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Impact of vision impairment and self-reported barriers to vision care: The views of elders in Nuwara Eliya district, Sri Lanka

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ABSTRACT

The growing burden of vision impairment (VI) among older people is a development challenge in Asian countries. This study aimed to understand older people's views and experiences about the impact of VI and barriers to eye care to inform policies to address this challenge. We conducted 12 focus group discussions in 2013 with retired Tamil and Sinhala elders in Nuwara Eliya district, Sri Lanka ($n = 107$). Data were analysed thematically. Older people described the broad impacts VI has on their lives. They worry about becoming dependent. VI restricts their ability to contribute to their families and communities, access information, socialise, maintain their health, and earn. Barriers to eye care services include transport difficulties, costs of treatment, fear, lack of knowledge, waiting times, and health staff attitudes. Older people experience and fear the impacts of VI on their health and well-being. Eye health promotion and care services need strengthening and integration with the primary health care system to address the backlog and growing need among older people in an equitable way. Older people should be consulted about how to overcome the economic, social, and cultural barriers to access to eye care and to minimise the impact of VI.

ABBREVIATIONS: FGDs: focus group discussions; GBD: global burden of disease; NCDs: non-communicable diseases; VI: vision impairment

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Vision impairment; eye health services; ageing; cataract surgery; Sri Lanka

Introduction

The growing burden of vision impairment (VI) among older people is a development challenge in low and lower middle-income countries in Asia (Prince et al., 2015). Older people make significant social and economic contributions to their families and communities, but this is undermined when they are unable to see well.

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Impaired vision is common among older people. In South Asia in 2010, 24% of those over 50 years were estimated to have moderate or severe VI, and 4.4% were blind (Jonas et al., 2014). Women are at greater risk than men. In Sri Lanka, 4.3% of those over 60 years were estimated to be blind in a recent national survey (Vision 2020 Secretariat, Ministry of Health, Sri Lanka, 2016). Most VI and blindness is due to cataract or refractive error and can be cost-effectively treated with cataract surgery or spectacles (Baltussen & Smith, 2012; Bourne et al., 2013). However, cataract surgery coverage remains low among older people, especially in rural areas, and for women (Lewallen, Mousa, Bassett, & Courtright, 2009; Rao, Khanna, & Payal, 2011; Vision 2020 Secretariat, Ministry of Health, Sri Lanka, 2016).

The impact of VI has been studied in developed countries, but there is a lack of information about impact in low and middle-income countries. The impacts of VI are likely to be different where older people are poor and lack access to spectacles and other vision services, and have higher rates of disability.

Preventable VI in Asia is expected to increase, as a result of both rapid population ageing and the increase in non-communicable diseases (NCDs), unless services improve in reach, equity, and quality (Jonas et al., 2014). In Sri Lanka, currently 12.3% of the population is 60 years or over (Department of Census and Statistics, Sri Lanka, 2012), and this is predicted to rise to 28.5% by 2050 (World Bank, 2008). The prevalence of diabetes and hypertension, which have ocular complications, is also increasing rapidly (Jayawardena et al., 2012).

The views of those most directly affected can help to inform policies and plans regarding the allocation of resources, encouragement to elders to seek vision care, and strengthening of equitable eye health care systems (Ramke et al., 2014). During focus group discussions (FGDs) for the Better Vision Healthy Ageing Program in the Nuwara Eliya district of Sri Lanka, we explored the impact of poor vision in old age, the barriers older people face in accessing vision care services, and their suggestions to overcome these.

Method

Setting

We conducted the study in the Walapane and Nuwara Eliya administrative divisions of Nuwara Eliya district between July and September 2013. This district, one of the poorest, is damp and hilly. Of the population of 711,644, 40% are Sinhalese, and 53% are Tamil (Department of Census and Statistics, Sri Lanka, 2012), brought by the British from India to work on the tea estates in the nineteenth and early twentieth centuries.

