Five Papers That Changed  
My Vision Rehab Practice

# Producer notes

{Notice to the reader about accessibility: This document meets the Government of Québec SGQRI 008-02 standard to be accessible to anybody, disabled or not. All notices between braces are alternative texts for images, abbreviations or to describe any other information conveyed by sensory characteristics that transmits information, indicates an action, prompts a response, or distinguishes a visual element.

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Notes: Make sure you modified your Jaws' reading parameters by activating language detection and most punctuations reading.}

# Special symbols

{n followed by a number, a \* or any other indicator} point out the presence of a footnote reference in the text and enters the corresponding footnote

{ms} minus sign

{¸} {/¸} frames elements placed in subscript

{<=} less-than or equal to

# Navigation links

[Producer notes](#_Toc512434946)

[Special symbols](#_Toc512434947)

[Navigation links](#_Toc512434948)

[Disclosures](#_Toc512434949)

[The WHO Rehabilitation 2030 Call for Action defined rehabilitation](#_Toc512434950)

[The WHO Rehabilitation 2030 Call for Action stated](#_Toc512434951)

[Vision rehabilitation interventions include](#_Toc512434952)

[It is a large task to search, read, assess and translate publications to practice](#_Toc512434953)

[Recent Reviews of Vision Rehab Literature](#_Toc512434954)

[How to select papers to present](#_Toc512434955)

[Michael Crossland, 2005](#_Toc512434956)

["To observe the development of the PRL in patients with central scotomas"](#_Toc512434957)

[Results: All patients developed PRL](#_Toc512434958)

[Author's discussion](#_Toc512434959)

[What influenced me?](#_Toc512434960)

[Limitations](#_Toc512434961)

[Since the 2005 Crossland study](#_Toc512434962)

[EFFECT trial – 4-arm RCT, n = 200](#_Toc512434963)

[EFFECT trial Results](#_Toc512434964)

[EFFECT trial](#_Toc512434965)

[Investigators' conclusions – we don't "know that it works"](#_Toc512434966)

[Why?](#_Toc512434967)

[EVT remains on the VR research agenda](#_Toc512434968)

[Alison Binns, 2012](#_Toc512434969)

["To provide a critical evaluation of the current literature regarding the effectiveness of different models of low vision service provision"](#_Toc512434970)

[Lack consensus about outcomes](#_Toc512434971)

[Few studies with strong design/low bias](#_Toc512434972)

[Relying on memory is a problem](#_Toc512434973)

[Evidence synthesis](#_Toc512434974)

[There was no significant relationship between follow-up time and effect size (Spearman's correlation p 0.05)](#_Toc512434975)

[There was a significant correlation between dose and effect size (Spearman's correlation coef, 0.48; p= 0.04)](#_Toc512434976)

[Cited a few well-designed studies](#_Toc512434977)

[Hilda van der Aa, 2016](#_Toc512434978)

[Results](#_Toc512434979)

[Strengths](#_Toc512434980)

[Limitations](#_Toc512434981)

[Summary](#_Toc512434982)

[Why did this impact me?](#_Toc512434983)

[Thomas Cox and Dominic ffytche, 2014](#_Toc512434984)

[Charles Bonnet Syndrome](#_Toc512434985)

[Cox & ffytche, 2014](#_Toc512434986)

["The era of CBS as an incidental curiosity has ended; for those with negative outcome, CBS now lies unequivocally within the clinical domain."](#_Toc512434987)

[ffytche, 2017](#_Toc512434988)

[Robert Buckman, 2011](#_Toc512434989)

[The S-P-I-K-E-S Protocol](#_Toc512434990)

[S – SETTING – Secure an appropriate area for the discussion](#_Toc512434991)

[P – PERCEPTION – Assess the patient's understanding of the seriousness of their condition](#_Toc512434992)

[I – INVITATION – Get permission to have the discussion. "*ASK BEFORE YOU TELL*"](#_Toc512434993)

[K – KNOWLEDGE – Explaining the facts](#_Toc512434994)

[E – EMOTIONS – The Empathic Response – Be Supportive](#_Toc512434995)

[S – STRATEGY & SUMMARY – Closing the interview](#_Toc512434996)

[The SPIKES Health Care Communication Model](#_Toc512434997)

[Summary](#_Toc512434998)

{Slide 1}

Five Papers That Changed  
My Vision Rehab Practice

Mary Lou Jackson, MD, FRCS(C)

19th Scientific Symposium on Visual Impairment and Rehabilitation

February 13, 2018

Montreal

{Slide 2}

# Disclosures

* Consultant – Astellas

{Slide 3}

# The WHO Rehabilitation 2030 Call for Action defined rehabilitation

*"set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment"*

{Logo Rehabilitation 2030 a call for action}

{Line break}

**La réadaptation, définie par Réadaptation 2030: *un appel à l'action de l'OMS***

"Ensemble d'interventions conçues pour optimiser le fonctionnement et réduire le handicap des personnes ayant des problèmes de santé en interaction avec leur environnement"

{Slide 4}

# The WHO Rehabilitation 2030 Call for Action stated

*"Rehabilitation is a highly person-centred health strategy; treatment caters to the underlying health condition(s) as well as goals and preferences of the user."*

{Line break}

«La réadaptation est une stratégie de santé hautement centrée sur la personne; les interventions répondent aux conditions de santé sous-jacentes ainsi qu'aux objectifs et aux préférences de l'utilisateur»

Dans Réadaptation 2030: *un appel à l'action*

{Slide 5}

# Vision rehabilitation interventions include

* Devices
* Training
* Environmental modifications
* Psychosocial supports
* Vocational services
* Community services…

… that assist patients with vision loss to continue to participate, do activities they value and to remain safe.

