

Review article

**Overcoming challenges to medicines use by visually disabled patients in Sri Lanka: A review of pioneering local research and the international trends**

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**Abstract**

Using medicines safely and effectively is a challenge to visually disabled patients. Some lived separately without assistance of sighted relatives and needed to self-administer medicines. Some of them needed to give medicines to their children or sick relatives. Several studies abroad and pioneering studies in Sri Lanka have revealed poor medication adherence, medicine use related problems and mishaps in them.

There were 3 main challenges to medicine use by visually-disabled patients identified by Sri Lankan and overseas studies

- Environmental and physical barriers in the general practice (GP) settings, clinics, hospitals and pharmacies.
- Poor access to information regarding the medicines they used.
- Difficulties in self-administration of medicines.

Health professionals should be aware of these challenges and help them overcome them by developing the necessary knowledge, skills, and attitudes in this regard.

The methods to enable the visually disabled patients to take medicines discussed and reported in this article have a special emphasis on resource poor settings such as Sri Lanka and are based on or supported by pioneering research in this field in Sri Lanka lead by the author of this paper.

**Prevalence of visual impairment globally and in Sri Lanka**

According to World health Organization, 285 million people have visual impairment worldwide; of them 90% are living in low income countries.<sup>1</sup> Vision 2020 Sri Lanka estimates that the prevalence of visual disability in Sri Lanka is around 0.5 % of the population but the statistics are incomplete and scanty.<sup>2</sup> According to 2001 census covering 18 districts excluding the Northern Province, 41 per 10 000 population had visual disability. If statistics from 30 year war affected Northern Province were also included the prevalence rates may be much higher.<sup>3</sup> Several studies done in different parts of the country in different groups from time to time gives a glimpse into the matter. Visual impairment in elderly (above 50 years) was 22.5 per 10 000 population; prevalence increased sharply above 75 years.<sup>4</sup> The prevalence of visual impairment of either eye was 24.3% in fishermen in a study done in year 2011 in Divisional Secretariat Division of Kalpitiya.<sup>5</sup>

**Challenges for visually disabled patients in using medicine**

Using medicines safely and effectively is a challenge to visually disabled patients. Several studies done abroad and those done for the first time in Sri Lanka by us over the past few years<sup>6,7</sup> have revealed that blind people and partially sighted people needed to use medicines like their sighted counterparts and sometimes even more for conditions such as epilepsy and eye conditions. They fell sick with

communicable and non-communicable diseases, acute and chronic similar to the general public.<sup>6,7,8,9,10,11</sup>

In a Sri Lankan study conducted by us,<sup>6</sup> the participants stated that they needed to take medicines at least once a month for conditions such as colds and coughs. 27.8% of them had chronic diseases. Seven % of them had epilepsy. Five % had asthma. Even though these patients required long term treatment for their health conditions there were significant gaps in their knowledge regarding their diseases and medicines. The epileptics had poor understanding regarding epilepsy and need for using antiepileptic drugs long term. The majority of the asthmatics on asthma inhalers had incorrect inhaler technique.

Another Sri Lankan study by us disclosed that some of them lived separately without the assistance of sighted relatives and needed to self-administer medicines. Some blind women needed to use medicines to prevent and treat conditions related or unrelated to their pregnancies. Some needed to give medicines to their children. They were affected by age related disorders for which they needed medicines. As a result they needed to use medicines throughout their lives just like others.<sup>7</sup>

There were 3 main challenges to medicine use by visually-disabled patients identified by Sri Lankan studies.<sup>6,7</sup>

- Environmental and physical barriers they faced in the general practice (GP) settings, clinics, hospitals and pharmacies.
- Poor access to information regarding the medicines they used.
- Barriers in self-administration of medicines.

#### **Strategies to overcome the challenges to medicine use by visually disabled patients**

##### **How to overcome environmental and physical barriers**

The local studies have disclosed that visually

disabled patients were reluctant to come to healthcare settings. Travelling, finding their way and access to the healthcare settings, stairs, counters, crowds, queues, and accessing support staff such as receptionists, attendants and nurses were major environment and physical barriers to them.