Participants

We conducted 12 FGDs with a total of 107 elders in groups of 8–12. Half the FGDs were with Tamil retired tea estate workers, living in estate communities. Participants in the other six FGDs were Sinhala retired farmers, living in rural village communities. Selection criteria for each group were that participants should speak the same language, include a range of ages over 60 years, and both married and widowed elders. VI was not one of the selection criteria. The elders were contacted through local government officers for the villages and through Estate Medical Assistants for the estate divisions. Table 1 shows the characteristics of the participants.

Table 1. Characteristics of focus group discussion participants.

FGD	Number in group	Ethnicity	Community type	Sex		Age group			
						60–64	65–69	70–74	75–80
1	8	Sinhala	Rural village	Female		2	3	2	1
2	9	Sinhala	Rural village	Male		2	3	3	1
3	10	Sinhala	Rural village	Mixed		3	4	2	1
4	8	Sinhala	Rural village	Female		3	4	1	0
5	8	Sinhala	Rural village	Male		2	2	2	2
6	10	Sinhala	Rural village	Mixed		6	3	1	0
7	8	Tamil	Estate community	Female		5	3	0	0
8	8	Tamil	Estate community	Male		4	2	2	0
9	9	Tamil	Estate community	Mixed		6	2	1	0
10	9	Tamil	Estate community	Female		5	3	1	0
11	8	Tamil	Estate community	Male		6	1	1	0
12	12	Tamil	Estate community	Mixed		7	3	1	1
Total	107			M54	F54	51	33	15	6

Data collection

A comprehensive question guide about health and well-being was developed based on review of the literature. This included questions about the impact of VI and barriers to accessing eye care services. The experienced local team refined the guide during the workshop to ensure that the questions were appropriate and relevant to the local context. These were translated into Tamil and Sinhala.

The FGDs took place in community venues such as the temple, dispensary, or village hall, or in the home of an elder. Gender may influence discussion dynamics so we conducted four groups with only women, four with only men, and four were mixed. The FGDs lasted about one hour (range 45–80 minutes).

Each group had a facilitator and a note-taker. The FGDs were audio taped with participants' permission. The facilitators were the four Program Officers (community development workers) and two field staff of the Better Vision Healthy Ageing Program, who spoke the same language as the participants. They took part in a two-day training and planning workshop.

Ethical considerations

The elders gave written informed consent to participate and the facilitators were trained to advise the participants that the discussion would be confidential and to request them not to talk about what was discussed with non-participants.

No compensation was provided but the elders were given refreshments and a Certificate of Thanks for taking part. They were treated with respect and efforts made to ensure their comfort. Approval was obtained from the Ethics Review Committee, Faculty of Medicine, University of Peradeniya, and from the Alfred Hospital Research Ethics Review Committee in Melbourne.

Data analysis

The tapes were transcribed verbatim and translated into English. The data were analysed thematically with an inductive approach. First, three researchers discussed and organised

the data under themes and sub-themes that emerged from the data. Key findings were then summarised, and illustrated with verbatim quotes. Interpretations were checked with the FGD facilitators.

Results

Impact of vision impairment

When discussing health, many elders emphasised the great significance of good vision:

We need vision to do anything. It is useless to live without vision. Vision is the most important thing in life. [Sinhala woman]

My visible God is the eye. [Tamil man]

They noted the impact of poor vision and their lack of spectacles on all aspects of life:

From traveling to having meals there will be problems. [Tamil man]

Even to go to a temple we need spectacles, and to do everything we need spectacles. [Sinhala woman]

When discussing the impact of VI these elders often talked in terms of emotions:

It is a sorrow. [Sinhala woman]

If we can see everything well that will bring happiness. [Tamil man]

Dependency

Both older men and women often described the impact of their vision loss on their family and neighbours, and feared becoming dependent on others:

If we don't have good vision we have to depend on others; it is a disturbance for them too. [Sinhala woman]

Several worried about what would happen if they became dependent:

We need vision to do our own work. If we don't have vision no one will take care of us. [Tamil woman]

If we can't see, the people in the house will help us for some time – but will become frustrated. [Tamil man]

Restricted lives

Both Tamil and Sinhala elders with poor vision described the many ways that their lives become restricted.