{Line break}

**Les interventions de réadaptation en déficience visuelle incluent:**

* Aides techniques,
* Entraînement,
* Modifications environnementales,
* Soutien psychosocial,
* Services professionnels,
* Services communautaires...

… qui aident les personnes avec perte visuelle à continuer à participer, à effectuer des activités qu'elles apprécient et à rester en sécurité.

{Slide 6}

# It is a large task to search, read, assess and translate publications to practice

{Charts}

* **Results by year**
  + 1997: 289 items
  + 2007: 619 items
  + 2017: 1,148 items

{/Charts}

C'est une grande tâche de rechercher, lire, évaluer et traduire des publications pour la pratique

{Slide 7}

# Recent Reviews of Vision Rehab Literature

* 2017 American Academy of Ophthalmology Preferred Practice Pattern
* 2018 WHO Bulletin Background paper – Review of Systematic Reviews (43 studies)

(Sarah Wallace, Hannah Cooper)

{Logo Vision Rehabilitation for Adults}

{Line break}

**Revues récentes de la littérature en réadaptation**

* 2017: Patrons de pratique préférés du American Academy of Ophthalmology
* 2018: Bulletin de l'OMS: revue de revues systématiques (43 études)

{Slide 8}

# How to select papers to present

* Most frequently cited
* Publications in higher impact journals
* Highest quality scores
* Importance of topic to our research agenda
* **Papers that addressed my clinical questions**

{Line break}

**Comment sélectionner des articles à présenter**

* Les meilleurs scores,
* Les plus fréquemment référencés,
* Publication dans un journal à impact élevé
* Importance du sujet,
* Le plus grand intérêt pour la pratique
* *Articles qui ont traité de mes questions cliniques*

{Slide 9}

# Michael Crossland, 2005

{Box}

**Preferred Retinal Locus Development in Patients with Macular Disease**

*Michael D. Crossland, PhD,1,2 Louise E. Culham, Phd,1,2 Stamatina A. Kabanarou, MD,1 Gary S. Rubin, PhD1,2*

**Objective:** To observe the development of the preferred retinal locus (PRL) in a group of patients with central scotoma caused by recent onset macular disease (MD).

{/Box}

{Slide 10}

## "To observe the development of the PRL in patients with central scotomas"

* N = 25
* Follow over 12 months
* Outcomes: Fixation, eyetracker, reading speed

{Illustration not described}  
Source: Crossland M, et al. Preferred Retinal Locus Development in Patients with Macular disease. Ophthal 2005 1579-85.

{Line break}

**Observation du développement du PRL chez des patients avec scotome central**

* N = 25
* Suivi sur 12 mois
* Mesures de résultats: fixation, dispositif de suivi du regard, vitesse de lecture

{Slide 11}

## Results: All patients developed PRL

* Half used final PRL at first assessment (within one month)
* PRL in all subjects by 6 months
* 56% using one PRL at end of study (baseline 36%)
* Reading speed not associated with PRL location
* No fixation location allowed faster reading

{Line break}

**Résultat: tous les patients ont développé un PRL**

* La moitié ont utilisé leur PRL final durant leur 1ère évaluation ({<=} 1 mois)
* PRL chez tous les sujets au 6e mois
* 56% ont utilisé un PRL à la fin de l'étude (36% à la mesure de base)
* Vitesse de lecture non associée à la localisation ni au nombre de PRL
* Aucune aire de fixation n'a permis une lecture plus rapide

{Slide 12}

* Considered if patient use PRL when asked to look straight
* 64% 'unaware' of using eccentric fixation
* Reading speed was better when not 'aware of PRL'

{Line break}

* Considéré si le patient utilise un PRL lorsqu'on lui demande de regarder droit devant lui
* 64% ne sont pas conscients qu'ils utilisent une fixation excentrique
* La vitesse de lecture était meilleure quand le patient n'était pas conscient de son PRL

{Slide 13}

## Author's discussion

"Our results suggest that patients who are trained to use an alternative PRL will not necessarily read any more quickly"

"Furthermore, the patients in the present study who were not aware that they were using a PRL read more quickly than those who were conscious of using a noncentral retinal area for fixation. It seems reasonable to assume that encouraging a patient to use an alternate PRL will increase awareness of eccentric viewing, possibly reducing reading speed"

{Line break}

«Nos résultats suggèrent que les patients entraînés à utiliser un PRL alternatif ne liront pas nécessairement plus rapidement»

«De plus, les patients de la présente étude qui n'étaient pas conscients qu'ils utilisaient un PRL lisent plus rapidement que ceux qui avaient conscience d'utiliser une région rétinienne non centrale pour la fixation. Il semble raisonnable de supposer que le fait d'encourager un patient à utiliser un PRL alternatif le rendra plus conscient de sa vision excentrique et réduira possiblement sa vitesse de lecture.»

