

What you need to know about low vision and quality of life

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Lecture Objectives

1. Compare vision-related quality of life measures
2. Explain the impact of low vision on quality of life
3. Evaluate the effectiveness of low vision rehabilitation



The importance of evaluating quality of life (QoL) and the patient perspective in low vision is now widely accepted.



Simply measuring visual acuity does not adequately reflect the impact of low vision on a person's QoL.

It does not capture important aspects of visual function from the person's perspective. (Massof and Rubin, 2001; de Boer et al., 2004)





“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1948)



Guidance for Industry

Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims

Additional copies are available from:

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December 2009
Clinical/Medical



Numerous questionnaires and instruments for measuring vision-related QoL have been developed in recent years.

These are not only useful for characterising the holistic **consequences of low vision** but for **evaluating the effectiveness** of various interventions and services, and in clinical trials.

What is health-related QoL?

- Effect of medical condition and its treatment on the patient
- Multidimensional
- Subjective



Dedicated to the promotion of excellence in the science of health-related quality of life.

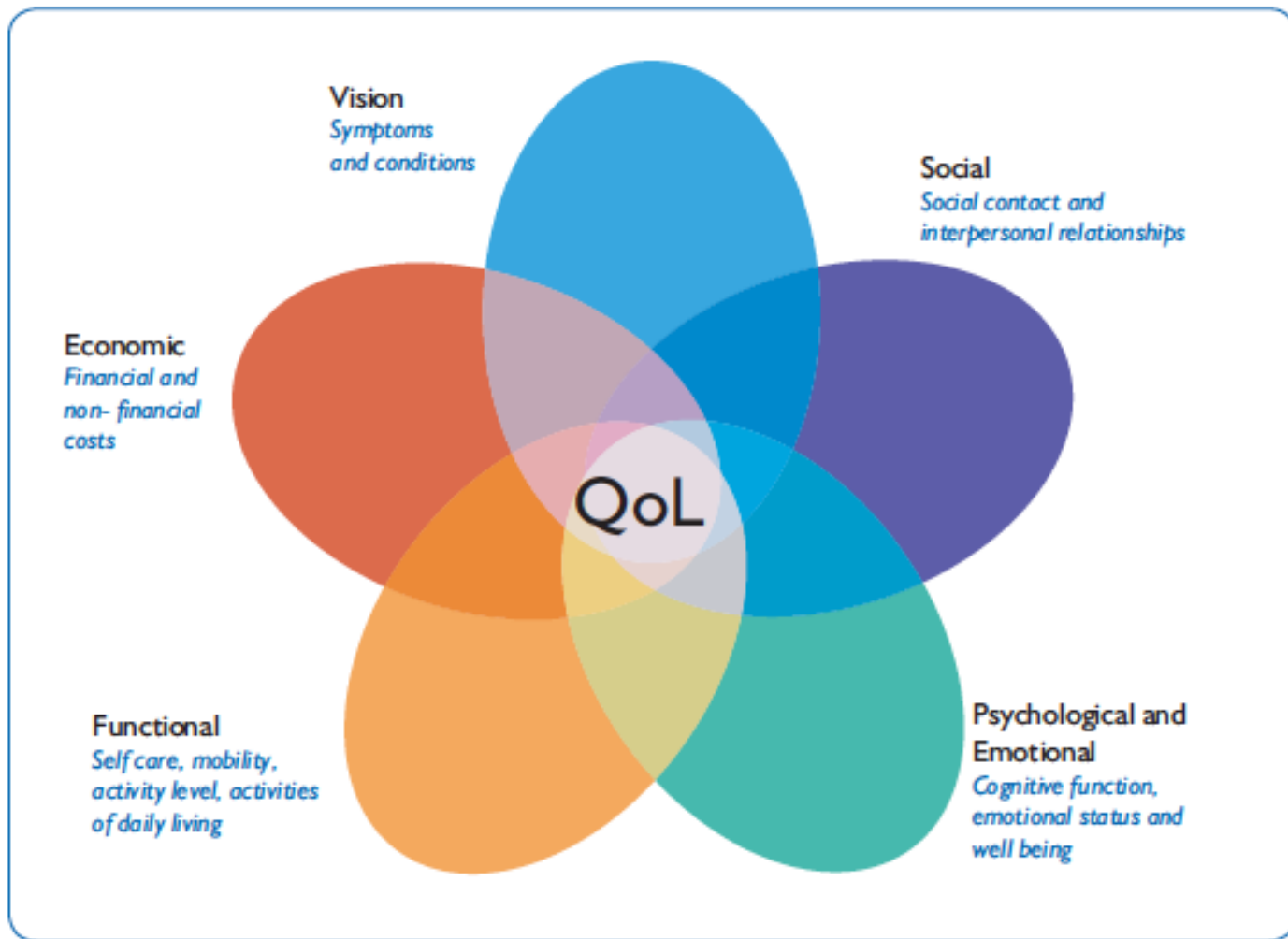
IT'S SUNDAY

**AND NO HANGOVER IN
SIGHT!**

memegenerator.net

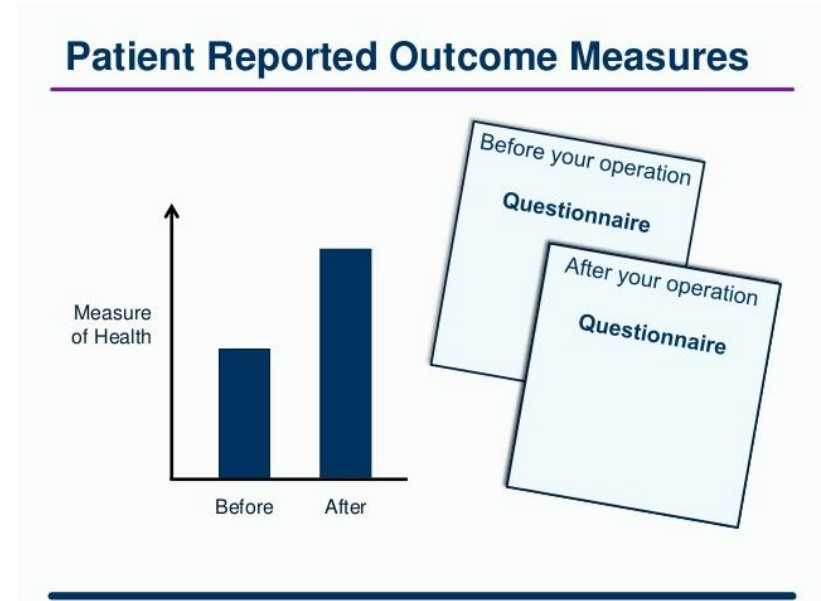


Quality



Centre for Eye Research Australia, Focus on Low Vision (2007)

- More than 100 vision-specific QoL measures have been developed over the past 20 years
- QoL is measured using questionnaires (instruments)
- Now might also be referred to as a type of 'Patient Reported Outcome' (PRO) measure



Khadka et al., OVS, 2013; de Boer et al., OPO, 2013)

- Vision-related QoL questionnaires typically include evaluation of:
 - ability to perform activities of daily living (visual functioning)
 - interactions with others
 - emotional well-being
 - independence
- Sophisticated research methodologies used to develop and test these



Several earlier measures based on classical test theory now re-designed using **Rasch analysis** to improve their measurement properties.

Rasch analysis = statistical technique that transforms measurement properties of questionnaire so can be used as true interval level measure (e.g. cm or logMAR), rather than an ordinal level measure.



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Impact of Vision Impairment Profile (IVI)

