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"I Am Not That Sick"

The Use of Assistive Mobility Technologies Among The Elderly

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Abstract

The use of mobility assistive technologies in different contexts seem to give a great promise to potentially improve mobility, functionality, social interaction as well as performance of daily activities for the elderly. Unused wheelchairs and abandoned crutches however were a common scene in the homes of the elderly people during this study. This paper presents stories of three elderly people from a bigger study on aging and the use of assistive technologies, drawing attention to the need for proper understanding and appreciation of the context before assistive technologies are assigned especially in old age.

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Introduction

Central to the study of ageing is high possibilities of acquiring disabilities and (therefore) the use of assistive devices. This is because ageing has been pointed out as one of the leading causes of disabilities all over the world, and disabilities are more prevalent among the elderly than in other population categories[1] In fact, more than 40% of older persons in Uganda were found to have a disability by the year 2006[2] indicating that disability increases with age; there are more chances of getting a disability as one grows older, and there are multiple disabilities at older age. The population of elderly people (60 years and above) in Uganda is estimated to be around 1.4 millions, making up 4.2% of the current total population of 34,856,813 people[3] but evidence suggests that the elderly population is growing faster in African countries than other continents of the globe. And as such, it is estimated that by 2025 the fastest increase in the ratio of older people to younger people will be happening in developing countries, particularly Africa[4].

The more specific common documented causes of disabilities among the elderly are; chronic diseases, injuries, mental impairment, malnutrition, HIV/AIDS and other communicable diseases [5].

As individuals age, their mobility is believed to reduce and for many, disabilities become part and parcel of the ageing process[6]. Mobility assistive technologies seems to give a great promise to potentially improve/re-establish their mobility, functionality, social interaction as well as performances of daily activities, for elderly people with disabilities [6,7]. Moreover, technologies are regarded as having preventive potential: They might reduce greater reliance of the elderly on family members, maintain their sense of themselves as full adult persons[8], increase safety and reduce the likelihood of falling while walking [9]. In summary, assistive technologies promise and promote what has been referred to as 'active and successful aging'[10,11] which suggests a condition in which an elderly person can remain healthy, active and mobile.

While most of the studies that highlight the importance of assistive technologies for the elderly have been conducted outside Africa, during this study too, I found different kinds of 'western made` and imported mobility technologies, especially wheelchairs in the homes of elderly people. This probably could be explained by the increased importation of such devices in Africa and the increased need to find solutions to improve the lives of elderly people. In fact studies within Africa have revealed the constrained care and reduced social support mechanisms for the elderly[12-15], and this could all explain the increased efforts to assign such devices to the elderly people. Unfortunately, many of them, especially wheelchairs that I focus on in this paper, were not used. In such cases, the elderly often used locally made devices, or improvised means to support their functionality.

In this paper i look at the complexities involved in using the wheelchairs especially in the three cases presented, and how some of the elderly people end up abandoning the wheelchairs and what issues surround this abandonment. I argue that the impact of some of these technologies may sometimes be negative and the social and physical environment in which the elderly live does not support their use. And that although technology has been documented to play such an important role in the lives of the elderly (especially with disabilities), this is assumed for the global population and unfortunately, unused wheelchairs were part of the normal home environment of many elderly people that I visited during my study.

This study is specifically significant for practitioners including health workers that assign and allocate assistive technologies to people with disabilities including elderly people.

Methods

The study was conducted in Wakiso District that lies in the Central region of Uganda. The population of the district is currently estimated to be over 2 million people, accounting for about 6% of the total population of Uganda[3] and 4 percent of the total population of this district had earlier been estimated to be elderly (60+ years)[16]. The district has 17 sub-counties, 153 parishes and 188 villages. The study was specifically conducted among 2 selected sub-counties; Makindye Ssabagabo and Wakiso sub-counties. The district has both rural and semi-urban populations. And the biggest part of it being semi-urban.

