. My wife draws water for me to have bath there. I sit on the floor for bath which is concrete and easier. (Kabir)

If they were using a shared tubewell, installed in a common place, they had to plan ahead:

If my mother, brother or aunt bath in the tubewell then I have to wait for them to finish their bath. Usually they bath at noon and collect clean water for cooking. The children also take bath in the tubewell before going to their school. So that, most of the time I have to bath afternoon or just before 12.00 midday daily. This mean I have to bath within a timeframe. (John)

Similarly most of the participants had to allow extra time for using a communal toilet, because they had to wait in a long queue and sometimes their catheter bag overflowed:

I have routine to change my catheter daily as I use common toilet so I have to wait for others and sometimes I get wet for it. (Liton)

Most of the participants felt there was an impact on family life and shared occupations:

I have to spend more time collecting clean water as it is far from our house so that I cannot contribute or spend more time within my other activities, even for my family. (Lotus)

Sometimes this impact was also due to the demands of managing a wheelchair, which caused pain and fatigued participants, who had to rest before engaging with family activities. All the participants were fully dependent on their family member or carer to access water and sanitation:

I have to spend more time in water related activities and sanitation that's why I cannot look after my children or contribute to my family. Even my family member assists me to do water related activities and sanitation. For example bathing, toileting and cleaning. (Rajib)

The impact of barriers to accessing water therefore was felt in many aspects of life and the severity depended on whether the toilet or water source was shared by the community, the distance of the water source from home and/or toilet, assistive devices/adaptations and individual coping skills.

4. Discussion

The findings suggest that although each participant had an individual way of managing access to water, there were common approaches and issues. One common issue arose from an inaccessible home environment, requiring the participants to be dependent on family members or carers for access to water and sanitation (Bailey & Groce, 2009; Hannan, 2005). It is important to note that in the rural Bangladeshi context, the home environment meant the whole village, with occupational therapists able to adapt access areas between where individuals lived and public water sources and toilets if funds were available. Thus provision of ramps and hard road surfaces enabled participants to access water and sanitation independently and easily (Jones & Reed, 2004). But such modifications were costly for those who live in the community and people with disabilities are widely acknowledged as being among the poorest of the poor (United Nations, 2006; Wara, 1998). Their contribution to family life was restricted by barriers to access and the need for assistance may also have prevented their carers from working too, making it more likely that the whole family will be poor. Thus an inaccessible environment was not only a barrier for the participants in accessing water and sanitation, but also had a financial impact on their family and community (Hannan, 2005; WHO, 2012). Disabled people, including paraplegics who are not earning members, are often excluded from decision-making for their family and society precisely because they are not earning (Bailey & Groce, 2009).

An appropriate balance of time and energy given to different occupations is beneficial to health and well-being (Crist, Davis, & Coffin, 2000). Conversely, an imbalance and deprivation in occupations is a risk factor for ill health (Wilcock, 1998). When the participants in this study had to spend more time and energy in gaining access to water and sanitation due to an inaccessible environment (United Nations, 2006), there was an impact on their occupational balance, restricting participation in other self-care activities, family life and work.

Assistive technology, including devices such as wheelchairs, bottles and buckets, eased some of the demands of accessing water and sanitation. Successful assistive devices included plastic buckets the right size for carrying on the wheelchair; small mugs and glasses with handles; and flexible pipes which could be used for washing after toileting. Wheelchairs were crucial for the participants, who not only accessed water and sanitation with their (water proof) wheelchair but also performed other activities like bathing and shopping. The design of a wheelchair may vary from person to person according to their individual requirements, with poor designs contributing to pain and fatigue, particularly in the upper limbs (Jones & Reed, 2004; Nichols, Norman, & Ennis, 1979; van Velzen et al., 2009). A well-designed wheelchair, with a seat and a cushion, wider handrims (known as rails in Bangladesh) and dynamic footrests, enabled easier access to water and sanitation and improved occupational balance (Crist et al., 2000). Assistive technology also included a wooden toilet chair with a hole, to be placed over the low Asian toilet pan but this required participants to transfer from their wheelchair and did not resolve the issue of access to water for washing after using the toilet (Water Aid, 2006). A better solution was a high commode in a cubicle with space for transfers and a water supply for washing). Otherwise, accessing the toilet was time consuming and participants felt obliged to let other people go first, regardless of their own need and suggesting an internalised stigma (Kendra, 2008).

Whilst accessibility and assistive technology have been shown to be important facilitators in access to water and sanitation, these were only part of the solution for participants. The findings from this study and others (Groce, Bailey, Lang, Trani, & Kett, 2011; Hannan, 2005; Howard & Bartram, 2003) indicate that many people with paraplegia develop their own individualised methods of access to water and sanitation in conjunction with their individual abilities and capacities. Provision of modifications and assistive devices to enable access to water and sanitation reduced stress, suggesting an interaction between the person, the environment and the everyday occupations which require water. A person with disabilities who has an accessible home environment and appropriate assistive devices for easy access to water and sanitation may have less stress (Sekaran et al., 2010). Conversely, an inaccessible home environment could cause stress and illness (Goodridge et al., 2015; Hannan, 2005; Wilcock, 1998).