To help them overcome environmental and physical barriers in the healthcare settings, the health professionals, other staff and public should develop a caring attitude, awareness and ability to assist them. Educational programs should be conducted for health professionals as well as the public to update their knowledge regarding these matters. Several study participants stated that they were neglected at different healthcare settings; for instance they missed their turn to see doctors, obtain medicines at pharmacies and had to wait long hours because other patients overtook them in the queues. The staff at the healthcare settings were wage and unskilled in directing and guiding them resulting in difficulty overcoming environmental and physical barriers. Therefore, it is important to be specific and caring when giving directions to a visually disabled patient.<sup>12,13,14</sup>

**Challenges in communicating with a doctor or pharmacist:** Some participants in the study<sup>6</sup> stated that when they were accompanied by a caregiver most of the time the conversation ensued between the health professional and the caregiver completely ignoring the patient. They stated this situation to be frustrating and disappointing. Therefore doctors and pharmacists should speak with the patient. He should be addressed by name. The health professional should identify himself as well. During the conversation he should attempt to stay in one place as it is hard for a blind person to locate a speaker who is constantly moving around.<sup>13,14</sup>

##### **How to improve access to medicines information**

The studies conducted by us<sup>6,7</sup> disclosed that visually disabled required specific and general medicine information regarding the medicines



they used and strategies to overcome barriers in self-administration of medicines. Doctors, pharmacists and caregivers were their preferred and accessible sources to obtain information on medicines they used. However, some of them thought that the pharmacists were not reliable sources to obtain medicine related information: They thought that pharmacists were more conversant in dispensing medicines than giving medicines information.<sup>15,16,17,18</sup>

**Methods to deliver information and instructions on medicines:** Because of the wide range of visual impairments in individual patients it is important to have several options available to deliver information adequately. Some may be able to recognize colours while some others may be able to read larger font sizes. Some may be totally blind,<sup>12</sup>

#### **Verbal communication**

This is a main method of communication with a visually disabled patient. Some other methods include giving information leaflets in larger font sizes, recording information, emailing information, providing information in Braille and writing on the palm (in the case of some deaf blind patients).

Verbalizing information and instructions on medicines prescribed, such as the dosage, and what it is for is important. If the person is with a companion, the health professional should give instructions to him only when absolutely necessary. The conversation, questions and comments should be directly with the patient.

#### **Using larger print and magnifying the print**

If the patient can read larger print the following options are suitable.

- Correcting his vision as much as possible with spectacles.
- Printing information using large print such as 16, 18, 20, and 22 point Arial bold font.
- Using a photocopier to enlarge existing information leaflets.
- Instructing him to use a large sheet magnifier to read instructions.

#### **Recording information**

Recording information to an audio tape, an audio CD or data carrier can be done depending on a patient's choice and computer skills. Some of the local study participants had access to these and knew how to use them.

#### **Sending medicines information by email**

This is another option for those who have the facility. Some vision impaired computer users have software that turns text into speech or Braille that allows easy text enlargement on the computer.

#### **Digital assistive information technology (DAISY)**

The studies we conducted<sup>6,18</sup> have disclosed that visually disabled students at special schools for the visually disabled and at higher education institutes were computer literate and knew how to use special software such as digital assistive information technology (DAISY) to access information.

#### **Braille**

Some patients use Braille. Therefore information leaflets can be provided in Braille medium. Such printing facilities are available at the Sri Lanka Council for the Blind, University of Colombo etc. Brail track tactile communicator is a device that contains Braille and raised character alphabet and numerals that are used by visually disabled persons.

In Sri Lanka most patients cannot read English Braille. Therefore translating prescription labels and product information leaflets to English Braille is of very limited use. Some of them use Sinhala Braille whereas others use Tamil Braille. Some have not learnt how to use Braille. Health professionals should be aware of this. Medicine labels in English Braille available at some leading local pharmacies are not useful for most Sri Lankan visually disabled patients. It should also be borne in mind when printing medicine information labels that the quality of the paper matters. Embossed Braille dots printed on poor quality paper can detach

from the label with repetitive fingering over it and lead to wrong instructions being conveyed regarding the dose, frequency, etc. Furthermore, Braille labels are quite large and may not fit into the front side of a medicine container. When the label ran into different sides of the container they found it difficult to understand the meaning conveyed.

