

RESEARCH PAPER

Access to low-vision rehabilitation services: barriers and enablers

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Background: The current mismatch between the need for and uptake of low-vision services has been attributed to various barriers including different service delivery models and referral pathways. This study evaluates the referral pathway and low-vision service provision of the Royal Society for the Blind (RSB) in South Australia.

Methods: All new referrals from the 2008–2009 financial year to the RSB were reviewed. Initially, patients were contacted by a triage officer within one week of referral. Initial appointments were made in the Low Vision Clinic with a multidisciplinary team. Reasons for declining the appointment or non-attendance were tracked via telephone.

Results: There were 1116 patients referred over a 12-month period and 1082 (97 per cent) were reviewed in the Low Vision Clinic. Most attendees (92 per cent) lived within 50 kilometres of the clinic. There were 34 referred patients, who declined or did not attend the assessment. All non-attendees also lived within 50 kilometres of the Low Vision Centre. Concurrent major health problems (27 per cent) and patients not feeling the need for low-vision rehabilitation (27 per cent) were the most common reasons for not accessing the service. Only 125 patients (11.6 per cent) accessed volunteer transport services and only 24 patients (2.2 per cent) needed an interpreter service.

Conclusion: The attendance rate is significantly higher than in other published studies. The distance to travel or transport difficulties were not significant barriers. Patient perception that either the service was not required or would not help them was the main barrier. The referral and triage process appeared to be a major enabler of low-vision service uptake.

Key words: barriers, enablers, low-vision services, referral pathway

Low vision is a state of visual impairment where refractive, medical or surgical treatment cannot improve vision. Low-vision rehabilitation involves making the most of a person's residual vision, specifically to try to overcome the visual disabilities that are most troublesome to them. Low-vision rehabilitation services can help enhance functional vision, potentially benefiting 90

per cent of patients with low vision.¹ These services significantly improve reading, access to information, emotional well-being and overall quality of life.^{2,3} The use of low-vision services has been shown to contribute to a decline in depressive symptoms.^{4,5}

Despite the many benefits of low-vision services, in Australia, fewer than one in

five patients with low vision accesses such services.⁶ The service uptake rate varies across the world three to 15 per cent.^{7–9} There is a clear mismatch between the need and the uptake of low-vision services. This has been attributed to a number of factors that occur at several levels. In some countries there is a limited availability of low-vision services or a lack of training in

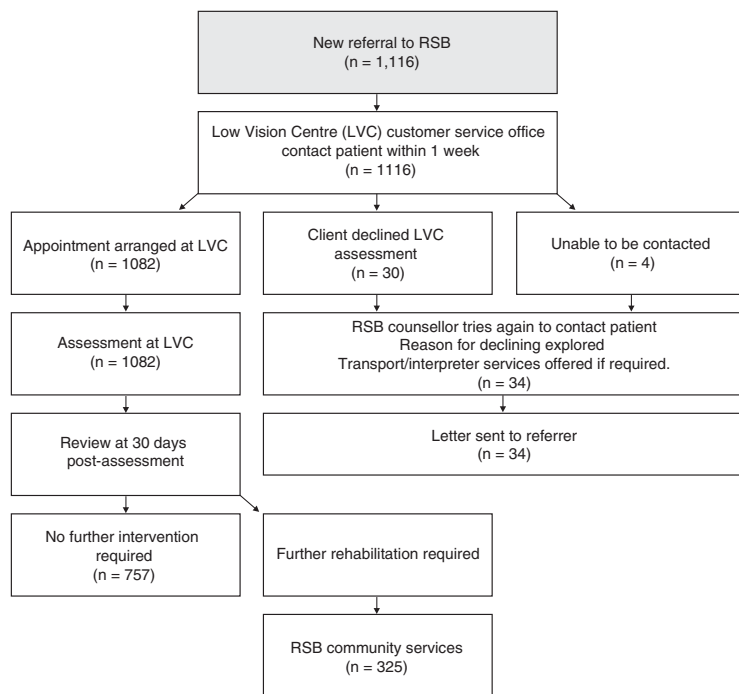


Figure 1. The Royal Society for the Blind of South Australia referral pathway flowchart

low-vision services.^{8,10} In developed countries, there may be an unequal distribution of services across urban and rural areas. At the referral level, lack of awareness of low-vision services from ophthalmologists and optometrists and a need for increased co-operation and referral between providers have been identified.¹¹ At the patient level, transport difficulties, language barriers and perceived ineffectiveness of vision rehabilitation may be barriers to accessing low-vision services.¹¹⁻¹⁴

