EFFECTIVENESS OF THE COMMUNITY BASED LOW VISION SERVICE WALES: A LONGITUDINAL STUDY

Running head: Longitudinal effectiveness of Low Vision Service Wales

B Ryan PhD,[1] J Khadka PhD,[2] C Bunce DSc,[3] H Court PhD[1]

1.School of Optometry and Vision Sciences, Cardiff University, Cardiff CF24 4LU, UK.
2. NH&MRC Centre for Clinical Eye Research, Discipline of Optometry and Vision Science, Flinders University of South Australia, South Australia, Asutralia.
3. Moorfields Eye Hospital, NHS Foundation Trust, London, UK

Corresponding author: Barbara Ryan, PhD.
School of Optometry and Vision Sciences, Cardiff University, Cardiff CF10 3NB, UK.
Tel: 029 2087 0233, Fax: 44 (0)29 2087 0233
Email: ryanb@cardiff.ac.uk

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Abstract

Aims: To evaluate the long term effectiveness of the community based Low Vision Service Wales (LVSW).

Methods: A longitudinal observational study.Participants were recruited from the LVSW (n=342; 246 female; median age 82) at baseline. The primary outcome measure was change (baseline-3 months, 3 months–18 months, baseline-18 months) in visual disability as evaluated by the seven-item NEI-VFQ. Secondary outcome measures included: use of low vision aids and satisfaction with the service provided.

Results: Questionnaires were sent to 281 participants (who responded at three months) at 18 months post-intervention. Responses were received from 190 (67.6%) people; 24 were deceased. Self-reported visual disability was significantly reduced (Wilcoxon Signed rank test : P <0.001) between baseline and 18 months by -0.28 logits (-1.24 to 0.52). This was less than that found between baseline and 3 months; -0.61 logits (-1.81 to 0.02). At 18 months 79% patients used their low vision aids at least once a week which was not significantly different to that found at 3 months (MW P = 0.127).

Conclusion: This study provides strong evidence that the effect of the LVSW persists over a period of eighteen months; disability is reduced but attenuated and use of low vision aids remains high.

Key words: visual impairment, questionnaire, visual disability, low vision service

INTRODUCTION

In 2004, a nationwide community based Low Vision Service Wales (LVSW) was established based in local optometric practices throughout Wales.[1] The LVSW has significantly reduced waiting times, increased the number of assessments and improved access to low vision services for people seeking the service.[2]

Over the last few years there has been a move towards evaluating low vision services based upon patients perception of ability after rehabilitation, rather than solely relying on clinical measures.[3-5] However, there are very few studies which report the long term effects of low vision rehabilitation based upon these measures. Stelmack 2008 showed improvement in self-report visual ability at 3 and 12 months post-intervention and Kuyk et al, 2008 reported a significant improvement in self-reported health-related quality of life at 2 and 6 months post-intervention.[6 7] However, it has been reported that over a long period of time the effects of low rehabilitation wash out.[8]

We have previously reported that the LVSW produces a clinically significant reduction in self-report visual disability at three months post-intervention (as measured with the 7-item NEI-VFQ).[2 9] Furthermore, we identified that the service was associated with high levels of patient satisfaction and use of low vision aids (LVAs). This is a report of the longitudinal follow-up of these same participants at eighteen months.

The aims of the study were to determine if;

1) the significant reduction in self-reported visual disability at 3 months remained at 18 months post-intervention and,
2) there was a significant difference in use of low vision aids and satisfaction with the low vision service between 3 and 18 months post intervention.

METHODS

Sample

Participants were recruited at baseline on a consecutive basis from the LVSW between October 2007 and December 2008. The inclusion criteria of participants was: >18 years of age, distance visual acuity (VA) of 6/12 or worse and/or; near acuity of N6 or worse or; significant contraction of visual field and a requirement for low vision rehabilitation. Vulnerable groups unable to provide informed consent were excluded from the study. LVSW participants were only recruited if they had a CF postcode and went to a practice within a CF postcode (with a registered practitioner from 07/12/2006). This represented 36% of the total patients assessed in the LVSW between October 2007 and December 2008.

Ethical approval was obtained from the All Wales Research Ethical Committee and all procedures adhered to the tenets of the Declaration of Helsinki.

Intervention

The intervention provided by the LVSW includes: assessment of a patient's understanding of their ocular condition and prognosis; discussion of needs

and initial goal setting; assessment of vision; provision of low vision aids, on loan and free of charge; advice about lighting and other methods of enhancing vision; provision of information about the ocular condition and other rehabilitative services; referral to additional services; re-appraisal of goals; and arrangement for follow up. Not all patients attend for a follow-up appointments, but these are arranged if a clinical need is identified.