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INSTRUCTIONS

Please read each question carefully and circle the answer that **BEST** applies to you.

Put one circle on each row.






If you use **GLASSES, CONTACT LENSES OR MAGNIFIERS** for some activities please answer according to how you can see when using them.

Here are two examples:

In the past month how often has your eyesight made you concerned or worried about...

	Not at all	A little	A fair amount	A lot	Don't do this for other reasons
Crossing the street?	3	2	1	0	8
Preparing a meal for yourself?	3	2	1	0	8

My In-Control Scale

1	 I lost it! I need a break!
2	 I'm beginning to loose it!
3	 I'm feeling a little unsure.
4	 I'm feeling pretty good!
5	 I'm feeling just fine!

More recently, measures applicable to children with vision impairment have been also developed.



Evaluating QoL Questionnaires

We use the ISOQOL minimum standards to guide our PROM research

1	Conceptual & measurement model	1a	Conceptual and measurement model	<ul style="list-style-type: none"> The rationale for and description of the concept and the populations that a measure is intended to assess and the relationship between them
		1b	Target population	
2	Reliability	2a	Test - retest reliability (= reproducibility)	<ul style="list-style-type: none"> Reliability: degree to which the PROM is free from random error Test-retest reliability (reproducibility) Stability of scores over time when no change is expected in the concept of interest Internal consistency Extent to which the items comprising a scale measure the same concept. The intercorrelation of items that contribute to a score.
		2b	Internal consistency	
3	Validity	3a	Content validity	<ul style="list-style-type: none"> Validity: degree to which the instrument measures what it purports to measure Content-validity appropriateness and comprehensiveness of the items and domains Construct validity hypotheses concerning logical relationships that should exist with measures of related concepts or scores produced in similar (or diverse) patient group Responsiveness instrument's ability to detect change over time
		3b	Construct validity	
		3c	Responsiveness	
4	Interpretability		Interpretability	<ul style="list-style-type: none"> The degree to which one can assign easily understood meaning to an instrument's quantitative scores. Cultural and linguistic adaptation and validation of the instrument
5	Translations		Translations	
6	Assessment burden	6a	Patient burden	
		6b	Clinician & admin.burden	<ul style="list-style-type: none"> The resources needed to administer the instrument (time, effort, and other demands)