{Slide 14}

### What influenced me?

* Spontaneous development of the PRL
* How quickly the PRL developed
* Progression from multiple to fewer/single
* Reading speed related to number of PRLs and re-referencing

{Slide 15}

### Limitations

* the retina was not imaged during reading
* the study was done monocularly
* the patients knew what the study was about
* the sample size was small
* the patients did get low vision devices
* the sample size was perhaps not sufficiently homogeneous

{Slide 16}

## Since the 2005 Crossland study

* Review of Reading Rehabilitation – Judith Pijnacker 2011
* Meta-analysis of Eccentric Viewing – Jon Howe 2012
* Review of Eccentric Viewing – Allanah Gaffney 2014
* LVR and Reading Speed – Noura Hamade 2016
* Cross-over study (eccentric viewing, oculomotor) – Wm Seiple 2010
* **EFFECT trial – 4-arm randomized trial of eccentric viewing -Gary Rubin**

{Box}

**UCL**First results from the EFFECT Trial, an RCT of eccentric viewing training for patients with AMD

Gary Rubin, on behalf of the Effect Study Team  
UCL Institute of Ophthalmology  
Moorfields Eye Hospital

{/Box}

{Line break}

* Revue sur la réadaptation à la lecture – Pijnacker 2011
* Méta-analyse sur la vision excentrique – Howe 2012
* Revue sur la vision excentrique – Gaffney 2014
* Réadaptation en basse vision et vitesse de lecture – Hamade2016
* Étude croisée (vision excentrique, oculomotricité) – Seiple2010
* Essai EFFECT-essai randomisé factoriel sur la vision excentrique-Rubin

{Slide 17}

"EVT is widely practiced in some European countries, especially Sweden, and in some low vision centers in the US and elsewhere. EVT is not generally available through the NHS in the UK. One reason it is not offered is the lack of evidence that EVT is effective."

(Gary Rubin 2017 ARVO Abstract)

{Line break}

«L'entraînement à la vision excentrique (EVE) est largement pratiquée dans certains pays européens, en particulier en Suède, et dans certains centres de basse vision aux États-Unis et ailleurs. L'EVE n'est généralement pas offerte par le système de santé publique du Royaume-Uni, entre autres parce qu'il manque de preuves sur son efficacité.»

{Slide 18}

### EFFECT trial – 4-arm RCT, n = 200

* Groups
  + No EVT standard low vision by optometrist
  + Contact time control No EVT (supervised reading)
  + EVT at PRL
  + EVT at TRL
* Outcome – Activity Inventory (baseline, exit, 6, 12 months)
* Secondary outcomes – reading speed MNRead, iResST, Reading Comprehension (Morgan), Fixation stability

{Line break}

* Étude factorielle randomisée contrôlée; N=200; Groupes: Pas d'EVE; basse vision standard en optométrie,
* Groupe contrôle: pas d'EVE; période de contact (lecture supervisée), EVE au PRL, EVE au PRL entraîné
* Mesure de résultat-Activity Inventory (pré, post, 6 et 12 mois)
* Mesures secondaires -vitesse de lecture (MNReadet iResST), compréhension de la lecture (Morgan), stabilité de la fixation

{Slide 19}

**EFFECT trial**

* Age 82 ± 7 years
* BCVA 0.65 ± 0.24 logMAR
* 61% female
* 33% dry AMD
* 80% treated
* 61% previous LVA

(Rubin 2017 Vision 2017)

{Line break}

* Âge 82 ± 7 ans;
* Meilleure acuité visuelle corrigée 0.65 ± 0.24 logMAR;
* 61% femmes; 33% DMLA sèche;
* 80% traités;
* 61% évaluation précédente en basse vision

{Slide 20}

* 170 completed follow-up
* Generally well received, did not like the supervised reading

(Rubin Vision 2017)

{Line break}

* 170 ont complété le suivi
* Généralement bien reçu; n'ont pas aimé la lecture supervisée

{Slide 21}

### EFFECT trial Results

#### Activity Inventory

**Change in Activity Inventory**{Chart not described}

{Slide 22}

#### Reading Speed

**Change in Reading Speed**{Chart not described}

{Slide 23}

### EFFECT trial

* Adjusted for age, gender, type of eye disease,
* Subgroups by baseline acuity,
* Subgroups by fixation stability,
* NO SIGNIFICANT DIFFERENCES.

(Rubin Vision 2017)

{Line break}

* Ajusté pour l'âge, le sexe, le type de maladie oculaire
* Sous-groupes par acuité mesurée à la base
* Sous-groupes par stabilité de fixation
* AUCUNE DIFFÉRENCE SIGNIFICATIVE

{Slide 24}

### Investigators' conclusions – we don't "know that it works"

* Could not demonstrate benefit of EVT
* Evidence does not support widespread practice, despite that trainers and patients are positive
* Future research for subgroups of patients

{Line break}

* N'a pas pu démontrer l'avantage de l'EVE
* Les preuves ne supportent pas la pratique répandue, malgré le fait que les entraîneurs et les patients sont positifs
* Recherche future pour des sous-groupes de patients
* L'EVE demeure au programme des recherches en réadaptation visuelle

{Slide 25}

### Why?

* Too little training (3 hours)
* Wrong training (certified by expert)
* Wrong trainer (optometrist)
* Wrong outcomes
* Other activities; not reading
* Training only useful for some LV patients

(Rubin Vision 2017)

{Line break}

* Trop peu d'entraînement (3 heures);
* Mauvais entraînement (certifié par un expert);
* Mauvais entraîneur (optométriste)
* Mauvaises mesures de résultats
* Autres activités: pas de lecture;
* Entraînement utile seulement pour quelques patients avec basse vision.