Baseline and three month post-intervention participant data

Patient clinical and demographic data was collected at baseline and three months via questionnaires and record cards. The protocol for collecting this data was described earlier.[9] A total of 342 participants completed questionnaires at baseline and 281 participants responded at three months.

Eighteen month post-intervention participant data

At eighteen months post-intervention, a questionnaire was posted to all participants who had returned questionnaires at three months. Along with the information about the LVSW, a cover letter addressing participants by name, a consent form and self addressed prepaid envelope was posted with the questionnaire. All questionnaires were produced in large font (Arial 16) and complied with the format suggested by Wolffsohn.[10]

In order to improve the response rate, participants who did not respond were sent questionnaire packs a maximum of three times. If participants failed to return any of the questionnaires then they were followed up by telephone call and a final request letter.

The same outcome measures used at baseline and three months were included in the eighteen month questionnaire.

Outcome measures

Visual disability measure

The primary outcome measure was change (baseline-3 months, 3 months-18 months, baseline-18 months) in visual disability as evaluated by the seven-item NEI-VFQ.[11] This is a short, reliable, psychometrically robust and highly focused measure which was developed specifically to enable evaluation of the LVSW.[11] Higher scores (from 1-5) indicate higher visual disability and a score of 6 ("stopped doing this for other reasons or not interested in doing this") was treated as missing data.[12]

Other patient centred measures

Use of LVAs and participant satisfaction were measured by four items from the validated Manchester Low Vision Questionnaire (MLVQ).[5]

In addition to the above, data concerning participant assistance required when completing the questionnaire was also collected via the questionnaires at eighteen months.

Analysis

Wilcoxon's Signed Rank test was used to assess whether visual disability at 3 months differed to that at 18 months and to see whether or not visual disability at 18 months differed to that at baseline. Logistic regression analysis was used to identify if any of the baseline factors were associated with the likelihood of responding at 18 months. Cross tabulations were drawn to compare responses at baseline with those at 18 months Wilcoxon signed rank tests were used to see whether LVA usage at 3 months differed significantly to that at 18 months and to compare satisfaction at each time point.

Non parametric methods were used throughout because of marked departures from normality which could not be remedied by simple transformation or because data were ordinal. All of the questionnaire data and record card data were entered into SPSS Ver. 12 for analysis. Data from the 7-item NEI-VFQ was converted to a logit linear scale using a pre-published conversion table.[11]

Results

A total of 281 participants were sent questionnaires at eighteen months post-intervention (these were the 281 participants who responded at three months). Questionnaire response rate at eighteen months was 67.6% (n=190; n=24 deceased, n=30 withdrawn, n=36 no questionnaire return, n=1 returned blank questionnaire). Table 1 identifies characteristics of the baseline sample and those who responded at eighteen months.

Table 1: Characteristics of the participants at baseline (n=343) and 18 months (n=190). Percentages reported are out of available data for that question, except for the numbers of missing / not reported which are out of n. (* data not collected at 18 months)

	Respondents (Baseline, n =343)	**Respondents (18 months, n =190)**
Age (median; IQR)	82 (75-86)	83 (77-88)
Female %	247 (72%)	137 (72.1%)
Reported registration %		
Blind	36 (11.8%)	39 (20.5%)
Partially sighted	76 (25.0%)	54 (28.4%)
Not registered	192 (63.2%)	74 (38.9%)
Not reported	39 (11.4%)	23 (12.1%)
Ocular pathology %		
Glaucoma	49 (14.3%)	*
Cataract	108 (31.5%)	*
AMD	241 (70.3%)	*
Home circumstances %		
Alone	164 (49.3%)	93 (48.9%)
With partner/spouse	123 (36.7%)	70 (36.8%)
With other relative	31 (9.3%)	17 (8.9%)
Sheltered accommodation	10 (3.0%)	2 (1.1%)
Residential care	4 (1.2%)	2 (1.1%)
Other	3 (0.9%)	4 (2.1%)
Not reported	8 (2.3%)	2 (1.1%)
Ethnicity		
White	327 (98.5%)	182 (95.8%)
Asian or Asian British	4 (1.2%)	3 (1.6%)
Black or Black British	0	0
Other ethnic groups	1 (0.3%)	0
Not recorded	11 (3.2%)	5 (2.6%)
Distance acuity (LogMar) Median, IQR	-0.65 (-1.00 to 0.40)	*
Missing number (% of N)	5 (1.5%)	*
Presenting near acuity: median, IQR	N12 (N8-N24)	*
Visual disability (logits): median, IQR	1.07 (-0.48 to 2.11)	0.42 (-1.39 to 1.94)
Missing number (%)	1 (0.3%)	0
General health item		
Excellent	6 (1.8%)	4 (2.1%)
Very good	33 (9.7%)	15 (7.9%)
Good	84 (24.8%)	50 (26.3%)
Fair	131 (38.9%)	83 (43.7%)
Poor	84 (24.8%)	35 (18.4%)

Missing	4 (1.2%)	3 (1.6%)
Mode of questionnaire completion		
By patient alone	92 (27%)	95 (50%)
With help from another person	254 (73%)	93 (48.9%)
Missing (n, %of N)	6 (1.7%)	2 (1.1%)

Logistic regression analysis identified that there were no baseline factors associated with an increased likelihood of responding at 18 months apart from mode of questionnaire completion. Participants who required help from another person to complete their questionnaire at baseline were less likely to return a questionnaire at 18 months (126 of the 245 (51%) subjects who completed with help at baseline responded compared with 61/91 (67 %) who completed by themselves at baseline).