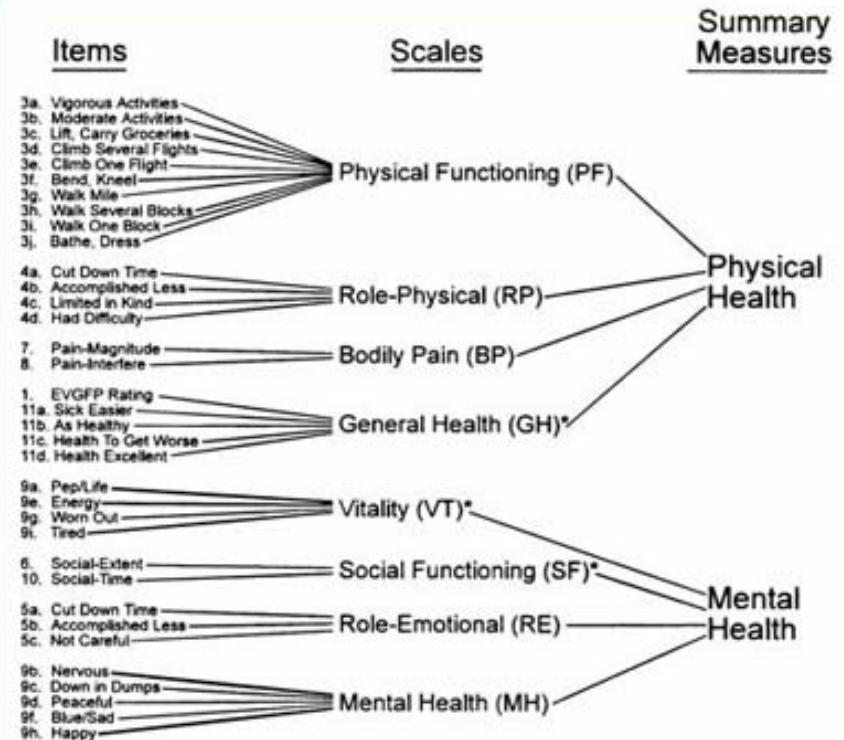
Mokkink et al., Qual Life Res, 2010

Evaluating QoL Questionnaires

Conceptual and measurement model

- What construct or concept was intended to be measured?
- The measurement model maps the individual items to the construct

SF-36® Measurement Model



* Significant correlation with other summary measure.

Evaluating QoL Questionnaires

Reliability

- Degree to which the instrument is free from measurement error

Internal consistency reliability

- Degree of inter-relatedness among the items

Test-retest reliability

- Ability to provide consistent scores over time in a stable population

Inter-interviewer reliability

- Ability to provide consistent scores with different interviewers

Validity

- Degree to which the instrument measures what it purports to measure

Content validity

- Does it include the most relevant and important aspects of the construct?

Construct validity

- Degree to which scores relate to other measures in a way that is expected (e.g. VA, VF)

Criterion validity

- Degree to which scores correlate with 'gold standard'

Responsiveness

- Extent to which the measure can detect changes over time

Interpretability of scores

- Degree to which one can assign easily understood meaning to the scores

Burden

- Time and effort required to administer (respondent and administrative burden)

Rasch analysis

- Threshold ordering (response categories)
- Precision (ability to discriminate between different abilities)
- Unidimensionality (one underlying concept)
- Targeting (adequately targets ability of participants)
- Differential item functioning (no bias in interpretation of items for subgroups, e.g. age, gender)

Clinical practice

- What are the goals? (e.g. service evaluation, promoting patient centeredness)
- Which patients and when – resource implications?
- Mode of administration (e.g. self, interviewer, web)
- Who will do the analysis and provide reports? (staff resource and training)
- How will the practice respond to issues raised?
- Evaluating the impact on the practice

Vision-Related QoL Questionnaires

Arguably, the most tested and high quality QoL instruments for adults with low vision and with MD to date:

- Veteran Affairs Low Vision Visual Function Questionnaire (VA LV VFQ)
(Stelmack et al., 2004; Stelmack et al., 2007; Stelmack et al., 2012)
- Impact of Visual Impairment (IVI) scales
(Lamoureux et al., 2006; Lamoureux et al., 2008)



Vision-Related QoL Questionnaires

Most tested and high quality QoL instruments for children with low vision to date:

- Cardiff Visual Ability Questionnaire for Children (CVAQC) (Khadka et al., 2010)
- LV Prasad Functional Vision Questionnaire II (LVP FVQ II) (Gothwal et al., 2012)