{Slide 26}

# EVT remains on the VR research agenda

{Slide 27}

# Alison Binns, 2012

{Box}

SURVEY Of OPHTHALMOLOGY VOLUME 57 – NUMBER – JANUARY-FEBRUARY 2012

**PUBLIC HEALTH AND THE EYE**JOHANNA SEDDON AND DONALD FONG, EDITORS

**How Effective is Low Vision Service Provision?  
A Systematic Review**

Alison M. Binas, PhD,1 Catey Bunce, DSc,2 Chris Dickinson, PhD,3 Robert Harper, DPhil,4 Rhiannon Tudor-Edwards, DPhil,5 Margaret Woodhouse, PhD,1 Pat Linck, MSc,5 Alan Suttie, CertEd,6 Jonathan Jackson, PhD.7 Jennifer Lindsay. BSc.7

{/Box}

{Slide 28}

## "To provide a critical evaluation of the current literature regarding the effectiveness of different models of low vision service provision"

* Included studies with comparison group
* 58 publications – 7 RCTs
* Many different models of care
* Many different outcomes (47)

{Line break}

**«Fournir une évaluation critique de la littérature actuelle concernant l'efficacité des différents modèles de prestation de services en basse vision»**

* Incluait des études avec groupe de contrôle
* 58 publications – 7 études randomisées contrôlées (ERC)
* Plusieurs différents modèles de soins
* Plusieurs différentes mesures de résultats (47)

{Slide 29}

## Lack consensus about outcomes

* Objective measures – acuity, reading speed,
* Activities / Function – Card Sort,
* Vision-related QoL – NEI VFQ 25 – IVI
* Health-related Qol – SF 36
* Psychological status – GDS
* Newer outcomes – Activity Inventory, SRAVF (Mary Warren)

{Line break}

* Mesures objectives -acuité, vitesse de lecture
* Activités / Fonction -Tri des cartes
* Qualité de vie (QdV) liée à la vision -NEI VFQ 25 – IVI
* QdV lié à la santé -SF 36
* Statut psychologique -GDS
* Nouvelles mesures de résultats -Inventaire des activités, SRAVF (Mary Warren)

{Slide 30}

## Few studies with strong design/low bias

* Designs often lack controls
* Sample size
* Bias
  + Outcome assessment not masked
  + Loss to follow up
  + Risk of type 1 error when many comparisons
  + Relying on memory

{Line break}

* Peu d'études avec une conception solide / faible biais;
  + Conception (sans groupe contrôle)
* Taille de l'échantillon;
  + Préférence;
  + L'évaluation des résultats n'est pas masquée
* Perte de suivi;
  + S'appuient sur la mémoire
* Risque d'erreur de type 1 lors de comparaisons multiples

{Slide 31}

## Relying on memory is a problem

"Walter et al… conducted a telephone interview approximately 1 year after the conclusion of rehabilitation to ask about change in rated difficulty of activities of daily living from pre-intervention to post-intervention. Of 417 respondents, 105 were ***unaware of even having participated in visual rehabilitation***."

{Line break}

**S'appuyer sur la mémoire est un problème**

«Walter et al... ont mené une entrevue téléphonique environ un an après la fin de la réadaptation, pour vérifier l'évolution de la difficulté cotée en lien avec les activités de la vie quotidienne, à partir de la pré-intervention jusqu'en post-intervention. Sur 417 répondants, 105 ne savaient même pas qu'ils avaient participé à une réadaptation visuelle.»

{Slide 32}

## Evidence synthesis

* Devices improve reading
* Patients value and use devices
* Rehabilitation improves ability to do daily tasks
* Some benefit of groups
* Less effect on mood
* Little evidence for enhanced models of care

{Line break}

* Les aides techniques améliorent la lecture
* Les patients valorisent et utilisent les aides techniques
* La réadaptation améliore la capacité à accomplir les tâches quotidiennes
* Moins d'effet sur l'humeur
* Peu de preuves pour des modèles améliorés de soins
* Certains avantages associés aux groupes

{Slide 33}

## There was no significant relationship between follow-up time and effect size (Spearman's correlation p 0.05)

**BINNS et AL**.  
{Chart not described}

Aucune relation significative entre le temps de suivi et la taille de l'effet  
(corrélation de Spearman p 0,05)

{Slide 34}

## There was a significant correlation between dose and effect size (Spearman's correlation coef, 0.48; p= 0.04)

**How effective is low vision service provision**{Chart not described}

Aucune relation significative entre la dose et la taille de l'effet  
(corrélation de Spearman 0.48; p= 0.04)

{Slide 35}

{Box}

"Overall the number of well-designed and adequately reported studies Is pitifully small"

{/Box}

{Line break}

"Globalement, le nombre d'études bien conçues et correctement rapportées est pitoyablement faible"

{Slide 36}

## Cited a few well-designed studies

* Girdler et al, 2010
  + Two armed study of self-management program
  + Outcome – Activity Card Sort