Primary patient-centred outcome: change in visual disability

Measurements of visual disability at baseline, three months and eighteen months are presented in table 2.

Table 2: Median and Interquartile ranges of visual disability at baseline, 3 months and 18 months

Visual disability	**N=190**		**Statistical comparison**
Baseline	1.07 (-0.47 to 2.05)		
3 months	-0.43 (-2.01 to 1.46)		
Change (Baseline- 3 months)		-0.61 (-1.81 to 0.02)	Singed Rank P<0.001
18 months	0.42 (-1.39 to 1.94)		
Change (3 months- 18 months)		0.33 (-0.23 to 1.23)	Singed Rank P=0.0012
Change (baseline-18 months)		-0.28 (-1.24 to 0.52)	Singed Rank P<0.001

There was strong evidence of, an increase in visual disability between 3 months and 18 months, but a significant reduction in visual disability between baseline and 18 months.

The measurements of visual disability at baseline, three months and eighteen months post-intervention are presented in figure 1.

Secondary patient-centred outcomes: Patient satisfaction and use of LVA

There was a significant reduction in patient satisfaction with the service eighteen months post-intervention compared to three months. However, there was little evidence of a change in LVA use between for the same time period (Table 3).

Table 3: Measurement of a) satisfaction and b) use of LVAs at 3 and 18 months

	3 months (N=190)	**18 months (N=190)**	**Statistical comparison**
a) Patient satisfaction item			
Extremely helpful	115 (60.5%)	72 (37.9%)	MW P<0.001
Quite a bit helpful	40 (21.1%)	51 (26.8%)	
Moderately helpful	18 (9.5%)	17 (8.9%)	
Slightly helpful	11 (5.8%)	18 (9.5%)	
Not at all helpful	3 (1.6%)	12 (6.3%)	
Not recorded	3 (1.6%)	20 (10.5%)	
b) Use of LVA's			
>4 times per day	97 (51.1%)	98 (51.1%)	MW P=0.127
1-4 times per day	53 (27.8%)	35 (18.4%)	
at least weekly	18 (9.5%)	18 (9.5%)	
<once a week	11 (5.8%)	13 (6.8%)	
Never	8 (4.2%)	19 (10%)	
No magnifier	3 (1.6%)	5 (2.6%)	
Not recorded	0	2 (1.1%)	

Other outcomes

Table 4 identifies the changes in participants reported registration, home circumstances, general health and mode of questionnaire completion between baseline and 18 months (190 participants).

Table 4: Crosstabulations of participants reported a) registration, b) home circumstances, c) general health and d) mode of questionnaire completion at baseline and 18 months (190 participants)

a)	Reported registration (18 months)				
		Blind	**Partially sighted**	**Not registered**	**Total**
Reported registration (baseline)	**Blind**	14	2	0	16
	Partially sighted	12	28	2	42
	Not registered	10	20	64	94
Total		**36**	**50**	**66**	**152**

b)	Home circumstances (18 months)							
		Alone	**With partner/ spouse**	**With other relative**	**Sheltered accom-modation**	**Residential care**	**Other**	**Total**
Home circumstances (baseline)	**Alone**	77	5	2	1	1	1	87
	With partner/ spouse	7	62	2	0	0	0	71
	With other relative	5	0	12	0	0	0	17
	Sheltered accomm-odation	2	0	0	1	0	1	4
	Residential care	0	0	0	0	1	1	2
	Other	1	0	0	0	0	1	2
Total		**92**	**57**	**16**	**2**	**2**	**4**	**183**

c)	General health item (18 months)						
		Excellent	**Very good**	**Good**	**Fair**	**Poor**	**Total**
General health item (18 months)	**Excellent**	2	1	0	0	0	3
	Very good	2	7	4	5	1	19
	Good	0	4	28	17	2	51
	Fair	0	2	15	45	12	74
	Poor	0	1	3	16	19	39
Total		**4**	**15**	**50**	**83**	**34**	**186**

d)	Mode of administration (18 months)			
		By patient alone	**With help from another person**	**Total**
Mode of administration (18 months)	**By patient alone**	50	10	60
	With help from another person	42	83	125
Total		92	93	185

Of the 190 participants who responded at 18 months, significantly more were registered $P < 0.001$), and significantly more had completed the questionnaire alone ($P < 0.001$). Living situation and general health status was not significantly different ($P = 0.647$, $P = 0.07$).