Vision-Related QoL Questionnaires

Impact of Visual Impairment (IVI)

- 28 items; ~15 mins
 - Emotional well-being
 - Reading and accessing information
 - Mobility and independence



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Vision-Related QoL Questionnaires

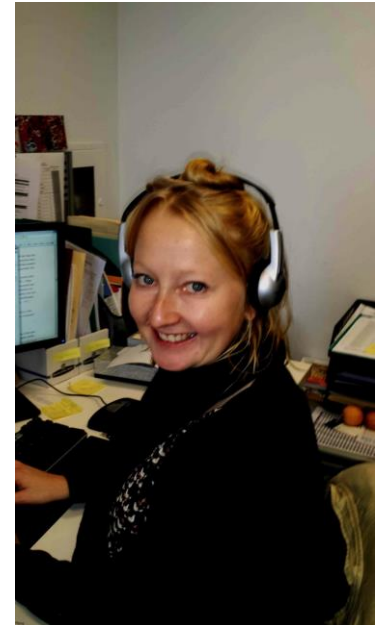
Impact of Visual Impairment (IVI)

- Self or interviewer administered
- Translated and adapted for Pacific Islands

(O'Connor et al., 2010), **Germany** (Finger et al., 2011),

Thailand (Ratanasukon et al., 2016),

China/Singapore (Fenwick et al. 2016)





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Impact of Vision Impairment Profile (IVI)

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Please answer about **YOUR** eyesight with **GLASSES, CONTACT LENSES, or MAGNIFIERS**, if you use them.
In the **PAST MONTH**, how much has **YOUR EYESIGHT INTERFERED** with the following activities:

	Not at all	A little	A fair amount	A lot	Don't do this for other reasons
1. Your ability to see and enjoy T.V?	3	2	1	0	8
2. Taking part in recreational activities such as bowling, walking or golf?	3	2	1	0	8
3. Shopping? (finding what you want and paying for it)	3	2	1	0	8
4. Visiting friends or family?	3	2	1	0	8
5. Recognising or meeting people?	3	2	1	0	8
6. Generally looking after your appearance? (face, hair, clothing etc.)	3	2	1	0	8
7. Opening packaging? (for example, around food, medicines)	3	2	1	0	8

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES, or MAGNIFIERS, if you use them.
In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:

	Not at all	A little	A fair amount	A lot	Don't do this for other reasons
8. Reading labels or instructions on medicines?	3	2	1	0	8
9. Operating household appliances and the telephone?	3	2	1	0	8
10. How much has your eyesight interfered with getting about outdoors? (on the pavement or crossing the street)	3	2	1	0	8
11. In the past month, how often has your eyesight made you go carefully to avoid falling or tripping?	3	2	1	0	8
12. In general, how much has your eyesight interfered with travelling or using transport? (bus & train)	3	2	1	0	8
13. Going down steps, stairs, or curbs?	3	2	1	0	8

	Not at all	A fair amount	A lot	Don't do this for other reasons
14. Reading ordinary size print? (for example newspapers)	2	1	0	8
15. Getting information that you need?	2	1	0	8

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES or MAGNIFIERS, if you use them. In the PAST MONTH, how often has YOUR EYESIGHT MADE YOU CONCERNED OR WORRIED about the following:

	Not at all	A little of the time	A fair amount of the time	A lot of the time
16. Your general safety at home?	3	2	1	0
17. Spilling or breaking things?	3	2	1	0
18. Your general safety when out of your home?	3	2	1	0
19. In the past month, how often has your eyesight stopped you doing the things you want to do?	3	2	1	0
20. In the past month, how often have you needed help from other people because of your eyesight?	3	2	1	0

**Please answer about YOUR eyesight with GLASSES, CONTACT LENSES or MAGNIFIERS, if you use them.
Think about how YOUR eyesight has made you FEEL in the PAST MONTH.**

	Not at all	A little of the time	A fair amount of the time	A lot of the time
21. Have you felt embarrassed because of your eyesight?	3	2	1	0
22. Have you felt frustrated or annoyed because of your eyesight?	3	2	1	0
23. Have you felt lonely or isolated because of your eyesight?	3	2	1	0
24. Have you felt sad or low because of your eyesight?	3	2	1	0
25. In the past month, how often have you worried about your eyesight getting worse?	3	2	1	0
26. In the past month how often has your eyesight made you concerned or worried about coping with everyday life?	3	2	1	0
27. Have you felt like a nuisance or a burden because of your eyesight?	3	2	1	0
28. In the past month, how much has your eyesight interfered with your life in general?	3	2	1	0

Impact of Visual Impairment (IVI)