Currently, low-vision rehabilitation is not provided within Australian public hospitals.^{15,16} Referral to low-vision services is usually provided by health care professionals to non-government (mostly non-profit) organisations. O'Connor and colleagues¹² suggested that different service delivery models may be a barrier to accessing low-vision services. Currently, the service delivery varies by state and individual organisation. For instance, some organisations rely on the patient to make the first contact with the low-vision service and failure of patients to follow up suggested referrals may contribute to the low access

to low-vision services.^{8,15} The range of services provided also differs, with some organisations offering low-vision clinics and some offering community services such as independent living training, employment and mobility training. It is estimated that only five to 10 per cent of people who could benefit from rehabilitation services are accessing the low-vision rehabilitation services.¹⁷ It is especially important to address this mismatch because there is a strong association between visual impairment, advancing age and an ageing population in Australia. The prevalence of visual impairment is expected to increase nationally, which will have significant economic implications and affect the provision of health and welfare services.¹⁸ Therefore, it is important to evaluate the pathway used by the Royal Society for the Blind to identify the barriers and enablers for the use of low-vision services.

The Royal Society for the Blind Inc. (RSB) in South Australia is one of two non-government organisations that provide low-vision rehabilitation in South

Australia and has a full range of community services, as well as the only multi-disciplinary Low Vision Clinic (LVC). This study reviews the referral pathway and tracks the patient journey for those referred to the RSB in South Australia to identify some of the barriers and enablers of access to low-vision rehabilitation services.

METHODS

Prospective reviews of all new referrals to the RSB of South Australia from 1 July 2008 to 30 June 2009 were included in the study.

To study the referral pathway, the patient journey was tracked. Referrals were made by an ophthalmologist or an optometrist. At the time of referral, this referral process involves the following stages (Figure 1):

1. Completing a referral form pro forma (Figure 2), which is faxed/posted to the RSB by the referrer.
2. The LVC customer service officer makes the first contact with the referred patient within one week of referral to organise an appointment at the LVC. Those who decline the LVC assessment are passed to a counsellor. The counsellor would help elicit reason(s) for declining, such as barriers like interpreters, transport and information on the benefit. The counsellor helps arrange interpreter and/or volunteer transport services, if required. The RSB writes to the referrer if a patient declines or is unable to attend.
3. If the customer service officer is unable to contact the patient the first time, a second attempt is made within one month of the initial referral. If, following two phone contacts, there is no response, a letter is sent to the patient. When there is no response following the two phone calls and the letter, it is recorded as unable to make contact.
4. The patient attends an initial appointment in the LVC with a multi-disciplinary team comprising an optometrist, an ophthalmologist and an occupational therapist/counsellor.

THE ROYAL SOCIETY FOR THE BLIND | Low Vision Centre

Referral Form

Name: Date of Birth:
 Address:
 Postcode: Telephone:

Ocular and Related Medical Condition

Diagnosis:
 Prognosis Stable Progressive
 Onset:
 Current Medications:
 Other Relevant Medical Conditions:

Current Visual Status (details of recent refraction within preceding 6 months)

Visual Acuity: Unaided Distance R _____ L _____
 Aided Distance _____
 Near _____

Present Glasses Sphere R _____ L _____
 Cylinder _____
 Axis _____
 Add _____

Present Refraction Sphere R _____ L _____
 Cylinder _____
 Axis _____
 Add _____

LEFT RIGHT

Indicate any visual field defect (if significant defect please enclose computerised field).

Comments:

Please either stamp or print Practitioner's name & address in full.
 Signed:
 Date:

FOR OFFICE USE ONLY

Knapman House, 230 Pirie Street, Adelaide, South Australia, 5000.
 Telephone (08) 8232 4777 Facsimile (08) 8232 4807

Figure 2. The Royal Society for the Blind of South Australia referral form pro forma

Letters regarding the LVC assessment are sent to the referrer.

5. A follow-up appointment is set for 30 days after the initial appointment. At this time, patients are referred to community services (for example, orientation and mobility, independent living) if further rehabilitation is felt necessary by the counsellor. No further services are required if the patient is satisfied with the LVC or if they do not attend the repeat appointment.

Data on all patient referrals were retained. As a result, all referred cases were recorded and followed by the RSB. The study focused on factors influencing access to the low-vision service. Both socio-demographical and clinical information were collected. Based on these data, the primary diagnosis was identified. Use of volunteer transport and interpreter services was also recorded.

RESULTS

There were 1116 patients referred to the RSB over the 12-month period. The mean age was 78.0 years (Table 1). Sixty-eight per cent of the referrals were from ophthalmologists and 32 per cent were from optometrists. The majority (1050/1116, 94 per cent) were from an ophthalmologist/optometrist in private practice and 66 (six per cent) were from the ophthalmology department of a teaching hospital. Two hundred and twenty-six patients had Department of Veteran Affairs entitlements.