Although this paper is based on stories from

three of my respondents, these are extracted from a larger study on "aging and the use of assistive technologies"[18,19]. The study adopted a sequential mixed methods design: both exploratory and explanatory [17]. A qualitative study, which involved 10 elderly people was conducted at the start, to establish what issues were at stake for elderly people with disabilities in the study area. The acquisition and use of assistive technologies emerged as one of the key issues, and a quantitative survey[20] involving 337 respondents, was then carried out, to establish among others; what types of assistive technologies are being used by the elderly, what were the sources and how many elderly people actually do use mobility devices among others. The survey provided the necessary insights for follow up with another in-depth qualitative study involving 30 elderly people, selected from the above sample. The qualitative in-depth study was intended to explain results of the quantitative survey, such as reasons for elderly people abandoning certain devices, the process of aging with or into disabilities, and coping mechanisms.

Interviews, observations and conversations were chosen as the most appropriate methods to collect information from elderly people in their home settings. General questions were asked and discussed with them, including their life history; how they acquired the impairments, how their lives changed since then, how they started using assistive technologies and how they negotiate the use of these technologies on a day today basis in carrying out their daily activities. All respondents were in the age range of 60 to 95 years. All participants lived, were interviewed and observed in their home settings.

Ethical clearance for the study was obtained from the School of medicine Institutional Review Board (IRB) in Makerere University as well as final approval from the Uganda National Council of Science and Technology (UNCST).

Findings

This section draws on findings of the study extracted from the three stories presented in this section. The findings reveal three issues; relying on external support (dependency Vs inter-dependency), nature of daily activities and the undesired image of the wheelchair . The findings suggest a need to think creatively on how technologies can best be suited to individual elderly people's needs as opposed to the universal designs. I will use three stories: Jaaja Mulokole (meaning saved grandmother)*, Nakazi and Mrs Nsereko* to illustrate these points.

Jaaja Mulokole, aged 65years, living alone in the small village of Sumbwe, has very weak limbs, cannot walk neither stand and moves (almost only within her house as she hardly goes out) by crawling. She acquired the impairment from a disease (that she is not able to name) that started with swelling legs when she was about 41years. She says that her limbs, have continued to get weaker and weaker and she has not been able to walk for almost 20 years. Jaaja Mukolokole lives in a small two roomed house that has relatively small doorways, rough floor surfaces and constructed out of iron sheets - both the roof and part of the walls, then the other parts are made of wood.

Her daily routine involved: preparing her meals using a small charcoal stove, washing her utensils and, attending to a small charcoal selling business inside her house. Jaaja Mulokole creatively and innovatively arranged and used several other tools and objects to carry out her daily activities: for instance, she used a stool (small table) to help her get on and off the bed. She could hold onto the stool and lift herself to the bed. With help of a male neighbor, she had reduced the height of her wooden bed by cutting off the bed stands. She had in her house a long stick, and with this, she could hang and pick her clothes from the line after washing and after drying. She also used this stick to pick up objects that were far from her, such as if she wanted to pick a saucepan when she is going to cook her food. Because Jaaja Mulokole could not move to go and fetch water from distant water sources as is commonly done in rural areas of Uganda where there is no piped water, she had manually connected gutters that collected water from her iron roof and the water could flow inside the house in a big plastic yellow container that is stationed right at the end of the gutter. With this locally, self-made and self-managed system, she could manage to perform her day to day activities even though she lived alone.

During our first encounters, Jaaja Mulokole owned no wheelchair, although she expressed a desire to have one. Jaaja Mulokole later acquired a wheelchair

from her neighbor's children, when their mum whom they had bought it for passed on. When we met at around the third time, she informed me that she had received a wheelchair, but wanted me to help her find a buyer so that she could sell it off. And when I asked why she wanted to sell it, she explained to me the challenges she encountered in using the wheelchair; "If I have to use it, I have to be outside the house. The uneven floor here in the house cannot allow me to use it, it is very heavy, and my body is heavy too and I cannot lift myself to sit in or to get out of it". From observation, the kind of activities she was engaged in daily, and the nature and size of her house in which she did them, required her to be much more physically flexibility (to be able to bend, turn easily etc), which she couldn't do with a wheelchair in such a small house.