- Improvements in VR QoL with low vision rehabilitation
(Gothwal et al., 2015; Wang et al., 2012; Lamoureux et al., 2007)
- Improvements with anti-VEGF for MD (Finger et al., 2014)
- Improvements in emotional well-being with the type 1 Boston keratoprosthesis (Ang et al., Br J Ophthalmol, 2017)



Vision-Related QoL Questionnaires

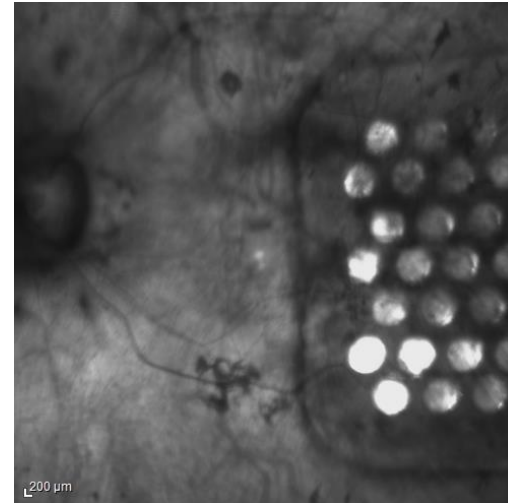
Brief IVI

- 15 items (Fenwick et al., Qual Life Res, 2017)
 - Emotional well-being
 - Visual function

Vision-Related QoL Questionnaires

IVI – Very Low Vision

- 28 items (Finger et al., IOVS, 2014)
 - Emotional well-being
 - Activities of daily living, mobility and safety



IVI_C

- 24 items (Cochrane et al., IOVS, 2011)
 - Children with vision impairment age 8 to 18 years
 - Child responds

The questions are all about how things are for you **because of your eyesight.**

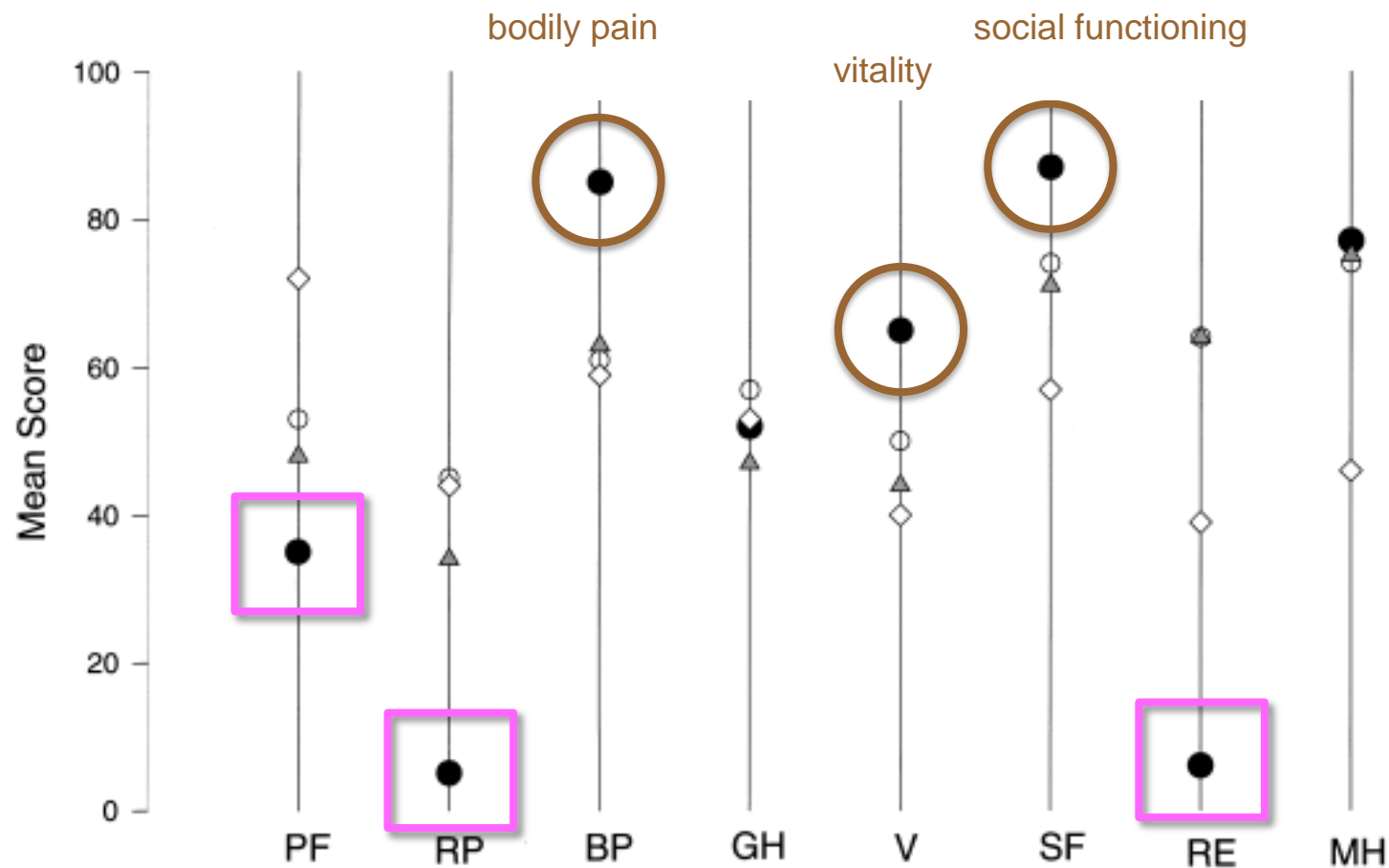
Q.		always	almost always	sometimes	almost never	never	no, for other reasons
17	Do your teachers understand your special needs?						
18	In the classroom, do you get all the same information as other students?						
19	Do you get all the information at the same time as the other students?						
20	Do you get enough time in school to complete the work set by the teacher?						