The attendance rate at the LVC was 97 per cent of all referrals (1082/1116). Of those, 92 per cent lived within 50 kilometres of the low-vision centre. There were 35 patients who lived 50 to 100 kilometres away from the LVC and 52 who lived more than 100 kilometres away but still attended the assessment. Only 125 clients (11.6 per cent) accessed volunteer transport services.

The attendees included people of 53 ethnic origins and reported 18 primary languages. When the patient's preferred language was requested and if an interpreter service was required, 95 per cent of patients (1024/1082) report English as

Age group	Attendees			Non-attendees		
	Female	Male	Total	Female	Male	Total
0-15	11	8	19	0	1	1
16-64	53	61	114	1	1	2
65-74	54	35	89	2	0	2
75+	578	282	860	21	8	29
Total	696	386	1082	24	10	34
Average age	78.8 years			77.7 years		

Table 1. Age and gender characteristics of participants

Ocular condition	Total number (percentage)
Macular degeneration	782 (72)
Glaucoma	73 (7)
Neurological vision loss	57 (5.3)
Diabetic retinopathy	50 (4.6)
Corneal	18 (1.7)
Cataract	17 (1.6)
Retinitis pigmentosa	10 (0.9)
Retinal detachment	7 (0.6)
Other	68 (6.3)
Total	1082 (100)

Table 2. Causes of low vision seen by the Royal Society for the Blind

Reason for declining referral	Number
Major health problem	8
Does not feel the need	8
Does not feel service could help	3
Deceased	3
Received low vision rehabilitation input by another service provider previously	2
Not eligible for service	1
Moved to aged care facility	1
Wants a home visit	1
Relocating overseas	1
Unknown reasons	2
Total	30

Table 3. Reasons for declining low vision service referral

the preferred language. Only 24 clients (2.2 per cent) requested an interpreter service and 34 clients (2.8 per cent) attended with at least one family member who acted as the interpreter.

Age-related macular degeneration was by far the most common cause of low vision (782/1082, 72 per cent) (Table 2). All other ophthalmic conditions were responsible for less than 10 per cent of the cases of low vision.

For the four people who were unable to be contacted, letters were sent to the refer-

ring clinicians. Thirty patients declined assessment at the RSB LVC. The mean age in this group was 77.7 years and there were 24 females and 10 males (Table 1). Eight of them (27 per cent) had major concurrent health issues precluding them from attending low-vision rehabilitation. The current health issues listed included cerebrovascular accident, lymphoma, an orthopaedic condition requiring bilateral hip replacement and a patient who had visual loss as a result of a motor vehicle accident and acquired brain injury who

was still undergoing physical rehabilitation and hence wanted to defer vision rehabilitation. Four people did not elaborate on their condition. The family of one of these four indicated that the client, aged 92, was too frail to travel and the family visited the LVC for an informal visit to look at a range of visual aids and information. Eight clients (27 per cent) did not feel the need for low-vision rehabilitation services. Most did not elaborate and interestingly, most (6/8) were declined by a family member such as the spouse or the son. Other reasons for declining are listed in Table 3.

There was no significant difference in age between those who attended the LVC versus the non-attendees (Table 1). Geography was not a reason for non-attendance and all 34 non-attendees lived within 50 kilometres of the low-vision centre. Twenty-two of the 34 were referred by an ophthalmologist (65 per cent) and 12 were referred by an optometrist (35 per cent). There were no significant differences in attendance and the referrer source.

DISCUSSION

A mismatch between the need for and uptake of low-vision rehabilitation services has been reported in Australia.^{5,9-11} It has been reported previously that many patients referred to services do not attend, therefore barrier analysis at the level of the service, the referral and the patient have been suggested to identify the changes required to improve service provision.^{9,10} In this study, a high attendance rate with a 97 per cent appointment uptake was noted. This rate is significantly higher than the finding by O'Connor and colleagues,¹² who reported the referral compliance rate was 49 per cent in a new low-vision rehabilitation service. In that service delivery model, the patients were asked to follow up the referrals and this may have contributed to the different uptake rate in their study.¹² Hence, the RSB service model that allows direct referral to the RSB, for example, by ophthalmologists and optometrists, with patients being contacted directly by the RSB within

one week of referral, appeared to be a major enabler in the high attendance rate. Services that were perceived to be enablers by the low-vision service, such as interpreter and volunteer driver services, were made available to the RSB patients. Our study found that geographical distances and languages were not identified as significant barriers because only 11.6 per cent of clients accessed volunteer transport services and 2.2 per cent used the interpreter services. All clients who refused the RSB service lived within 50 kilometres of the low-vision clinic centre. The major barriers to low-vision rehabilitation service uptake identified in this study were the presence of concurrent major health problems, perception that the service is not required and perception that the service would not be able to help (Table 3).

