

Assistive Technology awareness and utilization of its potential among lower limb amputees of Delhi, India

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ABSTRACT

Assistive Technology (AT) can do wonders in the life of the user but only one in every 10 people in need have access to assistive technology due to high cost and lack of awareness, availability, trained personnel, policy and financing. We conducted a study among 24 lower limb amputees in Delhi, India. We aimed to study the assistive technologies being used and their utilization. First author collected data and documented the experiences of users after amputation. We found that half of the participants were not aware of the AT options available initially and three quarter of them mentioned that they accessed the assistive technologies after an average time of one and half years after amputation. In this study, it was found that the awareness among the users on AT is dependent on the type of AT they use. Which makes it evident that many have lived through their productive age without a support and compromised both personally and professionally. Hence, the purpose of assistive technology lost to achieve its goal and due to lack of complete knowledge even after accessing people did not use the technology to its fullest potential. This is an example for the problems caused by adapting problem solving approaches in healthcare technologies that have limitations, which clearly raises a concern that, is making a solution available in the market enough? or are there more dialogues that need serious attention while introducing an AT to the marketplace. This reflect upon the knowledge gap between what is known and the assistive technologies available in place. Information, education and communication(IEC) is an essential element in any process of intervention development and distribution. Effective IEC determines the uptake and success of any intervention. The AT user must be made aware, educated and taught about the whys and hows of the technology to match and achieve optimal utilization of AT features. This paper highlights the importance of such interventions in a process of AT development and experiences of lower limb amputees in achieving the technological goals. This further has implication in users' life attainment outcomes. For the development of assistive technologies, the developers need to involve the users in every stage of development through adapting unconventional exploratory approaches to understand the needs of the user in a better way. Developers should also keep the social, economic and technological aspects of low-middle income countries in mind, along with engaging the users in all phases of the development of technologies to understand how to achieve utilization to the maximum extent when introduced at the right time and right place. That will improve the outcome and in turn would support the users to attain good life with empowerment, and will help in achieving social and emotional well-being.

INTRODUCTION

Assistive technology, an umbrella term about the systems and services associated with the assistive products and services. Assistive products maintain and improve the user's functioning and independence to promote well-being. The facts on the Assistive Technology suggests only one in 10 persons in need access the assistive technologies [1]The reasons associated with poor access are poor awareness about the technologies, accessibility and availability of such technologies, non-availability of personnel for training and finance and so on. It is also heartening to note the low and middle income countries are far below in access to assistive technologies. [2]There issues associated with the uneven distribution of such technologies among such countries due to insufficient resources and existence of large gaps between haves and have-nots.[3] Other reasons for poor diffusion of the technology are, ineffective promotional campaigns, service provider characteristics and attitude, higher cost for the product, non-availability of timely information, and others. [4,5,6] In the present scenario, the awareness among the users on AT is dependent on the type of AT they use. This could reflect upon the knowledge gap in the AT available.

Information, education and communication is an essential element in any process of intervention development and distribution. Effective IEC determines the uptake and success of any intervention. There are limited number of publications focusing on awareness of existing interventions in the world, which could be a determining factor for lower uptake of assistive technologies. There is also dire lack of health promotion activities in regard to persons with disabilities. Studies are limited in the field of disability that entirely focuses on the element of awareness as a determining factor in the utilization of the intervention. Role of health promotion focusing persons with disabilities is very limited. The present paper is an effort to address the gap in awareness on the assistive technologies for the persons with disabilities, with the specific reference to lower limb amputees.

METHOD

Using exploratory research design, total 24 lower limb amputees from 14 rehabilitation centers in Delhi and national capital region, India have participated in the study. There was homogeneity among participants from one center. Organization profile include, six privately run centers, four government operated centers, and four were run by non-government organizations. Data were collected during June to August 2018. Following ethical practices which included obtaining ethical clearance to conduct the study, all participants were consented to participate and the participation was voluntary. The participants profile includes they are in the age group of 18 to 49 years with the mean age of 35years. They hail from Delhi, Haryana, Jammu& Kashmir, Rajasthan, UP and Bihar. 70 percent are male, 50 percent unmarried, and with accident as major cause of accident. Using an interview tool questions on awareness about the assistive technologies, on utilization of such technologies, problems faced if any, and the availability and accessibility of such technology were asked. The first author conducted data collection and the interviews were recorded.

ANALYSIS

The recorded interviews and field notes were analyzed, using Weft QDA software (1.0.1) after transcription and translation. Then codes were generated following patterns We followed axial coding following lumping and splitting. Side by side, we were also writing memos for each of the quotes. Based the codes we grouped them in to different themes. Validation of the codes were done by sharing the codes between the authors. [7] The codes were not shared with the participants for the purpose of validation. This helped us theorizing the problem.

FINDINGS

The participants were of the age group of 18 to 60 years. Three quarter of them were below knee amputees, one of was bilateral amputee and the rest were above knee amputees. Only 20% of them had insurance coverage for the ambulatory care. The Assistive Technology used by the participants include, prosthesis, wheelchair, tricycle, crutches and cane sticks. However, there are instances that some used multiple assistive technologies in different circumstances. 22 of them used prosthesis which gives more mobility support and hence were considered better than other AT for amputees. While, others were still using cane sticks due to non-affordability of prosthesis, which are highly priced. The prostheses used were in the forms of modular prosthesis, ALIMCO (Artificial Limbs Manufacturing Corporation Of India) prosthesis [8]and Jaipur foot [9]. Based on the definition by the user in- local context, modular prosthesis is availed from a private center and has support higher activity levels, ALIMCO is the prosthesis that is produced and distributed under a national scheme which is deemed to provide moderate to high level activity support, and Jaipur foot is produced and distributed by a faith based non-governmental organization and has limited mobility and activity support.