Impact of Low Vision on VRQoL

Stelmack et al., Am J Ophthalmol, 1999

- 156 patients presenting to US low vision clinic
 - Mean age 72 years (SD 17)
- HRQoL SF-36 and VRQoL NEI VFQ
- “Marked impairment of QoL”





physical functioning

role limitations caused by emotional problems

role limitations caused by physical problems

● Low
Vision
Patients

○ Normals
≥ 75 years
of age

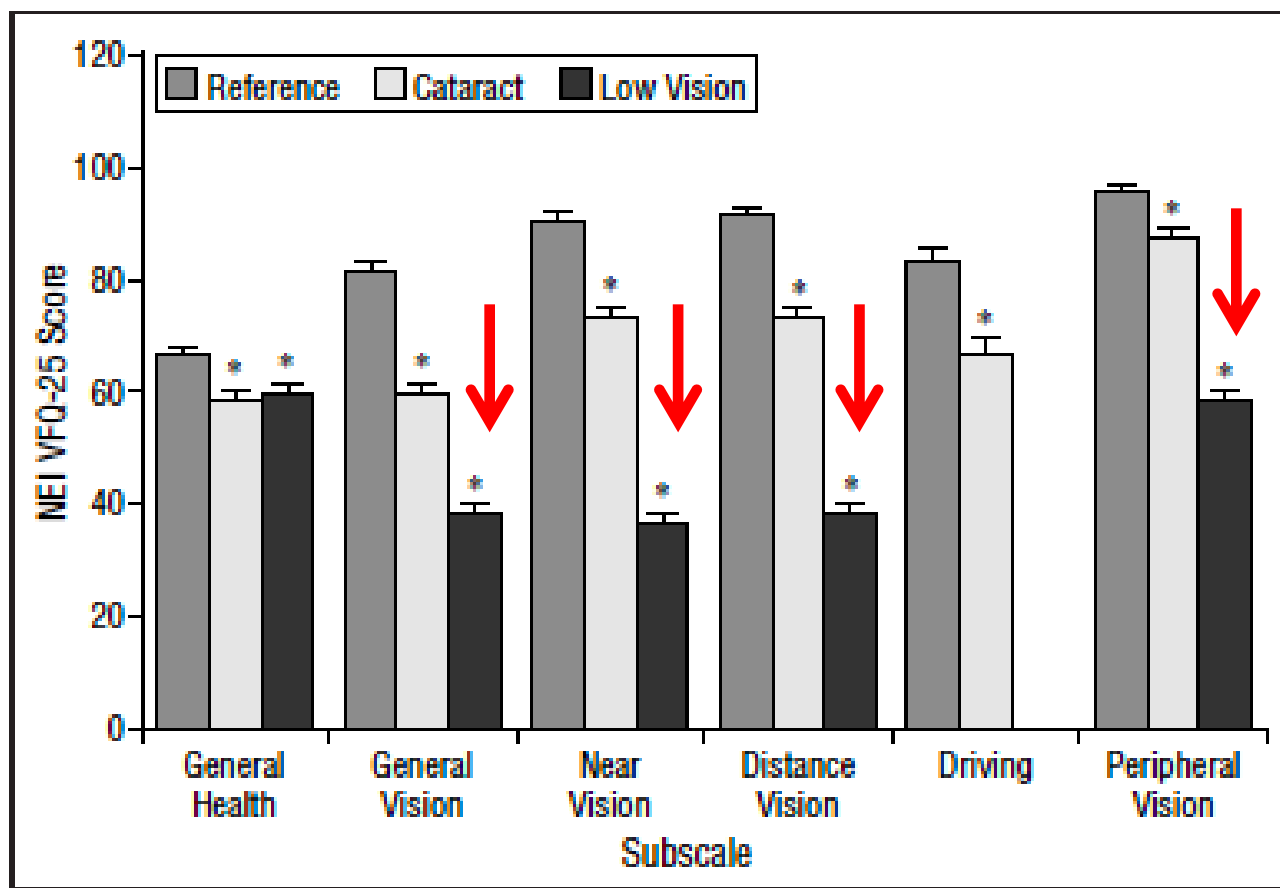
▲ Congestive
Heart
Failure

◇ Clinical
Depression

Impact of Low Vision on VRQoL

Mangione et al., Arch Ophthalmol, 1999

- 859 participants (US academic centres)
 - Mean age 63 years
- As part of development of NEI VFQ-25
- Moderate to strong correlation between VA and NEI VFQ subscales ($r = 0.39$ to 0.70)
- Glaucoma, VF score moderately correlated with NEI VFQ



Mangione et al., Arch Ophthalmol, 2001)

Impact of Low Vision on VRQoL

Chia et al., Ophthalmic Epidemiol, 2009

- 1174 participants (Australian 'Extension BMES', population based study)
 - Mean age 61 years
- NEI VFQ-25
 - Bilateral greater impact than unilateral visual impairment
 - Impact of non-correctable greater than correctable

Effectiveness of Low Vision Intervention

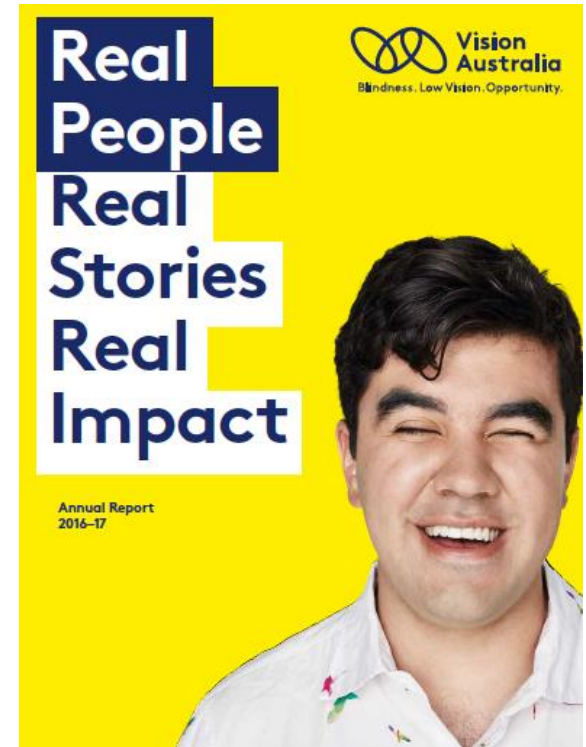
- High quality research is limited
 - Only 15 RCTs
 - 9 using PRO / VRQoL
- Comparisons difficult because use of different measures

Ehrlich et al., Patient, 2017

Effectiveness of Low Vision Intervention

Lamoureux et al., IOVS, 2007

- 192 participants, mean age 80 years
- Before and 3-6 months after comprehensive interdisciplinary LVR
- Vision Australia, Victoria, Australia



Effectiveness of Low Vision Intervention