### Medicine help line

Participants of our studies<sup>18</sup> liked to receive continued medicines information and instructions from the doctor by phone as and when necessary. They also listened to the radio and television. Therefore, medicine related targeted information can be provided by these media.

### How to overcome barriers to self-administration of medicines

With vision loss there are many challenges to using medicines. Local studies have brought to light that they had difficulty remembering the instructions given by the doctors and pharmacists on taking medicines, remembering the timing of doses, reading prescription labels and information sheets, identifying individual medicine containers, distinguishing medications, and measuring and taking correct dose of a medication. They tried to overcome these limitations by self-adopted coping strategies some of which were unsuitable and were even a threat to their health.<sup>6,7,8</sup>

There are several methods and devices in the developed world that help patients with visual impairment take medicines safely and effectively.<sup>12,19,20,21</sup> Most of these devices are not available and affordable to visually impaired patients living in the developing countries.

To remind the time to take medicines they should be encouraged to use a talking wrist watch. These are provided by Sri Lanka council for the blind and other charity organizations. There are other portable reminding devices that are more advanced and can record time, dose, and frequency of taking medicines with alarm systems;

however only few patients had access to them. To enable patients to read prescription labels and information sheets, instruct them to use a magnifier or provide prescription labels and information sheets in Braille. Talking labels providing guidance in identifying and taking medications; these could be attached to standard medication packaging and are available in the developed countries but are not a cost effective option for our patients at present.

To overcome some of the above mentioned difficulties in self-administering medicines and to enable visually disabled persons to identify individual medicine containers and to aid them take the correct medication in the correct dose and frequency we have researched several assistive devices in the local setting. Containers with different shapes, sizes and textures were recognized by the participants with ease. Color coded rings and caps helped differentiate medicine containers by partially sighted participants. We studied several medicine containers providing instructions on taking medicines via tactile clues. The different containers studied; almost all the patients were able to understand the information provided via the container in Figure 1. The main advantages of these containers are the simplicity of their design and the ability to prepare using low cost material readily available at home. Therefore they would be advantageous for resource poor settings.<sup>22</sup>

In Figure 1, the three elastic bands around the container indicate morning, mid-day and night from the lid end of the container respectively. The number of buttons stitched to the bands indicates the number of tablets to be taken at each time. For example, in this illustration one tablet should be taken in the morning, two tablets at mid-day and one tablet at night.

Dropping, spilling and loosing medicines during oral administration was an issue for most of them. To help remove pills from blister packs without dropping, assistive devices such as pill extractors, pill pop out,



pill punch out, magnifying pill splitter etc are available in developed world but are not readily available to our patients.



Figure 1

Automatic pill dispensers that release the correct pills in the correct dose are also available elsewhere but are relatively expensive. In the local setting to overcome this difficulty patients should be instructed to sit at a table and to keep their pill boxes on a tray with raised edges. They should open the lids and take pills out holding the container over the tray.

Measuring liquid medicines were also a great challenge as disclosed by our study participants. They needed to measure liquid medications especially for their children. Tactile measuring devices and non-spill measuring devices used in some countries recommended for visually disabled patients are not available for our patients.

For resource poor settings such as our country to measure small amounts of liquid without spilling, patient should be educated to store the medicine in a container with a wide mouth. The container should be placed on a tray when measuring the liquid. A measuring syringe or dropper with the correct volume to be measured should be used.

## Conclusion

Local studies done by the authors of this article and international studies indicate that there were many challenges to medicines use in the visually disabled patients. There are many

deficiencies in the Sri Lankan health care system that should be addressed to enable these patients to use medicines safely and effectively.

**Recommendations and way forward:** Further studies should be undertaken to explore their difficulties and challenges. The health professionals should develop an active interest to improve the situation in Sri Lanka regarding visually disabled patients. The government policies and acts should consider about this population to facilitate the process. The patients and the caregivers should be actively involved in the process towards developing a better system.

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