About 17 percent of the participants were employed regularly prior to amputation and it was reduced to eight percent at the time of interview. The average time taken to seek care was 19 months which is very much higher than the recommended period for seeking ambulatory care (2 to 180 months). The reason for the delay was lack of financial assistance. The sources of financing for the users are, family saving,

property mortgage, loans from unorganized money lender, personal savings. Two third of the assistive

technology users spent over ₹ 2,00,000(INR). It was found that exorbitant prices and no funding resources for such high cost were the reason for most of the participants to prefer the aids that support restricted mobility. For the question on the sources of information on the Assistive Technology providers, respondents majorly identified a) friends, b) acquaintances and c) other AT users, . No participant reported receiving any information either from the rehabilitative care provider or the general health care provider providing treatment. This finding indicates poor health information sharing by the healthcare providers.

DISCUSSION

According to the science of sustainable consumptions, public awareness plays an important role. It is important to note that the awareness about the number of interventions available are shared and awareness created among the potential users will address the problem as well as achieve the purpose of developing such technology. The success of any assistive technology will depend on the effort put on creating awareness and knowledge among the users. [10] Even though on paper evidences suggest there are more number of high mobility supporting interventions or assistive technologies for people in need, the number of people using them are still not been documented.

Affordability and Accessibility

This study found a majority of people with lower limb amputation are using lower mobility supporting assistive technologies and it is an important topic that needs to be addressed. It is also important to note that the technology options that are available for lower limb amputee with better functionalities are either unaffordable to many or if they are affordable then are not found to be appropriate. The cost, availability, knowledge about the features of assistive technologies with higher features still needs to be addressed. Another important issue emerged from the study was the assistive technologies are not locally available and people have to travel larger distances for availing them.

Awareness

Even the sources of information on the assistive technology providers are mostly through informal communication channels. The healthcare providers who were engaged in ambulatory care did not inform the appropriate aids to be used by the users.

Outcomes of the assistive technology use could be best described by the uptake and utilization quantitatively but the performance improvement is a qualitative aspect which is not studied vigorously and could be important in accessing the success point of an intervention when used to its fullest potential.

Participants appear not to be aware of the basic uses of the prosthesis in terms of, the duration- how long is it advisable to use the prosthesis, what could be the cause of pain in daily use of prosthesis and does it need to be attended, what are the activities that can be performed while one uses the prosthesis. The change in the trend of the employment status of the user from being employed to unemployed or under employed after the amputation even after using assistive technology is an important scenario suggesting the lack of utilization of the technology to its fullest potential.

The development of an intervention is supposed to be user centric but the data presented in this study indicates that there are system failures system is failing in providing the awareness, knowledge about the product to the user which is resulting in the under-utilization of the intervention.

Lack or poor quality of User Training

Participants who were using the prosthesis with higher mobility support mentioned not being able to carry out day to day activities such as, climbing up the stairs, sitting while using prosthesis for longer duration, walking without a support and so on Completely making the activities such as physical exercise, cycling, jogging, brisk walking all out of reach and context for users. Though the investigator identified that the prosthesis had a potential to support all activities, the users were not aware of it. They were not provided with any proper training to carry out those activities and also there was a lack of motivation to do so. This clearly reflects to the social and economic outcome. People even after having the best service in terms of the assistive technology they own, were not utilizing it and were compromising on their comfort and their capabilities. This could be a reason that there is still a stigma attached to the persons with disabilities. Though a person with amputation can go back to normal life when fitted with a good prosthesis but when the person fails to use it, they fail in being a complete member of the society. It is still a wonder for people in lower middle income countries to see a person wearing a prosthesis and carrying out the daily life independently. This is indicative of the dire need of awareness raising and making the intervention more useful.

Need of the hour

It would be necessary to work with the users to find a way to raise awareness on increasing the uptake, awareness and utilization of the intervention. Success stories would set out positive examples. Involving a user throughout the process of ideation, development, launch, strategizing, awareness building, and rehabilitation through an intervention is necessary.

Paying vigorous attention towards bridging the knowledge gap between what is available and known is as important as developing new technologies. Making the existing technologies available and accessible for anyone who need it would fill in a lot of void in the field of assistive technology and rehabilitation. Mapping the points of intervening for knowledge transfer and channeling the information through a systematic process is essential. Mass communication along with targeted, clear, concise, correct, coherent, complete and courteous communication is the key along with other approaches.

CONCLUSION

Even after six years of Sustainable Developmental Goals (SDGs), we have not progressed much on inclusion of persons with disabilities on various aspects. The field of assistive technology is blooming with interventions to support persons with disabilities relapse to socially acceptable complete life. But even today there are districts which has no rehabilitation centers is an important thing to be addressed. With the rise in expenses of treatments, absence of any social security schemes and insurance, lack of knowledge and awareness potential AT users are still not utilizing the interventions. Structural changes without understanding the barriers in utilization will lead to non or under-utilization of such facilities.

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