Lamoureux et al., IOVS, 2007

- Improvement in overall IVI score
- Improvement in reading and accessing information and emotional well-being subscale, but not mobility and independence
- Smaller than expected effect: no control group; variation in services used

Effectiveness of Low Vision Intervention

Stelmack et al., Arch Ophthalmol, 2008

- Veteran Affairs Low Vision Intervention Trial (**LOVIT**)
- 126 participants, white male veterans, mean age 79 years
- Macular disease
- Multicentre RCT, US (waitlist control group)
- VA LV VFQ-48 4 months after comprehensive interdisciplinary LVR
- Included devices and 10 hours of therapy (plus home visit)



VA

U.S. Department
of Veterans Affairs

Table 2. Mean Changes in Primary and Secondary Outcome Measures^a

	VA LV VFQ-48 ^{24,34-36} Score, Mean (SD) ^b		Treatment vs Control	
	Treatment Group ^c (n=64)	Control Group (n=62)	Difference (95% CI)	Effect Size
▶ Reading ability				
Baseline	0.32 (1.0)	-0.03 (1.1)		
Change from baseline to 4 mo	2.06 (1.2) ^d	-0.37 (0.55) ^d	2.43 (2.07-2.77)	2.51
▶ Mobility				
Baseline	0.52 (1.0)	0.46 (1.1)		
Change from baseline to 4 mo	0.57 (0.7) ^d	-0.27 (0.7) ^e	0.84 (0.58-1.10)	1.14
Visual information processing				
Baseline	0.45 (0.9)	0.17 (0.8)		
Change from baseline to 4 mo	1.19 (0.8) ^d	-0.2 (0.5) ^e	1.38 (1.15-1.62)	2.03
Visual motor skill				
Baseline	0.23 (1.0)	0.09 (0.9)		
Change from baseline to 4 mo	1.47 (1.0) ^d	-0.04 (0.53)	1.51 (1.22-1.80)	1.82
Overall visual ability				
Baseline	0.35 (0.9)	0.13 (0.8)		
Change from baseline to 4 mo	1.43 (0.8) ^d	-0.2 (0.4) ^d	1.63 (1.40-1.86)	2.51