Jaaja Mulokole was unable to use the wheelchair. But relied on self-made devices to improve her mobility, and stay functional to accomplish those activities that she deemed important to her. With this kind of system set up in Jaaja Mulokole`s house, it was possible for her to remain functional and carry out her daily activities, not without difficulty but it made it possible for her to manage her life nearly without day to day support.

Nakkazi (about 60 years old) acquired her disability as a result of falling. After trying to seek for treatment for almost 2 years and living with her children in Kampala, she decided to return to the village where she lived, but could not work again on her tailoring machine, which she used to do before she got this impairment, although she still had hopes of getting well. Nakkazi was asked by the doctors to buy a wheelchair from the hospital, which she did, with financial support from her children. Nakkazi narrated to me how it was such a big hustle starting to use this wheelchair. Her caretaker, who was a grandchild, would have to lift the wheelchair and take it outside the house, in her compound, and then lift her and take her outside too especially that this is where she loved to spend her day and not inside the house. And often she had to call a neighbor for help and she wouldn't manage to lift her alone. This would be the same story whenever she wanted to come back into the house. Problems came when her caretaker was away from home, and then it started raining while still outside in a wheelchair but not able to push herself back to the house. In such situations Nakazzi often relied on any person passing by to help push her back to the house. She would yell to attract attention of any one nearby for help. To solve this problem, she modified her house to enable her to use the wheelchair more effectively. She widened the doors, removed the steps to and from her house, and built a ramp to her house.

Nakazi, different from Jaaja Mulokole, put in extra resources to make use of the acquired assistive technologies. This however did not only require financial investment, but a hope and desire to be more active and engage in earlier life income generating activities (the tailoring). Many elderly people on the other hand had kind of lost this hope or desire to actively engage in other activities outside their homes again.

MrsNsereko, 83 years suffered a stroke over 10 years ago. She uses a stick to walk but walks extremely slow and she finds difficulties in moving from one place to another even within and around her house. As a result, she hardly leaves home, apart from times when a neighbor comes for her in a car to take her to the bank to receive her monthly pension having been a government employee (teacher). She says she is unable to attend church services, burials or visiting the sick – which she did before and regards as very important. Her slow movements made it difficult for her to take care of her frail husband, Nsereko John Mary. Although she owned no wheelchair, when we had a discussion with her concerning the use of the wheelchair, as her husband had one, Mrs.Nsereko frowned and nodded her head in rejection, and boldly told me that she was "not that sick to the level of using a wheelchair". Commenting about her walking stick she noted; "I love my stick just as I love matooke (staple food for Baganda). It is the only thing that I can compare it with. It is my parent, my child and my everything. It helps me get what I need to get and gives me a reason to continue living, without it, life would be meaningless now". To make matters worse, her husband whose two limbs were broken, refused to use the wheelchair but kept it in a small room in the house. Nsereko first told me that he has no one to push him in the wheelchair and he couldn't manage to do it himself. But, when I realized that actually his teenage grandchildren do quite more challenging tasks for him than probably pushing the wheelchair, such as lifting him if he has to sit on the

bucket (for toileting) or if he has to leave the bedroom to the sitting room, I probed further on why the same children wouldn't help to push him in the wheel chair. This time he told me that he did not like the wheelchair, because he feels pain in his pelvic joint when he sits in it, and further mentioned that he would rather keep in the house than be seen to be disabled in a wheelchair. And that when he returned from the hospital and sat in his wheelchair, people that came to see him were all surprised and making statements like, "ohhh sorry, it is so sad…now he is in a wheelchair…"

Looking at the above stories , my respondents present different reasons for not using the wheelchair. At first Nsereko mentioned the absence of a helper to support him in using the wheelchair, then he went on to mention about his pain and finally the image that the wheelchair that made him appear disabled. Not wanting to appear *so sick* and *disabled* propels the decision to forego the use of the wheelchair. While the wife did not explain reasons why she herself wouldn't use the wheelchair, her facial expression depicted a strong dislike for the same. Even when it appeared to be the most recommended form of assistive device for the elderly by health care professionals, the wheelchair seemed to be placing such a strong undesired image that was strongly desisted by many of the participants. Having a wheelchair signified a new identity of being *completely disabled*, with a *changed body* and therefore *changed identity*.