If we have vision it is a best thing, it is a pleasure and strength for us. It is the most important thing. We can go here and there. We can read books. Now I can't walk even in day-time. [Sinhala man]

They often mentioned restrictions in carrying out domestic tasks, and their concern at the resulting inability to contribute to their families:

We can't cook. [Sinhala woman]

My grandchild goes to school and after that he asks my help to do his homework – ‘Dear Grandpa, I can't understand this, please teach me and please answer these questions, or the teacher will hit me’, when my grandchild says like that I wanted to teach him, but I can't see well because my vision is poor, so it shocked me, when I feel that I can't read or teach my grandchild. [Sinhala male]

Several referred to poor vision restricting their access to information:

If we don't have good vision then we will only know things from others. [Tamil woman]

Poor vision also restricts social participation and opportunities to contribute to the community:

In the night we can't go and meet our friends because of our vision problems. [Tamil man]

If we could see we could give support to social activities. [Sinhala man]

The elders' ability to earn an income is also restricted by poor sight:

We need vision to do our jobs. [Sinhala man]

Difficulty maintaining health

We heard how poor vision affects older people's ability to remain healthy and to manage chronic conditions. Inability to read reduces exposure to health promotion messages. They are more likely to spend time at home, resulting in greater exposure to smoke from the cooking fire, and to be less physically active. VI also increases difficulties in attending for health care and in buying and taking medicines:

We have to ask someone's support to attend clinics. [Sinhala woman]

If we don't have close vision we can't read instructions which we have been given with our medicine, then we can't use medicine properly. [Sinhala woman]

Some elders described injuring themselves after falling as a result of poor vision, and others talked about their fear of falling:

We may fall down when we walk on the road, and we may get hit by a vehicle. [Tamil man]

Figure 1 summarises the findings about impact of VI.

Barriers to accessing vision care services

Financial barriers

Elders talked most often about the costs of accessing care:

We have to spend a lot of money to buy a pair of spectacles or get our eyes checked or have surgery. We need money to go to a hospital – those are problems for us. [Sinhala woman]

Elders in most groups mentioned that lack of money to pay for transport prevents them attending hospital or clinics. Several elders also mentioned the cost of having someone to accompany them:

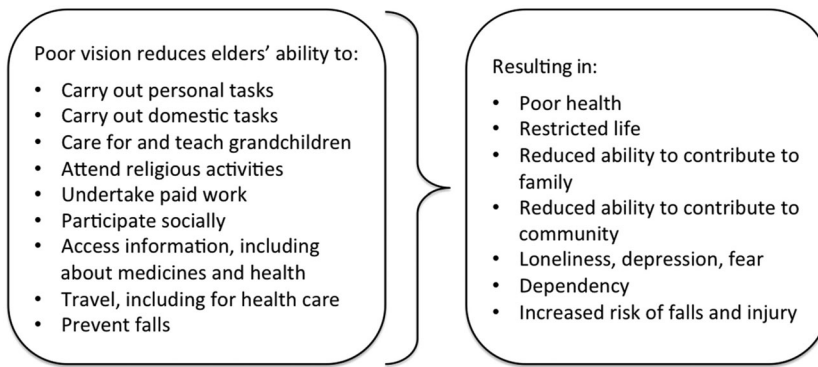


Figure 1. Summary of findings on the impacts of vision impairment for elders.