A combination of accessibility with assistive devices was seen as a vital strategy for sustaining access to water and sanitation independently. The literature in this area has focused predominantly on wheelchair-friendly environments (Hannan, 2005; Wara, 1998; WHO, 2012), and well-designed assistive devices in community settings (Bailey & Groce, 2009; van Velzen et al., 2009). However, other studies (Wara, 1998; WHO, 2012) contradict these findings and report that inaccessibility remains the main barrier for accessing water and sanitation, with assistive devices playing a reluctant supporting role—the more accessible the facility, the less the need for assistive devices. This contradiction could be explained by the high proportion of participants in this study who were skilled in wheelchair management. These skills were important: when this was not the case the participants were more competent using the assistive device, though a combination of both is often required (For example, ramp [accessible facility] + bucket and wheelchair [assistive device]). The transactional person-environment and occupation (PEO) model (Law, Polatajko, Baptise, & Townsend, 2002) suggests the demands of occupations such as bathing can be met through successful personal adaptation for example by learning skills, as well as through environmental change. Thus the PEO model could be used to inform a wider range of strategies for improving access to water and sanitation facilities.

Another occupational perspective recognises the importance of routine (Wilcock, 1998) as a way of managing daily occupations: participants who collected water from a long distance and used a common water point or toilet developed a routine and timeframe for occupations involving water. Some studies have indicated that time management techniques can enable participants to organise their daily balance of occupations (Bailey & Groce, 2009; Howard & Bartram, 2003). However other authors have argued that without considering the distance, it is difficult to allocate time for shared toilet and water sources for each activity in the community (Gleick, 1996; Hannan, 2005). These findings were reflected in participants' experiences. Some participants described allocating time to spend with family whereas others found doing so a source of pressure. Some water-related activities could be located nearer to the water source, saving time and energy thereby ensuring a greater contribution to the family and greater opportunities for rest.

Few participants were content with their access to water and sanitation in relation to daily activities, and were struggling to manage. The resulting tensions were attributed primarily to environmental barriers, though they were compounded by the demands of self-care, a finding strongly supported by other studies (Corcoran & Gitlin, 1997; Howard & Bartram, 2003). Local initiatives to improve access to water and sanitation initiatives, including removing steps and creating hard surfaced roads, are becoming more widespread, but are inconsistent. A systemic approach involving the government, NGOs, international policy and local decision makers is required. One strategy could be a Community-Based Rehabilitation (CBR) programme addressing the consequences of uneven or stepped roads and other barriers. This could be supplemented by implementing wider toilet doors, larger toilet spaces, longer tubewell handles and ramps using local materials like sand, cement, metal and brick which are available and cheap in community settings in Bangladesh. Whilst these initiatives have clear financial implications, there are benefits in terms of improving access to water

and sanitation facilities and reducing the dependency on family members or carers; in turn, these allow people to participate in and contribute to family life and other forms of productivity.

Another important finding suggested that environmental barriers (Centre for the Rehabilitation of the Paralysed [CRP], 2012) to water and sanitation persist because of a lack of knowledge and awareness of disability issues (Bailey & Groce, 2009). Disabled people are rarely consulted and considered when planning infrastructures like building homes, toilets, tubewells and roads (CRP, 2012). This results in disabled people remaining marginalised and excluded from mainstream society (Jones et al., 2002). This issue of disability awareness, people's rights, and access to a wheelchair friendly environment can be strengthened through a CBR programme with the collaboration of local government, national and international non-governmental organisations like the WHO, UN and the World Bank, who have an interest in achieving the Sustainability Development Goals and ensuring access to 100% water and sanitation in Bangladesh. This could improve the lives of all disabled people and their families, not just people with paraplegia.

In rehabilitation settings, there is a potential role for occupational therapists, who could assess the components/determinants of individual barriers in access to water and sanitation (environmental, assistive device, activity demand and access mechanisms; coping strategies) to identify specific areas of loss, dependency and dissatisfaction. Occupation is seen as a basic human right (World Federation of Occupational Therapists, 2006), so an occupational therapist working with people with paraplegia must seek to uphold their rights to achieve what they desire and need for their personal growth. The therapist could then facilitate a process of re-evaluation and re-organisation aimed at achieving congruence between the individuals' skills, capacity and their daily occupation, whilst ensuring that they have the necessary support in access to water and sanitation. The work of occupational therapists with individuals could be aligned with community-based initiatives, for wider and sustainable benefits (Cleaver & Nixon, 2014).

This study has relatively few participants and was mostly carried out in a facility-located area in Bangladesh, due to time constraints, and challenges with transportation and the distance to reach participants' homes. These factors limit the potential for transferability of the findings.

5. Conclusion

The participants in this study faced wide and competing activity-demands in accessing water and sanitation. These demands arose from issues such as accessibility, availability of assistive devices and skills training. The most widely reported experience was of environmental barriers and the need to spend more time and energy in accessing water and sanitation, leaving participants with insufficient time and energy for their family, community or leisure. Independence in toileting means people with paraplegia and family members can use their time more productively both at home and in the workplace (Jones & Reed, 2004). Having a private, accessible toilet at home could benefit the economic and social status of people with paraplegia, particularly if it means they are better able to not only maintain their dignity but also to have the time and energy to engage more effectively with other occupations. Indeed, a reciprocal relationship emerged between the amount of time and energy participants apportioned to their access to water and sanitation, and occupational balance. So in considering the implications of these findings, which are well supported by the literature (WHO, 2012; Wilcock, 1998), it is evident that barriers in access to water and sanitation are a significant problem which has serious implications for people with paraplegia. The findings from this and other studies (Bailey & Groce, 2009; Kendra, 2008) indicate that CBR programmes are needed to address these issues. Finally, the findings from this study are relevant to occupational therapists, who can facilitate improved access, appropriate design of assistive devices and the development of practical coping skills, enhancing occupational balance, health and wellbeing.

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Competing Interests

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Author details

Md Jahangir Alam¹

E-mail: Mohammad.alam@sept.nhs.uk

Wendy Bryant²

E-mail: wbyrant@essex.ac.uk

¹ SEPT (South Essex Partnership NHS Trust), Essex, UK.

² School of Health and Human Sciences, University of Essex, Essex, UK.

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