(Vision self management for older adults: a randomized controlled trial.  
Br J. Ophthalmol. 2010; 94: 223-8)

{Line break}

* Girdler et al, 2010
  + Étude avec groupe parallèle d'un programme d'auto-gestion
  + Mesure de résultat – Tri de cartes

{Slide 37

* Reeves et al 2004
  + Randomized parallel groups:
  + Outcomes VCM-1 (vision QoL), SF-36; psych, task, use, ADL restriction
  + No benefit of enhanced
    - Clinic, Clinic + home, Clinic + sham

(Enhanced low vision rehabilitation for people with age related macular degeneration: a randomized controlled trial. BrJOphthalmol. 2004; 88: 1443-9)

{Line break}

* Groupes parallèles randomisés
* Résultats VCM-1 (QdV liée à la vision), SF-36; psych, tâche, utilisation, restriction dans les AVQ
* Aucun avantage associé au modèle amélioré
  + Clinique, Clinique + domicile, Clinique + simulacre

{Slide 38}

{Chart}

* Scott et al., 1999
* Wolffsohn & Cochrane, 2000
* McCabe et al., 2000
* Reeves et al., 2004 (1)
* La Grow, 2004
* Smith et al., 2005 (prism 1)
* Smith et al., 2005 (prism 2)
* Smith et al., 2005 (no prism)
* Stelmack et al., 2006 (OPC 1)
* Stelmack et al., 2006 (OPC 2)
* de Boer et al., 2006
* Hinds et al., 2007
* Lamoureux et al., 2007
* Walter et al., 2007
* Pearce et al., 2011 (optometrist)
* Pearce et al., 2011 (hospital)
* Court et al., 2011 (primary)
* Court et al., 2011 ...
* Wang et al., 2012
* Stelmack et al., 2006 (BRC)
* LOVIT

{/Chart}

{Line break}

Citation de quelques études bien conçues

{Slide 39}

* Useful summary
* Stressed the importance of consensus about outcomes
* Importance of controls, masking and sample size
* Was the Binn's paper a good review?  
  (scored 4/10 on AMSTAR quality assessment checklist)

{Line break}

* Résumé utile
* Soulignement de l'importance du consensus sur les résultats
* Importance des contrôles, du masquage et de la taille de l'échantillon

L'article de Binn était-il une bonne critique?  
(score 4/10 sur la liste d'évaluation de la qualité d'AMSTAR)

{Slide 40}

# Hilda van der Aa, 2016

{Box}

REVIEW PAPER

**Psychosocial interventions to improve mental health in adults with vision impairment: systematic review and meta-analysis**

Hilde P.A. van der Aa{n1}, Tom H. Margrain{n2}, Ger H. M. B. van Rens{n1,3}, Martijn W. Heymans{n4} and Ruth M. A. van Nispen{n1}

{n1}Department of Ophthalmology and the EMGO + institute for Health and Care Research, VU University Medical Centre, Amsterdam, the Netherlands, {n2}School of Optometry and Vision Sciences, Cardiff University, Cardiff, UK, {n3}Department of Ophthalmology, Elkerliek Hospital, Helmond, and {n4}Department of Epidemiology and Biostatistics, VU University Medical Centre, Amsterdam, the Netherlands

**Citation information:** van der Aa HPA, Margrain TH, van Rens GHMB, Heymans MW & van Nispen RMA. Psychosocial interventions to improve mental health in adults with vision impairment: systematic review and meta-analysis. *Ophthalmic Physiol Opt* 2016; 36: 584-606. doi: 10.1111/ opo.12313

**Keywords:** anxiety, depression, mental health, meta-analysis, systematic review, vision impairment.

{/Box}

{Slide 41}

## Results

* 27 papers (8 individual/12 group interventions)
* Brody – reduced distress; reduced depression if depressed at baseline
* Birk et al, Wahl et al – benefits deteriorated over time
* Girdler et al – benefit
* Rees et al – no effect

{Line break}

* 27 articles;
  + 8 interventions individuelles;
  + 12 interventions de groupe
* Brody – réduction de la détresse; réduction de la dépression si la personne est déprimée à la base
* Birk et al, Wahl et al. -les bénéfices se sont détériorés avec le temps
* Girdler et al – bénéfices
* Rees et al – aucun effet

{Slide 42}

* Few good-quality studies
* Interventions had small significant effect on depressive symptoms
* Less effective in older patients

{Line break}

* Peu d'études de bonne qualité
* Les interventions ont eu un faible effet significatif sur les symptômes dépressifs
* Moins efficace chez les patients âgés
* Une donnée aberrante identifiée (Jalali et al 2014)
* Effet non significatif lorsque la donnée aberrante est supprimée