Someone needs to come with us to hospital. We have to spend a lot for two people, so we don't have enough money. Our children are also in an economically difficult situation. [Sinhala woman]

Elders reported that they have to pay for the intra-ocular lens, white clothes, and medicines when they have cataract surgery. None of the elders mentioned that poor elders can apply for a free lens from the Ministry of Social Services. Several elders mentioned that after having one cataract removed they cannot afford a second operation. Affording spectacles was a particular problem for some:

We can get a check up in the hospital but they will ask us to buy the spectacles in private shops. It is not a small amount – we may need 7,000, 8,000 rupees (US \$48, 55). [Tamil man]

Many elders undertake casual work to earn income; the time involved in travelling and attending the clinic is also an opportunity cost. Elders were reluctant to ask their adult children for financial help.

When we ask our children for money they tell us we'll give it to you tomorrow, and they borrow from someone else and give it to us. Therefore transport costs are very difficult. Adult children are helping them because they are the father and mother, but in some houses children ignore their parent's needs. [Tamil man]

Elders in all the Tamil groups asked for help with their vision problems because they cannot afford to seek care themselves.

Lack of knowledge

Both Tamil and Sinhala elders mentioned that they lacked information about seeking help for vision problems:

We don't know about those doctors and the places where we can get those services. And we don't have a way to get that information. [Sinhala woman]

We don't know anything about it. You are creating awareness. We understand little. We should know the right way. [Tamil man]

They also described not knowing how to obtain or use spectacles:

Doctors check us and recommend to buy from a particular shop. When we go to the shop the salesman look at that prescription and give the spectacles, but we don't know about the quality, and we don't know how to use it. They don't provide enough instructions to us. [Sinhala man]

It is important to raise awareness about eye care, and that assistance is available. The elders also wanted more information about preventing vision problems:

People don't know about eye health and how to protect their vision. In most TV programs also, they talk about high blood pressure, cancer, heart disease and asthma, but they don't talk about vision problems. [Sinhala man]

There should be a lot of opportunities or programs to make people aware about their eyes and eye health. [Sinhala man]

One elder mentioned a lack of confidence in the doctors, which may be based on a lack of understanding of the eye:

When we get older we get problems with our vision. When we show our eyes to the doctor they say you have good eyes but you may need to use spectacles. But we know we have a problem in our eyes. [Tamil man]

Some elders have a traditional belief that cataract is a punishment from God, '*poo viluthal*', which makes them less likely to seek treatment. Others conveyed the common belief that loss of vision is a natural part of ageing that cannot be helped:

Vision is decreasing. When we get old our vision will go down. Doctors will ask us to wear spectacles. When we get too old, operations will not be done. [Tamil man]

Transport problems

Lack of transport and difficulties in travelling on public transport were frequently mentioned barriers. These include cost, long waits for buses, inability to stand on the bus, and arriving late at the clinic.

When we go to hospital we have transport problems. We don't have enough buses to travel. We have two buses, which are very crowded. We have to stand, and we can't travel like that. [Sinhala woman]

Sometimes we get to the clinic too late and the doctors have gone so we have to come back. [Tamil woman]

Village elders often have greater access to buses than those living in the tea estates, but some reported that no one gives up their seat for them, and that bus conductors do not help them. Both older men and women mentioned their need to have someone with them when they travel as a barrier to seeking care:

There's no one to take me to hospital. [Sinhala woman]

I am afraid to go alone in the bus. [Tamil man]

Clinic waiting times and attitudes of health care providers

Elders in several groups reported their fear of crowds and long waiting times once they reach the clinic.

There is a huge crowd when we attend clinics. We have to wait in a big queue until we get our chance. It's very hard to stand in that queue. [Sinhala woman]

We have to be in a line to do the tests. Then to get the tablets we have to be in another line. By the time we finish and return home it will be 5 pm. [Tamil man]

We also heard that clinic nurses and doctors are not always respectful towards elders:

There are problems in screening – some medical officers make elders frightened. And officers should speak to elders in a kindly way. [Sinhala man]

Fear of surgery

Several elders mentioned that fear of surgery, or adult children's fear on their behalf, prevent them attending for examination or care:

Yes, earlier, elders were like that. They don't like to see these cuts and blood. Now this has changed, but still they get frightened. [Sinhala woman]

We believe in the doctors, but if we need to get consent from our children – they don't sign because they also fear about operations. [Sinhala man]

Hearing about unsuccessful cataract operations was mentioned as a cause of fearing surgery.