The above stories of three of my respondents reflect three important interrelated aspects on the use of assistive technologies among elderly people in Uganda and in similar settings.

Independency vs Inter-Dependency.

The use of the wheelchair specifically, required support from someone else. As all wheelchairs owned by my respondents were manual, the environment in which they had to use the wheelchairs required that someone is available to support in pushing the wheelchair, especially that the level of their strength would significantly keep reducing as they age. Many of the elderly hardly had a full time helper at home. Many of them were helped by a grandchild who also often had to go and do some work outside the home to earn money to sustain the family, and often these also had to do all the laundry work, cooking and cleaning and sometimes very personal activities like bathing and taking the elderly or supporting them to go to the latrine, but they could only do these activities at particular times of the day, like either early morning and evening, and they had to go elsewhere to look for money the rest of the hours of the day. It thus became so difficult to have someone to help them through the hours of the day, and the technology made one feel more dependent on their caretakers.

Discussion

The findings from these selected stories raise some critical issues in relation to assistive technology among elderly people. There is no doubt that technology has potential to improve the lives of elderly persons especially those that have disabilities. This study reveals the various attempts by various parties and the elderly people themselves, to access and use an assistive device to improve their mobility increase their functionality and compensate for the reduced strength. The same findings reveal however that for several reasons, not all elderly people are able to benefit from the use of assistive technologies, bringing us to question what qualifies to be an assistive technology. The discussion specifically points out three critical issues that need to be re-examined in the process of assigning and providing assistive technologies especially to elderly people in similar setings.

First, are the assumptions made on the need for assistive technologies. Jaaja Mulokole`s story for instance shows on one hand the efforts of different players in providing assistive technologies to the elderly, but also the assumptions contained in the belief that elderly people with disabilities need to have an assistive mobility technology to aid their mobility.

On the other hand, the story shows the efforts of the elderly people themselves to improvise with what works best, suiting their physical and social environment. The stick, the stool and the water harvesting mechanism in this case was a self-made innovation, not exactly for mobility but for their day to day functionality, and appropriated for the user`s mobility. For the activities she needed to do, she managed to put together a set of devices, tools and means to enable her function, and these become assistive technologies for her.

Second, is the need to question; functionality or mobility for what? Whereas some elderly people advanced the reason of not having children to push them in the wheelchair as a reason for not using one, interestingly, others refused to use the wheelchair because they have children who can help them to do most of the household chores for which they would have wanted to be mobile. Ms. Namusoke (another respondent) asked me when I was discussing with her on why she did not use a wheelchair that she had kept in her bedroom since she acquired it, 5 years ago, or try to use her crutches that she kept in one corner of the house, "*where do I want to go?..i have my grandchildren, I can send them anywhere, they bring me food right here, they bring me tea right here, now what else do I want? For me this age I should just sit and eat*". The absence or presence of children as helpers therefore being an important aspect but this seemingly could have a positive or negative influence on the use of wheelchairs.

In Uganda, and many parts of Africa, children do provide labor for domestic chores [21] and this is not perceived as child labor, but the role of children in the family. The elderly therefore, even without a disability, would often send children for almost everything within the house and around the home. In Uganda, an adult person would feel dignified if they have a younger person to fetch water for them, to cook food, wash clothes and clean the home, and what is left to be done are usually the personal activities such as bathing, dressing, for which no wheelchair is required but other simpler artifacts if not techniques (learning to use their bodies differently). As they often referred to old age as a time to *sit and eat,* revealing how they weren't expected to "struggle" or be physically very mobile but the younger ones are expected to do most of the chores.