{Slide 43}

|  |  |  |
| --- | --- | --- |
| Rees et al. 2015 | {Illustration not described} | 0.00 [{ms}0.32, 0.32] |
| Bryan et al.2014 | {Illustration not described} | 0.22 [{ms}057, 1.01] |
| Jalali et al. 2014 | {Illustration not described} | {ms}4.53 [{ms}5.48, {ms}3.57] |
| Rovner et al. 2014 | {Illustration not described} | {ms}0.27 [{ms}0.60, 0.06] |
| Rovner et al. 2013 | {Illustration not described} | {ms}0.13 [{ms}0.40, 0.14] |
| Sun et al. 2012 | {Illustration not described} | {ms}0.98 [{ms}1.39, {ms}0.56] |
| Girdler et al. 2010 | {Illustration not described} | {ms}0.18 [{ms}0.63, 0.27] |
| Rayner et al. 2007 | {Illustration not described} | 0.00 [{ms}0.29, 0.28] |
| Wahl et al. 2006 | {Illustration not described} | 0.11 [{ms}0.54, 0.76] |
| Wahl et al. 2006 | {Illustration not described} | 0.52 [{ms}0.18, 1.21] |
| Brody et al. 2006 | {Illustration not described} | {ms}0.52 [{ms}1.25, 0.21] |
| Brody et al. 1999 | {Illustration not described} | {ms}027. [{ms}0.81, 026] |
| Kaluza et al. 1996 | {Illustration not described} | {ms}0.17 [{ms}0.89, 0.55] |
| Ueda et al. 2013 | {Illustration not described} | 0.35 [{ms}0.24, 0.93] |
| Ueda et al. 2013 | {Illustration not described} | {ms}0.41 [{ms}1.32, 0.50] |
| Birk et al. 2014 | {Illustration not described} | 0.38 [{ms}0.50, 1.26] |
| Trozzolini et al. 2003 | {Illustration not described} | {ms}0.02 [{ms}0.59, 0.54] |
| Evans et al. 1982 | {Illustration not described} | {ms}0.45 [{ms}0.89, {ms}0.02] |

{Slide 44}

* Outlier – Jalali et al 2014
* 2-arm RCT; n = 60, blind
* Group-based rational emotive behavioural therapy
* Follow up at one month
* Younger patients (20-40 yr)

{Line break}

* Donnée aberrante – Jalali et al 2014
* ERC avec groupe parallèle; n = 60, aveugle
* Thérapie comportementale émotive rationnelle de groupe
* Suivi à un mois
* Patients plus jeunes (20-40 ans)

{Slide 45}

## Strengths

"In contrast to previous systematic reviews, all types of psychosocial interventions, offered in different settings, aimed at increasing mental health in people with visual impairment were included, and meta-regression analyses were performed to identify sources of heterogeneity between the studies."

A large number of studies were found (i.e. 22) and current state-of-the-art meta-analytic techniques were used.

{Line break}

«Contrairement aux revues systématiques précédentes, tous les types d'interventions psychosociales proposées dans différents contextes, visant l'amélioration de la santé mentale des personnes malvoyantes, ont été incluses et des analyses de méta-régression ont été réalisées pour identifier les sources d'hétérogénéité entre les études.»

Un grand nombre d'études ont été trouvées (c.-à-d. 22) et les techniques de méta-analyse les plus récentes ont été utilisées.

{Slide 46}

## Limitations

* Few high quality studies
* Possibility of publication bias
* Questionnaires not validated in visually impaired
* Variety of interventions (self-management, PST, behavior activation)
* Outcomes not homogeneous  
  (7/11 on AMSTAR checklist)

{Line break}

* Peu d'études de haute qualité
* Possibilité de biais de publication
* Questionnaires non validés chez les personnes avec déficience visuelle
* Variété d'interventions (autogestion, thérapie de résolution de problème, activation du comportement)
* Résultats non homogènes (7/11 sur la liste de contrôle AMSTAR)

{Slide 47}

## Summary

* Need for well-designed trials
* Need for better reporting

{Line break}

* Besoin d'essais bien conçus
* Besoin de meilleurs rapports

{Slide 48}

## Why did this impact me?

* Important topic
* Resource-intense interventions
* Multiple studies subsequently
  + Van der Aa 2015 Stepped care for depression and anxiety in visually impaired older adults: multicentre randomised controlled trial.
  + Heppe et al. 2015 Testing the effectiveness of a mentoring intervention to improve social participation of adolescents with visual impairments: study protocol for a randomized controlled trial.
  + Schakel et al. 2017 Exploring the patient perspective of fatigue in adults with visual impairment: a qualitative study.

{Line break}

* Plusieurs études par la suite

{Slide 49}

# Thomas Cox and Dominic ffytche, 2014

{Box}

**BJO Online First, published on May 13, 2014 as 10.1136/bjopthalmol-2014-304920**

**Negative outcome Charles Bonnet Syndrome**Thomas M Cox, Dominic H ffytche

{Logo OPEN ACCESS}

Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bjophthalmol-2014-304920>).

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**ABSTRACT**

**Background**.  
Charles Bonnet Syndrome (CBS) is widely considered a transient condition without adverse consequence, questioning the need for treatment. Yet, while this view may be true of the majority of people with CBS, it is recognised that some have negative experiences and outcomes. Here, we attempt to better understand negative outcome CBS and the factors that influence it.

{/Box}

{Slide 50}

Charles Bonnet was a naturalist who, in 1769 described the hallucinations experienced by his visually impaired and cognitive intact grandfather.

{Illustrations not described}

{Slide 51}

## Charles Bonnet Syndrome

* Recurrent vivid hallucinations
* Vision loss
* Insight when explained
* No other neurological or psychiatric diagnosis to explain

{Illustrations not described}

{Line break}

* Hallucinations vives récurrentes
* Perte de vision
* Insight quand expliqué
* Aucun autre diagnostic neurologique ou psychiatrique à expliquer

{Slide 52}

"Many people who come to this clinic see things which they know are not there. They see animals, faces or patterns. Do you see this?"