Elders' suggestions to improve access to eye care services

Several elders, especially those in tea estates, suggested that it would be helpful if services could be provided closer to their homes:

It is good if eye testing is done in the estates where we live. [Tamil man].

We can organise all the elders to come to one place and it is very easy for us, otherwise we can't get spectacles even if we go three or four times. [Sinhala woman]

Elders' Club meetings provide an opportunity for screening:

We can make a list of elders who are in need, through the Elders' Clubs, and we can inform those who are responsible for doing these services that there are this many numbers, you can come and conduct eye screening or eye clinic, then we can solve this problem.

The Better Vision Healthy Ageing Program has since selected and trained elder volunteers (Eye Health Promoters) in first stage visual acuity screening and they have successfully screened and referred their peers at the Elders' Clubs.

Discussion

There are few published studies that have used qualitative methods to explore the views of older people in low income settings in relation to vision loss. In 2012, Nyman et al. undertook a systematic review of 17 qualitative studies of emotional well-being and adjustment to vision loss in later life from the USA, Australia, and European countries (Nyman, Dibb, Victor, & Gosney, 2012).

Impact of vision impairment

Our findings show that these elders view loss of vision as having a major impact on health and well-being. A survey in Gampaha, Sri Lanka, found that elders with cataract had significantly worse quality of life (Nanayakkara, 2009), as did a study in Kenya, the Philippines, and Bangladesh (Polack et al., 2010). Reviews of studies in high income countries have shown a strong association between VI and depression among older people (Burmedi, Becker, Heyl, Wahl, & Himmelsbach, 2002; Nyman et al., 2012).

The elders often referred to the loss of ability to contribute to family and community, while Nyman et al. noted that in the high income country studies 'the most challenging aspect of vision loss appeared to be the consequent loss of independence' (2012). This may reflect the difference in proportion of elders who live with adult children in high and lower income countries. Prince et al. also noted the enormity of the societal cost of VI in old age (Prince et al., 2015).

The elders' accounts show that both near and distance vision problems restrict the lives of elders. We have found that community Elders' Clubs can reduce the social isolation of elders who cannot see well (Holmes & Joseph, 2011).

Falls are a major problem among older people, especially when cataract and glaucoma alter their depth perception, visual acuity, peripheral vision, and susceptibility to glare (Coleman et al., 2004). These also expose them to higher risk of pedestrian road traffic injuries; 44% of pedestrian casualties in Sri Lanka are over 60 years (Sri Lanka Police, 2011). It is important to reduce fall hazards in homes, to raise elders' awareness of road safety, and to tell drivers to take additional care with older pedestrians.

Our finding that these elders view the impact of vision loss as very severe is at odds with the impact assessments for the influential Global Burden of Disease (GBD) studies. There has been much debate about the recent reduction of the disability weighting (or impact) assigned to VI (Nord, 2013; Taylor et al., 2013). The early GBD studies determined weights for different conditions from the views of experts, while for the 2010 and 2013 studies, surveys were conducted with the public, predominantly in developed countries (Salomon et al., 2015). The result was a significant drop in the disability weight for blindness from 0.60 to 0.195 (2010), and 0.187 (2013), which in turn reduces the estimated burden of disability attributed to VI (Salomon et al., 2015). Although the method has been refined to include treatment for some conditions, the descriptions of VI did not mention availability of spectacles. The resulting weighting for presbyopia was very low (0.011); the respondents were unlikely to be aware that large numbers of poor, older people do not have access even to reading glasses (Holden et al., 2015). Our findings emphasise recommendations that countries undertake their own assessments of impact (Nord, 2015).