Third, the Image and social meaning of the wheelchair. The sources and process of acquiring the wheelchair gave it meaning once acquired. Elderly people acquire devices from their sons and daughters as a form of social responsibility and obligation, health workers as a form and part of medical care, Christian organizations as a form of charity and good works, neighbors as well as other concerned members of the community, and from local artisans when assistive technologies are provided as a form of business. It is clear that the source influenced use and people clearly tagged meaning to the source of the device: devices acquired from children, such as "modern" metallic walking sticks, were so treasured, loved and valued. On the other hand, often times, devices acquired from the hospital were a symbol of sickness. Elderly people often when I asked why they are no longer using the wheelchair or crutches, it was common to receive a response like "I was given that device because I was sick in the hospital". I noted that the response was never "because I couldn't move or because I became immobile". And many rejected the wheelchair because they were "*not that sick*". Therefore there was a strong image of the wheelchair relating it to severe sickness and being crippled.

In Uganda, the wheelchair has no local name, but it is usually referred to as " *akagali ka `balema*" literally meaning *small bicycle for the lame*.

A lot has been documented on the social aspects of technology, and recognizing the fact that designers of technologies should have the social aspects in mind, considering empathy and context are essential for effective innovative designs. Caitrin Lynch refers to technological inappropriateness as "the right solution to the wrong problem" [7]. In fact the use of assistive technologies, is expected among other things to improve the social interaction and social functioning of the elderly [9], just as it should for other groups of people. Regrettably however, some of the elderly will abandon the device because they find it socially embarrassing or wondering what other people in their community will think of them when they use such devices.

On the contrary, the walking stick for example did not portray the same image, and this could have to do with the cultural acceptance of the same. The walking stick in Buganda (*muggo*), formed part of the dressing code of older men who were married (*Ssemaka*) as a symbol of power and authority. And the King (*Kabaka*) of Buganda handed a traditional stick (*Ddamula*) to the prime-minister (*Katikiro*), also a symbol of authority (*muggo ogwobuyinza*) [22]. Although walking sticks talked about in this study were all used as assistive devices to support mobility for the elderly, their cultural symbol, one could argue that made it easier for it to be accepted, and used more effectively.

Generally, old people are made to appear as withdrawn from social interaction processes of society and culture, hence no surprise that they are offered wheelchairs to enable them remain social and interactive. But there is need to understand what they consider important socially, culturally and contextually. In fact, Peter Coleridge notes that culture is not simply a factor to consider, or be taken into account, but is the entire context within which interventions should be done [23]. Even though it is assumed that elderly people everywhere would like to remain active, mobile and socially functioning, their desires and goals related to social interaction and communalism are different from one context to another. The kind and nature of Activities of Daily living are also different in the different contexts.

Designers of assistive technologies should not take care of only the *what* (technology) and *how (design)*, but why, *for who* and *for what* of the technology. This would help to make a meaningful contribution in the lives of the elderly people and rebuild the seemingly broken bridges between the elderly people and the rest of the society. Very important also is the need to asses if what the elderly person requires is a technology or simply a technique (a skill to be able to perform or function within their context). The improvement in technical aspects of technologies therefore, or providing better infrastructure for the elderly or all people with disabilities generally, is not likely to improve uptake and use of such technologies for particular groups of people, if cultural and social aspects are not carefully considered.

A limitation of this study was its scope, in terms of numbers and length of the study. The qualitative part of the study involved 30 respondents in total, and only three of these have been selected for this paper, and these were observed for a period of 12 months. There is need for larger studies specifically focusing on the use of wheelchairs among the elderly in similar settings.

Conclusion

The non-use of the mainstream assistive technologies among the elderly calls for a thorough understanding and appreciation of social realities before assistive technologies are allocated for the elderly in such settings. The provision of universally designed assistive technologies that end up being abandoned reveals an innovation gap and a need to provide devices or technologies that address the functionality needs of the elderly and tailored to the particular settings.

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