Effectiveness of Low Vision Intervention

LOVIT

- VRQoL and functioning decreased in waitlist control group
→ services should be offered early
- Follow-up study (Stelmack et al., Arch Ophthalmol, 2012)
 - Effectiveness maintained at 12 months
- Applicability to other groups?
- What aspects of the intervention are important?

Effectiveness of Low Vision Intervention

Acton et al., IOVS, 2016

- 67 participants, mean age 75 years
- Single site RCT, UK (waitlist control group)
- 6 months after **home-visit-based-LVR**
- 1 to 11 visit by one therapist including all aspects of LVR except low vision devices

Acton et al., IOVS, 2016

- Moderate improvement in overall VA LV VFQ score
- Kitchen training most often stated as useful



Effectiveness of Low Vision Intervention

Stelmack et al., JAMA Ophthalmol, 2017

- Veteran Affairs Low Vision Intervention Trial (**LOVIT II**)
- 323 participants, white male veterans, mean age 80 years
- Macular disease, better eye VA 6/15 to 6/60
- Multicentre RCT, US
- Low vision devices alone (basic) vs. devices with LVR
 - LVR = instruction, homework, eccentric viewing, environmental modifications
- 4 months follow-up

VA LV VFQ-48 ^b	Mean (SD)		LV Rehabilitation vs Basic LV Services		
	LV Rehabilitation (n = 163)	Basic LV Services (n = 160)	Difference (95% CI)	P Value	Effect Size ^c
All Patients					
Reading ability					
▶ Baseline	0.51 (1.43)	0.51 (1.44)	0.34 (0.0005 to 0.69)	.05	0.22
Change from baseline to 4 mo	1.29 (1.66) ^d	0.95 (1.46) ^d			
Mobility					
Baseline	0.71 (1.31)	0.60 (1.16)	0.19 (−0.06 to 0.45)	.13	0.17
Change from baseline to 4 mo	0.31 (1.15) ^d	0.12 (1.16)			
Visual Information processing					
▶ Baseline	0.62 (1.35)	0.72 (1.26)	0.27 (0.01 to 0.53)	.04	0.23
Change from baseline to 4 mo	0.67 (1.21) ^d	0.40 (1.13) ^d			
Visual motor skill					
▶ Baseline	0.73 (1.38)	0.67 (1.32)	0.37 (0.08 to 0.66)	.01	0.28
Change from baseline to 4 mo	0.77 (1.47) ^d	0.40 (1.19) ^d			
Overall visual ability					
Baseline	0.61 (1.10)	0.61 (1.02)	0.27 (0.06 to 0.49)	.01	0.28
Change from baseline to 4 mo	0.70 (1.06) ^d	0.43 (0.89) ^d			

Effectiveness of Low Vision Intervention

Stelmack et al., JAMA Ophthalmol, 2017

- Both treatments effective
- With LVR more effective than basic only for those with better eye VA 6/19 to 6/60
- Basic sufficient for those with mild vision impairment
- Issues:
 - Those with poorer VA?
 - Private patients (no cost for devices through Veteran Affairs)

Effectiveness of Low Vision Intervention

It works!!

- Despite diverse service models evaluated, various follow-up times, various measures
 - ✓ Improvement in VRQoL
 - ✓ Particularly aspects related to improvements in reading and near activities

Binns et al., Surv Ophthalmol, 2012

Effectiveness of Low Vision Intervention

More research is needed!!

What are the characteristics of an effective LVR program?

How much is required?

What type of service achieves the best results?

What about working age adults and children?

Cost-effectiveness of LVR?

Summary and Conclusions

- A gold standard VRQoL measure is needed so studies can be compared
- Low vision clinics are now using VRQoL measures to gain insights from clients and evaluate services
- Clients feel better understood
- However, so far, few measures address patient goals



Summary and Conclusions

- We must continue to develop and evaluate new low vision interventions (not just develop questionnaires)
- Consider using a validated questionnaire to guide your low vision practice



Summary and Conclusions

- Vision impairment, VRQoL and depression are interrelated
- Depression is 2 to 5 times more prevalent among people with vision impairment than the general population
 - Affects 25-45%



1. “During the past two weeks, have you been bothered by little interest or pleasure in doing things?”
2. “During the past two weeks have you been bothered by feeling down, depressed, or hopeless?”

PHQ-2

Yes → REFER



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Thank you
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