One of the major barriers identified in this study is patient perception. Eight patients out of 30 (27 per cent) did not feel that they needed low-vision rehabilitation services and three (10 per cent) did not feel the rehabilitation services would help. The aim of rehabilitation is to maximise residual vision and improve function. The patient may not wish to take up low-vision rehabilitation due to misconceptions about low-vision rehabilitation services, inadequate understanding of their visual impairment and lack of knowledge on the available services.^{11,19}

People often have the misconception that low-vision services are for people much more disabled, to the level of legal blindness, and thus are unaware that there is a range of visual aids and counselling that would be helpful in the low-vision (visual acuity less than 6/18) stage. Patients may be scared and confused at the time of their diagnosis and may go through a period of denial,²⁰ at which time referral to a low-vision rehabilitation service may not be given proper consideration.¹¹ Some people may see referral to the low-vision service as a stigma to be labelled as 'blind' and do not perceive their vision to be poor enough to need the referral.^{19,21,22} Some may have multiple co-morbidities, as seen in the present study, which would be a major reason for declining assessment,

because they may have hesitated committing to the LVC assessment with the fear of multiple appointments and additional testing.¹⁹ Identifying the barrier will help channel the implementation of better low-vision rehabilitation service such as the need to educate the general public, particularly those in their senior years, about visual changes and the benefits from using vision rehabilitation. Many people do not understand what the low-vision rehabilitation services provide and, consequently, how they could benefit from using them.¹⁴ An integral component of the Canadian National Institute for the Blind model of low-vision service delivery is public education. When seeking treatment and rehabilitative services, individuals with failing vision (and their friends, families and caregivers) must first be aware of eye conditions, their causes, prevention and the service options available.²³

Our study showed that one of the barriers precluding uptake of vision rehabilitation services is medical co-morbidities. This reflects the demographics of the clients in this study with a mean age of 78 years and age-related macular degeneration being the leading cause of low vision. The demographics in this study are consistent with those reported in other low-vision rehabilitation services in developed countries¹⁸ and the data on the causes of vision impairment in Australia.^{18,24,25} The counsellor who contacted the non-attendees did not change the attendance rate but helped to elicit the reasons for declining. One of the clients refused LVC assessment because he was too frail but asked whether a home visit was possible. Resources are often the issue for vision rehabilitation agencies but analysis of the potential barriers can help guide strategic planning in service delivery and practice implementation for the individual organisation such as the consideration for mobile clinics or outreach services. A cost versus benefit analysis, taking into consideration the organisational resource and patient quality-adjusted life years needs to be undertaken for effective service planning.

The Queensland Referral Pathway Pilot Project identified late referral with

advanced visual loss as an issue and that many eye health professionals are still unaware of the services provided by each agency.²⁶ Adam and Pickering¹¹ noted that 62 per cent of Canadian ophthalmologists consider vision of less than 6/60 should be referred, suggesting that referrer awareness and education play a large part. The same problem was identified by an Australian study¹⁵ and represents a deficiency in ophthalmologists' perceptions of the visual rehabilitation process. Our study supports that raising awareness of the low-vision rehabilitation services is an important issue to the health care provider as well as patients and their carers.

A limitation of the present study is that the data come from a single centre. The RSB is one of two non-government organisations that provide low-vision rehabilitation in South Australia and thus, there is the potential that these findings reflect national patterns. Another limitation is that this study does not address the barriers to low-vision service for people who have not been referred to the LVC. It is possible that other barriers could be identified and strategies developed to overcome these. For example, greater proactivity from referring clinicians in identifying candidates for low-vision care might increase suitable referrals.^{10,16} Our study population is mostly older people at an average age of 78 years, with relatively few younger clients. Therefore, this study may not reflect the barriers and facilitators in younger people.

In conclusion, study of the service delivery models of the RSB of South Australia noted a high referral compliance rate (97 per cent) compared with other published studies. The major enabler is the referral pathway with direct referral and the triage process used by the low-vision service. Geographical distances, the presence of transport and interpreter services were not significant factors affecting service delivery. Concurrent health issues and patient perceptions are major reasons for non-attendance, thus, raising patient awareness of the rationale behind low-vision rehabilitation and service availability might help increase the low-vision rehabilitation service uptake.

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