Barriers to accessing eye care services

The elders described barriers to seeking, reaching, and receiving eye care services that have implications for planning equitable provision of cataract surgery and spectacles (Figure 2). Although women are reported to have lower cataract surgery coverage rates (Lewallen et al., 2009), in this qualitative study, we heard similar barriers from both men and women.

Barriers to seeking eye care services

The decision to seek health care depends on perception of need and desire for care (Levesque, Harris, & Russell, 2013). Our findings suggest that many elders do not seek care because they anticipate poor vision as an inevitable part of ageing or fear surgery. A study in Kandy district, Sri Lanka, also found that many older adults with cataracts had not attended for care because they had no desire to improve vision, feared surgery, or lacked awareness (Athanasiov et al., 2009). These were also reasons why about half of older adults with cataracts in Kenya, Bangladesh, and the Philippines did not attend when offered free surgery (Syed et al., 2013). In a study in poor fishing communities in Karachi, Pakistan, 22% of those who said they had no vision problems were found to have significant VI, attributed to beliefs that visual loss is an inevitable part of ageing (Ahmad, Zwi, Tarantola, & Chaudhry, 2015). Education is important to emphasise that the common causes of poor vision in later life can be treated. Older people who have experienced successful cataract surgery can be trained and supported to inform and reassure their peers. Information materials should be prepared and provided to elders and their family members. Although cataract surgery outcomes are excellent in most countries, some settings do have high rates of poor vision outcomes, which contribute to fear of surgery (Farmer, Innes-Wong, Bergman-Hart, Casson, & Crompton, 2015; Shields et al., 2015). Efforts are needed to improve quality.

Barriers to reaching eye care services

Transport problems are difficult to overcome in remote areas. Strategies to reduce the cost of reaching eye care services might include arranging for groups of elders to have their vision screened in their communities. Estate management have a role to play in providing transport for retired workers. Elders are eligible for identity cards that entitle them to reduced bus fares, but many do not yet have them, and they are often not recognised

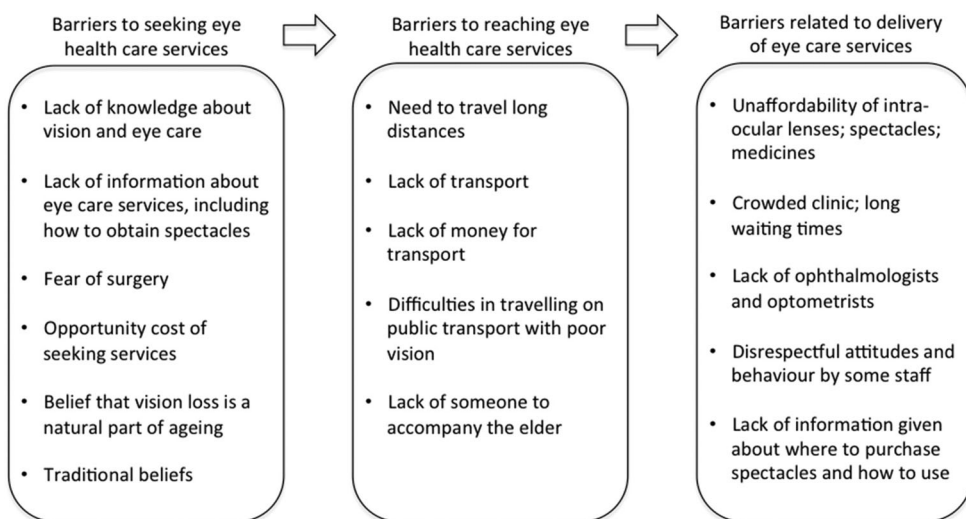


Figure 2. Summary of barriers to seeking, reaching, and receiving eye care services.

by bus conductors. Bus drivers and conductors could be trained to provide more help to elders, and a public education campaign could encourage younger people to give up their seats. There is a role for volunteers to assist or accompany elders; Elders' Clubs enable elders to organise to travel together for health care.