* N = 224, prospective
* 33% Reported Hallucinations (74/224)

(Jackson et al, 2006)

{Line break}

«Beaucoup de gens qui viennent à cette clinique voient des choses qu'ils savent ne pas être là. Ils voient des animaux, des visages ou des motifs. Vois-tu ça?»

* N = 224, prospectif
* 33% d'hallucinations signalées (74/224)

(Jackson et al, 2006)

{Slide 53}

## Cox & ffytche, 2014

* Survey of 4000 members of the Macular Society (UK): 492 CBS
* 75% have hallucinations for 5 years+
* 32% had 'negative outcomes' – (Frequent, fear-inducing, longer- lasting, affecting daily activities, attributed to mental illness, not knowing CBS at onset)

{Line break}

* Sondage auprès de 4 000 membres de la Macular Society (UK): 492 SCB
* 75% ont des hallucinations depuis 5 ans +
* 32% avaient des «résultats négatifs».
  + Hallucinations fréquentes et induisant la peur, Hallucinations durables, Affectant les activités quotidiennes, Attribuées à une maladie mentale grave, Ne sachant rien à propos du SCB au début des symptômes.

{Slide 54}

**Figure 1.** Emotional responses to Charles Bonnet Syndrome hallucinations. Bars indicate% of hallucinators reporting each emotion. Dark grey indicates emotions at the onset of symptoms, light grey at the time of the questionnaire. X² corrected for multiple comparisons \*\*\*p{¸}corr{/¸} < 0.00; \*\*p{¸}corr{/¸} < 0.01; NS p{¸}corr{/¸} > 0.05.

{Chart not described}

{Slide 55}

### "The era of CBS as an incidental curiosity has ended; for those with negative outcome, CBS now lies unequivocally within the clinical domain."

{Box}

O5-04-04

**VISUAL HAL LUCINATIONS IN DEMENTIA: PRELIMINARY FINDINGS FROM THE STUDY OF HALLUCINATIONS IN PARKINSON'S DISEASE, EYE DISEASE AND DEMENTIA (SHAPED)**

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**Background**: Visual hallucinations in dementia are distressing for both patients and carers and currently lack effective treatments. They also occur in eye disease (Charles Bonnet Syndrome – CBS) and Parkinson's disease (PD). If the brain dysfunction underlying visual hallucinations is the same across conditions, treatments used for CBS or PD hallucinations might also be used in dementia.

{/Box}

{Line break}

«L'ère du SCB comme curiosité incidente est terminée; pour ceux ayant un résultat négatif, le SCB se situe maintenant, sans équivoque, dans le domaine clinique.»

{Slide 56}

## ffytche, 2017

"The ongoing NIHR-funded SHAPED programme is collecting rich phenomenological data in well-defined cohorts of patients with dementia (Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies), eye disease and PD."

**Positive symptoms in SHAPED**{Chart not described}

{Line break}

«Le programme SHAPED en cours, financé par l'INRS, recueille de riches données phénoménologiques auprès de cohortes bien définies de patients atteints de démence (maladie d'Alzheimer, démence vasculaire, démence de Lewy), d'une maladie oculaire et la maladie de Parkinson.

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{Slide 58}

# Robert Buckman, 2011

{Box}

Journal Lists – CMAJ – v.183(5); 2011 Mar 22 – PMC3060185

CMAJ. 2011 Mar 22; 183(5): 559-571.  
doi. 10.150/cmaj.090113  
PMCID: PMC3060185

**Empathic responses in clinical practice: Intuition or tuition?**

Robert Buckman, MD PhD, James A. Tulsky, MD, and Gary Rodin, MD  
Author information – Copyright and License information

***This article has been cited by other articles in PMC.***

During recent interviews for admission to medical school, candidates were asked to respond to a hypothetical situation so that their communication skills could be assessed. They were told that a patient in the emergency department had just been informed that he had suffered a minor heart attack, to which he had exclaimed "Oh no! A heart attack! That's terrible!" They were then asked to provide an empathic response to the patient's distress, one that clearly identified and acknowledged at least one of the emotions the patient had expressed. Most of the candidates responded appropriately with statements such as "I realize that's a big shock to you" or "Clearly that news feels overwhelming," However, one candidate replied "I did say it was a small heart attack, you know."

**What is empathy?**

{Box}

**The doctor who had time for people**

Barbara Amiel on the death of her cousin, Dr. Robert Buckamn  
*Barbara Amiel*October 17, 2011

Illustration not described  
Source: Michael Stuparyk / TorontoStar

{/Box}

{Illustration not described}  
Legend: Communication Skills in Clinical Practice, Part 1 – The Basics By Dr. Robert Buckman

{/Box}

{Slide 59}

## The S-P-I-K-E-S Protocol

* **S** Setting Up the Conversation
* **P** Perception
* **I** Invitation
* **K** Knowledge
* **E** Emotions
* **S** Strategy and Summary

{Box}

**The Complete Guide to Communication Skills in Clinical Practice© including:**

* Breaking Bad News
* Addressing Emotions
* Discussing Medical Errors
* Cultural Competence
* Challenging Emotional Conversations with Patients & Families
* Effective Communication in Supervision

**Walter F. Belle, M.D.**Professor, Behavioral Science & Psychiatry  
Director, Interpersonal Communication And Relationship Enhancement [I\*CARE] Program

{/Box}

{Slide 60}

### S – SETTING – Secure an appropriate area for the discussion

* Have the conversation in a quiet undisturbed area.
* Prepare for what to say and anticipate the patient/family reaction.
* Have the key people (whom the patient wants) in the room.
* Seat the patient closest to you and have no barriers between you.
* Sit down, try to be calm, make eye contact.

