

Limitations for effective health care among a group of South Asian deaf students and strategies adopted by them to overcome these limitations

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Abstract

Introduction: In spite of modern world advancements the deaf community still faces numerous problems. In this pilot study we assessed the limitations to effective medicine use in a group of deaf and mute teenage students and strategies adopted by them to overcome limitations.

Objectives:

- Study their general health status
- Study requirements for medical care among them
- Identify limitations faced by them at medical consultations and at the pharmacy.
- Identify limitations to effective administration of medicine.
- Identify the coping strategies adopted by them to overcome limitations.

Methodology: A descriptive cross sectional study was carried out at a specialized school for hearing disabled students in Sri Lanka. 44 deaf students in the 14-19 year age group were studied. An interviewer administered questionnaire was used for data collection.

Results: Their literacy was considerably low. They experienced communication difficulties at the pharmacy and had problems during drug administration. Various strategies were adopted by them to overcome these limitations.

Conclusions and recommendations: The participants had difficulties in obtaining effective health care and use of medicines. In order to provide better standards of care for the hearing disabled students it is essential to take measures to overcome the discovered limitations.

Keywords: Deaf, sign language, interpreters, consultations, pharmacy, limitations

Introduction

Deaf and mute people represent a significant proportion of the world's population. According to the WHO statistics 360 million people suffer from hearing impairment worldwide.

Despite advancements in technology, facilities, and services the Deaf population faces various problems in day to day life. The social image of deafness is still poor in many countries due to the deeply rooted stigma, (Loew et al, 1998) stereotypes,

(Cambra,1996) and prejudiced attitudes toward the deaf.(Cumming and Rodda,1989) The need of medical care is found to be higher in the deaf community compared to the normal population, (Klein, 1982) thus medical care is an important aspect in their day to day life.

People who have congenital deafness or acquire deafness during infancy or early childhood do not accept deafness to be a disability. They regard themselves as belonging to a separate community and communicate primarily by sign language. Poor understanding and awareness in society regarding these socio-cultural requirements of the hearing disabled and how to communicate with them have unfavorably influenced medical, legal, and educational policies for the deaf. (Munoz-Baell and Ruiz, 2000)

Only few studies have been conducted internationally on limitations towards health care among the deaf population and these are mostly from developed countries where the quality of life and services for the disabled is comparatively better. Available evidence suggests that despite modern assistive technologies hearing disabled residing even in the developed world face difficulties and have limitations in this regard. Situation of hearing disabled persons, living in developing countries, is largely unknown and is a neglected area of research impeding the provision of effective and satisfactory health care for this community.

This study which focused on limitations to effective use of medicine among students in a school for the deaf and strategies adopted by themselves to overcome the limitations was an attempt to develop some insight regarding this neglected area. The objectives of the study were to identify types of medical problems faced by them, the current level of medicine use, their limitations to medicines use and strategies adopted by them to overcome these.

To make medical consultations effective and to provide good medical care to the deaf, health care professionals should be aware of the problems faced by the hearing disabled in the health care system. There is limited research data especially in the South East Asian region in this regard. This pilot study was planned to develop some insight regarding the matter to facilitate planning of future studies and methods to overcome the identified limitations.

Methodology

A descriptive cross sectional study was conducted at the school for the Hearing Disabled, Ratmalana, Sri Lanka. Hearing disabled students from most areas of Sri Lanka attended this special school.

Ethical clearance by the Ethical Review Committee of the Faculty of Medicine, University of Colombo was obtained to conduct the research. Permission was obtained from the Ministry of Social services and the principal and staff of the said school. Permission and consent was obtained from the legal guardian in case of students who were minors and in such instances the informed assent to participate was obtained from the students. Consent was taken from all other participants. The communication between the participants and researchers for the consenting process was mediated through sign language interpreters at the school.

The study population comprised students attending this specialized school for the hearing disabled above the age of 14 years. Since the study population was restricted in numbers all consenting students from this setting who fulfilled the inclusion criteria and gave assent or consent to participate were taken as the study sample. One such student was considered as a study unit. Mentally retarded students and those below the age of 14 years were excluded from the study.

The study instrument was an interviewer administered questionnaire. Since the

investigators were limited in their ability to use sign language, communication and filling of the questionnaire was assisted by sign language interpreters. A teacher of the students was present throughout the interview and also assisted in communicating with students.

Personal information such as name, age, and address was not taken. Data collection sheets were kept under lock and key. Information entered into computers for statistical analysis only contained a serial number. Privacy, confidentiality and anonymity of the participants were ensured by the above procedures.