Barriers to receiving eye care services

The costs of eye health care services were a major barrier. Although health services are free in Sri Lanka, patients are often asked to pay for intra-ocular lenses and medicines. Publicity is needed to raise awareness of the availability of free intra-ocular lenses for poor elders from the government, and how to apply. New approaches are needed for the procurement and distribution of low cost distance vision spectacles. Provision of low cost reading glasses could be undertaken as an income generating activity by trained elders, because examination by an eye care professional is not required. The Sri Lanka National Vision (2020) programme has identified specific suppliers of spectacles and lenses and negotiated lower prices.

Eye care clinics should adopt new processes to reduce crowding and long waiting times, such as providing queue numbers, prioritising frail elders, and employing volunteers to manage crowds. Well-signed, accessible toilets make long waits easier and reassure those with incontinence. Role-play training for health care providers could help encourage respectful and friendly attitudes and address ageism. Community-based monitoring of health care services has been found to be an effective strategy to increase accountability of health care services (Nygqvist, de Walque, & Svensson, 2014).

In addition to the barriers described by these elders, Sri Lanka, like most low- and middle-income countries, lacks sufficient ophthalmologists and optometrists to meet the growing need (Holden et al., 2015).

For those who cannot be helped through cataract surgery or the provision of spectacles, low vision services and magnification devices are important, but have tended to focus more on children and young people than older people (Kempen, Ranchor, Ambergen, & Zijlstra, 2014; Liu, Brost, Horton, Kenyon, & Mears, 2013). Simple home modifications, such as hand-rails and white stones to mark pathways, can reduce falls (Jones, 2013).

Many of these older people feared losing their vision and were aware of the impacts. The desire to preserve vision could be a motivator to encourage individuals to prevent and better manage diabetes. Efforts to address NCDs, promote healthy and active ageing, and prevent and treat vision loss are not well integrated. Older people can be valuable advocates in raising awareness with policy makers and health officials.

The WHO report on tracking Universal Health Coverage recognises 'cataract surgical coverage' as a useful indicator of access to health care by older people (WHO, 2015). More efforts are needed to address inequitable access to eye care and the barriers faced by older people in rural areas. Ramke et al. (2014) provide a useful framework. Ageist attitudes remain a problem. The WHO 2014–2019 Global Action Plan for 'Universal Eye Health' emphasises 'Access for everyone, including the poor, minorities, indigenous peoples, persons with disabilities, women and those in rural areas', but age should be considered too (WHO, 2013). Monitoring data should be collected at hospital eye clinics and analysed by area of residence, age, and sex.

Strengths and limitations

A strength of the study was that it asked the views of a large sample of poor, rural older women and men, including retired estate workers, who have the highest risk of VI and the greatest difficulties in accessing care. The findings are relevant to several other areas of Sri Lanka, but may not be transferable to more urban settings. Vision was one of several topics explored in our study; we did not measure the visual acuity of the participants. Other qualitative studies have included only vision impaired participants (Nyman et al., 2012). Nevertheless, we found it useful to hear the range of views of a large sample of elders with a typical spectrum of visual acuity from those with diabetic retinopathy to those with presbyopia who lack reading glasses. Their views help to inform prevention as well as eye care interventions.

Conclusion

VI has many significant impacts on the health and well-being of older people, their families and communities. There is an enormous challenge for eye care services in addressing the backlog of need among older people and the growing increase in need, in an equitable way. Eye health promotion, care, and provision of spectacles need to be integrated with the primary health care system. Older people, and their family members, should be consulted about how to overcome the barriers to providing eye care and to minimise the impact of VI. These findings should help to inform interventions to improve equitable access to eye care services.

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