Since method of form completion was associated with response at 18 months, we assessed whether or not treatment response at 3 months differed between self-completer and those who needed assistance. We found little evidence of any difference, (MW, $P = 0.48$) and thus it seems that our findings are robust to missingness.

Discussion

This study provides the first evidence that low vision rehabilitation services in the UK are effective over the longer term; those using LVSW had significantly reduced self-reported visual disability at 18 months and had no significant drop off in the use of low vision aids was found. The effect on self-reported visual disability at 18 months was less than that found at 3 months. [9] However, such a decline over time has also been found in other low vision rehabilitation services and is thought to be a result of a general decline in baseline function. [3 7 8 10] Indeed, without access to low vision rehabilitation intervention, people with a visual impairment experience a decline in self-reported visual ability.[3]

In the USA, Stelmack et al demonstrated that the positive effects following an intensive inpatient Veteran Affairs low vision rehabilitation programme were still apparent after 12 months [3] although the measures used were different. The Veteran Affairs programme lasted approximately 40 days, represents a dose of about 240 hours and was estimated to cost about US$ 43,682 per person.[13] This is in stark contrast to the outpatient LVSW, which offers an

annual hour long assessment, shorter follow up appointments as required and provides low vision aids including electronic portable devices.[14] Even taking into account the support from state funded special social services, which is also provided to many people who use the LVSW,[14] like other state funded low vision rehabilitation services in the UK , services in Wales have a dose of a few hours and a cost of a few hundred pounds.[13] Whilst there is a need for cost benefit analysis of low vision services,[13] the long lasting outcomes found in this study suggests that the low dose, low cost intervention provided in optometry practices in Wales is very good value for money.

Elsewhere in the UK, despite reports of good low vision aid usage, only very small changes in self-reported quality of life were found 6 months after low vision intervention in Fife and no effect a year after intervention in Manchester .[15 16] However, these studies used less specific generic measures of Health Related Quality of Life which are thought to be less sensitive than vision-specific Quality of Life measures when measuring the outcomes of low vision rehabilitation services.[13] The LVSW is similar to others services provided by the National Health Service (NHS), including the services in Fife and Manchester.[9 15 16] Therefore, it is likely that the results of this study are applicable to other NHS low vision services, especially as no significant difference in outcomes was found at three months between the community based LVSW and a hospital low vision service in Wales.[9]

The LVSW is a low dose, low cost rehabilitation intervention which is effective over a period of 18 months. However, there may be room for improvement.[3] For example, group based interventions have been found to be very effective over the long term and the cost benefit of piloting the addition of these to NHS low vision services should be investigated.[17] A pilot trial is already underway to determine the benefits and cost effectiveness of incorporating interventions targeted at reducing depression into the rehabilitation programme for older people using the LVSW.[18]

There was a reduction in satisfaction with the service over the 18 months and the reasons for this require investigation. However, for such a low dose

intervention in a group experiencing a deterioration of their sight, the fact that, 83% of those using the service still found it helpful after 18 months is commendable.

Over the 18 months of this study, more people using the LVSW were registered as sight impaired or had their registration status changed. The significant change in registration status found is not surprising. The LVSW offers early intervention; at first assessment, less than a third of those who use the service meet the visual acuity threshold for registration and just less than half have consulted with an ophthalmologist.[19 20] By using the LVSW and other examinations offered under the Welsh Eye Care Initiaitive,[14] many patients with non-treatable conditions (such as dry age-related macular degeneration) can be managed in primary care until they are eligible for registration as sight-impaired.[21] The results indicate that the practitioners are identifying people who are eligible and referring people to secondary care for registration as sight impaired. In other words the LVSW facilitates registration as sight impaired.

The questionnaires used in this study used large bold print. At 18 months, significantly more had completed the questionnaire alone than at baseline, that is, those that were unable to complete the question alone were less likely to respond. This calls into question the use of print questionnaires for people with a visual impairment as it may bias the results. This finding is at odds with that of Wolffsohn et al who found that people with a visual impairment can self-complete questionnaires as long as large bold print is used.[22] However, neither baseline visual disability nor visual acuity was associated with response at eighteen months. This suggests that the longterm effectiveness at eighteen months is not reserved for those of better ability at baseline. Rather, it is possible that co-morbidities, which are progressively more common with age, [23] may be influencing ability to complete a questionnaire at eighteen months or people may find it harder to find someone to help them.

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Figure legend

Figure 1: Box plots of baseline, 3 month and 18 month visual disability (n=190)