Results

Of the 44 students included in the study 37 students (84.1%) were deaf since birth. 7 students have developed auditory impairment later. None of the students had useful hearing. 8 students (18.2%) had very poor speech ability that was limited to a few words and simple sentences. The rest were unable to produce coherent speech. 40 students (90.9%) were prone to frequent illnesses such as fever, cold and cough, mainly due to respiratory tract infections. One student had bronchial asthma.

Utilization of health care

Most of them got primary contact care from general practitioners (GP). Students were taken to the government hospitals if the general practitioner recommended it. 21 of the 44 students were treated by a GP for the last illness experienced by them and 5 were treated at government hospitals.

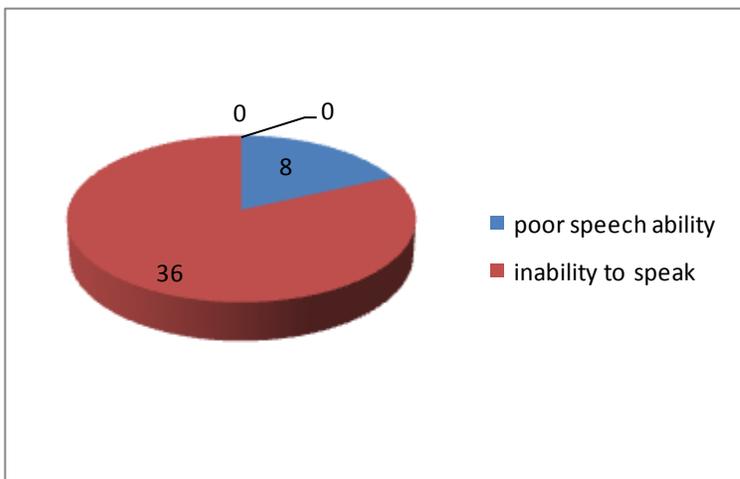


Fig 1: Speaking ability of the study population (deaf students).

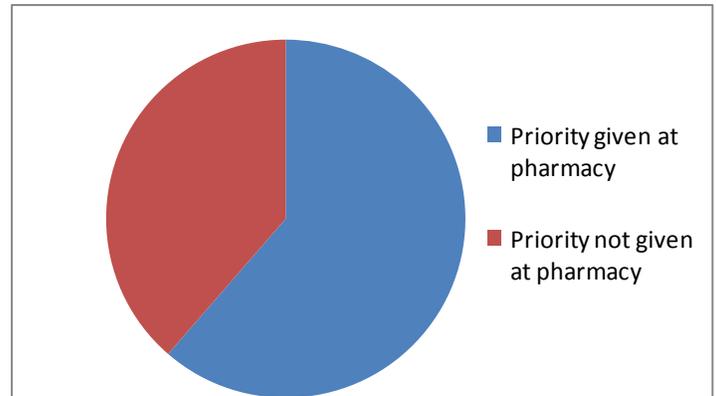


Fig 2: Priority at pharmacy.

Table 1: Utilization of health care facilities in last 27 cases of illness.

Mode of treatment	Number
Treated by general practitioner	21
Treated at government hospital as out patient	5
Hospital admission	1

Table 2: Strategies adopted when self-consuming medication by the nine students who handled drug consumption on their own.

Strategies adopted by deaf students when self-administering drugs	Number of students
Using different coloured containers to store drugs	2
Using their reading ability	7

They were reluctant to go to see doctors.

All of them stated that they were unable to communicate with the medical practitioners. Therefore they had to be always accompanied by people who knew sign language. They were reluctant to visit doctors due to the communication difficulties they had.

While waiting to see the doctor.

The staff at the out patient departments of hospitals and doctors private practices seemed unaware of the difficulties they had and did not provide any special assistance to book appointments or to tell them their position in the queue to enter the doctor's room.

Difficulties in communicating with doctors.

None of the medical practitioners who had seen these students could communicate with them directly. Translators were invaluable to enable proper communication with the doctor and other health care personnel providing medical care. They all conveyed details of the illness to the doctors with the help of the translators and using body language. All the medicine information was given to the translator to be conveyed to the student. Whenever a single translator took more than one student to see the doctor there was a high chance of confusion especially with complicated treatment regimens.

Because of the disability, a longer time seemed to be taken for the medical consultation especially because all the communication had to be relayed through the sign language translator.

Difficulties at the pharmacies.