### P – PERCEPTION – Assess the patient's understanding of the seriousness of their condition

* Ask what the patient and family already know.
  + *"Tell me what you understand about your condition so far."*
  + *"What did the other doctors tell you?"*
  + *"I'd like to be sure we are on the same page with understanding your condition, so can you tell me..."*
* Assess the patient and family members' level of understanding.
* Take note of discrepancies in the patient's understanding and what is actually true.
* Watch for signs of denial.

{Slide 61}

### I – INVITATION – Get permission to have the discussion. "*ASK BEFORE YOU TELL*"

* Set goals for the discussion – ask the patient if they want to know the details of the medical condition/treatment.
  + *"I'd like to go over the results, would that be ok?"*
  + *"Today my plan is to discuss... is that okay?"*
* Accept the patient's right not to know.
* Offer to answer any questions the patient/family member may have.

### K – KNOWLEDGE – Explaining the facts

* **Avoid** medical jargon by explaining the facts in a manner that the patient will understand.
  + **NOT: *"You have a nuclear grade 1ER/PR positive spiculated 4-centimeter lesion."***
  + BETTER: ***"You have a fairly good sized tumor in your breast."***
* Fill in any gaps that were evident in the "Perception" stage.
* Present the information in small chunks.
* After each chunk, verify the patient's understanding.
  + *"Are you with me so far?"*

{Slide 62}

### E – EMOTIONS – The Empathic Response – Be Supportive

* Deal with emotions as they occur (patients who are very emotional will not comprehend what you say).
* Use open-ended and direct questions to explore what the patient is feeling.
  + *"Can you tell me more about how you feel?"*
  + *"Did that make you angry?"*
* Respond to emotions with empathic and affirming statements.
  + *"I can see you weren't expecting this."*
  + *"Most people would be upset finding this out."*
* Use *"tell me more"* statements.  
  PT: *"I don't know how I'm going to tell my kids."*  
  MD: *"Tell me more about that."*
* Try to keep your own emotions from taking over.
* **AVOID** responding with false reassurance such as:
  + *"Everything will be fine."*
  + *"I've seen lots of miracles happen."*

**Note: You don't have to have the same feelings as the patient nor do you have to agree with the patient.**

{Slide 63}

### S – STRATEGY & SUMMARY – Closing the interview

#### Strategy

* Decide what the best medical plan would be for the patient.
* Appraise in your mind or clarify with the patient their expectations of treatment and outcome.
* Recommend a strategy on how to proceed.
* Collaborate and agree on the plan.
* Ask the patient to repeat to you their understanding of the plan.
* Have a clear treatment plan in writing for the patient to take home with them.

#### Summary

* Summarize the conversation.
* Offer to answer questions. (be prepared for tough questions):
  + PT: *"Does this mean I'm going to die?"*
  + MD: *"Tell me more about what concerns you?"*
  + PT: *"Can I be cured?"*
  + MD: *"I'm sorry to say that it is unlikely. Our goal is to keep it in check."*
  + PT: *"How long do I have to live?"*
  + MD: "I can discuss that with you, but first tell me why you ask?"

{Slide 64}

{Box}

## The SPIKES Health Care Communication Model

* **S** – *Setting*: The clinician is seated, appears comfortable, and does not interrupt when the patient speaks.
* **P** – *Perception:* "What have you been told about your driving u to now?"
* **I** – *Invitation:* "How much detail would you like to know about the licensing requirements?"
* **K** – *Knowledge:* "Today I do need to discuss your driving with you." (Warning shot)

**E** – *Empathy:* "Hearing that you do not meet the licensing requirements is clearly a major shock to you. I wish the news were better."  
(The patient cries, and the clinician pauses and looks away.) "I see that this news upsets you. Let's just take a break now until you're ready to start again."

* **S** – *Strategy and summary:* " So the summary of all this is that your vision does not meet the requirements to maintain a valid driver's license, and, unfortunately, you will now not be able to drive.

{/Box}

Jackson ML. Communication with patients who have low vision. JVIB 2007; 101(8): 489-493.

{Slide 65}

# Summary

* Crossland 2005: PRL Development in Patients with Macular Disease
* Binns 2012: How Effective is Low Vision Service Provision: A Systematic Review
* Van der Aa 2016: Psychosocial Interventions To Improve Mental Health In Adults With
* Cox ffyche 2014: Negative Outcome Charles Bonnet Syndrome
* Buckman 2011: Empathic Response in Clinical Practice

{Line break}

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* Binns 2012: Quelle est l'efficacité de la prestation de services de basse vision: revue systématique
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* Buckman 2011: Réponse empathique dans la pratique clinique

{Slide 66}

**Thank you!**