The support and care received by the deaf students at the pharmacies were generally poor. 17 students (38.6%) were not given any special assistance at the pharmacies whereas 27 (61.4%) received such assistance by the pharmacist. Probably this would have been caused due to the fact that the

pharmacists were unaware of their disability at a glance. The deaf students preferred to visit the same pharmacy, where the staff was aware of their disability. The pharmacists were unable to convey the drug information to the deaf students and the interpreter was essential in the communication. As all of them were accompanied by the caregivers, information was provided to the caregivers and not the patients. Because of poor written language skills they were not able to identify the drugs by the name. Disability also prevented them from clarifying any instruction that was not clear.

Consuming medications: problems and strategies

Due to lack of written language skills all found it difficult to differentiate the drugs by name. They had tried to remember the drug name by how it appeared on the package (size and colour of fonts etc.) but due to various drugs with different trade names being prescribed and most drugs being dispensed in envelopes of the same colour and size this also had proved unsuccessful. The correct way of using various drugs was difficult to learn.

Drug administration of the students while at the institution was supervised and handled by the caretakers as the students were unable to handle drug administration on their own.

Nine students had self administered drugs while at home whereas the others were helped by parents and relatives. Two of the students who had self administered medicines used different coloured containers to store drugs and memorized the drug regimes. The other seven students claimed to be using their reading ability to identify instructions provided on the drug packages and use the drugs accordingly. Though they were able to read numbers most of them did not perceive simple instructions given on drug packages such as 'to be taken before or after meals' Probing more into the drug administration of these 7 students we noticed that 4 of them perceived the

information wrong leading to wrong doses and dosage frequencies.

Method of communication- sign language.

Sign language was their primary method of communication. Sign language interpreter assistance was necessary for the investigators to communicate with them. Several limitations and difficulties were identified during this method of communication. It lacked signs for certain terms. For example headache and fever were both expressed in the same way. Furthermore sign language used by the different students was different leading to confusion at time even among the sign language interpreters.

Doctors are likely to be unaware of the difficulties the hearing disabled students have in using the written languages used by the hearing community. Therefore they may try to use written information and instructions to communicate with their Deaf patients. During the study we noticed that their literacy was at a very low level. Due to their lack of hearing, teachers of the institution found it very difficult to teach them normal written language. Their level of reading even at advanced level classes was around that of a main stream school grade 1 or 2 student.

Discussion

This pilot study has brought to light that the hearing disabled students had several limitations and difficulties in accessing healthcare effectively. The strategies adopted by them to overcome these limitations were few and inadequate.

The study population has very low speech development with a limited vocabulary of few words so that communication was done via sign language. Their literacy skills were quite low that almost all of them found it difficult to understand simple written language. These findings were somewhat similar to those obtained from research conducted in the developed world, where

literacy skills were found to be lower than that of the normal population. (Musselman, 2000)

Medical professionals are likely to think that the deaf people could read written language and be unaware of their inability to understand a prescribed simple drug regimen.

The participants were always accompanied by caregivers. The participants of our study were totally incapable of making the doctors perceive their problem without an interpreter in sign language and satisfaction on medical care was noted in the presence of competent interpreters. This fact has been confirmed by several researches worldwide (MacKinney et al, 1995) while in our study interpreter assistance has shown a stronger correlation with the level of satisfaction than in other researches. Our study group being an adolescent population was always accompanied by a caregiver who knew sign language. This could have contributed to this observation.

All of them confirmed the necessity of interpreter assistance at the pharmacy. However in spite of the presence of a competent interpreter; nearly one third had barriers in understanding information provided.

Most students were given their medication by caregivers of the institute or by parents. Difficulties were faced when identifying drug types. Availability of translators, various dosage forms of different appearances, various colored tablets, and capsules eased this difficulty to a certain extent at times but lead to confusion at other times.

Communication problems were a barrier when assessing the deaf population. The low literacy of the population warranted the need of interpreters for them to understand and respond to the questionnaire. This limited the information gathered from the deaf population. Bias would have occurred when the same interpreter was interviewing multiple subjects.

Strategies adopted by patients in order to overcome the limitations such as using colour coded systems and handing administration with their limited reading ability were not always effective.. This field needs further exploration in order to identify and evaluate strategies, identify wrong practices and substitute them by better strategies which are currently being practiced in other countries such as container systems, pill boxes, and pictorial drug information systems.

In order to attend to this deficiency another study conducted was conducted in Sri Lanka on developing a pictorial labeling system locally for the deaf population. This study showed that medicinal instructions could be effectively given to hearing disabled persons using pictograms and visual sequence maps. They showed high preference for using pictograms in the said study.

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